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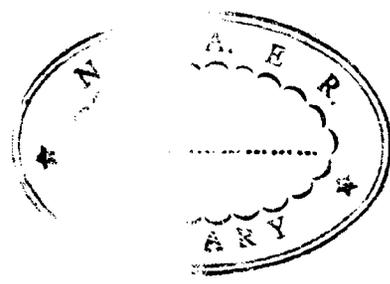
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Socio-Economic Impact of HIV and AIDS in India

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सत्यमेव जयते

K. Sujatha Rao

Additional Secretary & Director General



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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.

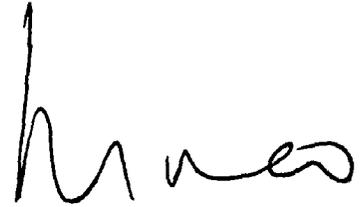
There are many issues of concern highlighted in this study. The additional financial burden imposed on households with PLWHA is forcing them further into poverty. An important indicator is the reduction in the aggregate income of the PLWHA households surveyed by around nine percent. This has a devastating 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 that 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.

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.

A handwritten signature in black ink, appearing to read 'K. Sujatha Rao', written in a cursive style.

(K. Sujatha Rao)



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 AIDS 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 who 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. 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.

A handwritten signature in black ink, appearing to read 'Maxine Olson'.

Maxine Olson
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Message

The first AIDS case in India was detected in 1986 and since then the HIV and AIDS epidemic has emerged as a serious public health problem in India. As on December 2005, an estimated 5.21 million persons were living with HIV infection and till 31 July 2005, 111,608 AIDS cases had been reported. HIV and AIDS is more than a health problem and its impact reaches far beyond the health sector. HIV and AIDS affects the individual, the family and the community at the micro-level and the various sectors of the economy at the macro-level. This report focuses on the socio-economic impact of HIV and AIDS on the affected individuals and their households in the six high-prevalence states of India. The economy-wide and sector-wide impact has been dealt with in a supplementary report.

The study is based on a sample of 2,068 HIV households (covering 2,385 People Living with HIV and AIDS {PLWHA}) and 6,224 non-HIV households as a control group. To our knowledge no such study has been carried out in India on such a large scale. This study combines quantitative research techniques with qualitative approaches like case studies and focus group discussions. It focuses on the impact of HIV and AIDS on household income and on the pattern of consumption and savings and reflects the devastating effect of the disease on the household economy due to loss of income and increased medical cost. The impact on the education of the children of the affected families is assessed by comparing the enrolment and dropout rates of the children from HIV households with children from non-HIV households. On the employment front, it is not only the affected individuals who face the brunt of the disease, but also other family members who are the caregivers of the affected persons.

The individuals and families affected by HIV and AIDS not only bear the heavy financial burden, but also have to face stigma and social isolation attached to the disease. The study looks at this stigma and discrimination faced by the PLWHA and their families in different settings such as family, community, at the workplace and health facilities. As this prejudice arises mainly due to lack of knowledge, awareness and misconceptions about the disease, the study also attempts to note the awareness level and the views and attitudes of the general population.

We are grateful to the National AIDS Control Organisation (NACO) for entrusting this important and sensitive study to NCAER and to the UNDP for funding the project.

We hope that the findings of this study would be helpful to NACO and other organisations working in this field for designing and implementing various programmes for the welfare of the people living with HIV and AIDS.

I would like to thank Dr. Basanta Pradhan and his team for the successful completion of this pioneering, important and sensitive study.

Suman Bery
Director-General

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AIDS Control Society (APSACS).

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Finally, we would like to thank all the respondents who shared the information without any hesitation. Their contributions made this study rich and unique.

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Abbreviations

AIDS	Acquired Immuno Deficiency Syndrome
APSACS	Andhra Pradesh State AIDS Control Society
CGE	Computable General Equilibrium
CII	Confederation of Indian Industry
CPI	Consumer Price Index
CSIS	Centre for Strategic and International Studies
F/M	Females/Males
FGD	Focus Group Discussion
GDP	Gross Domestic Product
HAART	Highly Active Antiretro Viral Therapy
HH	Households
HIV	Human Immunodeficiency Virus
ICMR	Indian Council of Medical Research
IDU	Injecting Drug Use
IEC	Information, Education and Communication
ILO	International Labour Organisation
INP+	Indian Network for People Living with HIV and AIDS
KSAPS	Karnataka State AIDS Prevention Society
LPG	Liquified Petroleum Gas
MC	Municipal Corporation
MDACS	Mumbai District AIDS Control Society

MSACS	Manipur State AIDS Control Society
MSAPCS	Maharashtra State AIDS Prevention & Control Society
MSM	Men having Sex with Men
N	Number (Total)
NACO	National AIDS Control Organisation
NCAER	National Council of Applied Economic Research
NEDHIV	North Eastern Drug, HIV Training Centre
NGO	Non-Governmental Organisation
NSACS	Nagaland State AIDS Control Society
NSSO	National Sample Survey Organisation
OBC	Other Backward Castes
OI	Opportunistic Infection
PLWHA	People Living with HIV and AIDS
PPTCT	Prevention of Parent to Child Transmission
SACS	State AIDS Control Society
SC	Scheduled Caste
ST	Scheduled Tribe
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
TB	Tuberculosis
TNP+	Telugu Network for People Living with HIV/AIDS
TNSACS	Tamil Nadu State AIDS Control Society
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCTC	Voluntary Counselling & Testing Centres
WFPR	Work Force Participation Rate
WHO	World Health Organisation

Executive Summary

Introduction

HIV and AIDS are a serious challenge for the developing as well as the developed world. India, with an estimated 5.206 million people living with HIV in 2005, accounts for nearly 69 percent of the HIV infections in the South and South-East Asian region. This is despite it being a low prevalence country with an overall adult HIV prevalence rate of 0.91 percent.

India has six high prevalence states - Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland. Of these six states, Andhra Pradesh has recorded the highest prevalence of two percent among the antenatal clinic attendees and 22.8 percent among STD clinic attendees in 2005.

Socio-economic impact analysis

Globally, the adverse socio-economic impact of HIV and AIDS is visible at the household, sectoral, and at the macro level. Given the low overall HIV prevalence in India, there has not been any significant effort to study the impact comprehensively. Focus so far has been on studying the impact at the level of the individual and the households.

A comprehensive 'Socio-Economic Impact of HIV and AIDS' study, was sponsored by UNDP and NACO, and undertaken by NCAER. This study assessed the impact of HIV at the level of households using household survey. It also assessed the impact on select sectors (industry, agriculture, health and tourism) and made projections of likely impact at the macro level using CGE modeling. The findings at the household level, which are reported in this volume, were based on analysis of data from an independent primary survey conducted by NCAER in the six high-prevalence states. The survey was supplemented with information gathered through focus group discussions and case studies. The unique aspects of the study include the large sample size- almost 8,000 households - and the comprehensive nature of the analysis which ranges from the economic impact in terms of consumption, savings and health costs to the impact on education, health and level of stigma and discrimination.

The findings of such can studies contribute to effective and evidence based planning. This study is especially well timed because its findings can enrich the third National AIDS Control Programme, which is currently being finalised.

Data and methodology

For every HIV household surveyed in a village/urban block, three non-HIV households belonging to similar socio-economic strata were interviewed. This ratio was chosen to reduce the variance in the non-HIV sample and select a large number of households with matching characteristics to each HIV household. This ratio was also influenced by budgetary considerations.

Overall, the survey covered 2,068 HIV households and 6,224 non-HIV households spread over the rural and urban areas of the six HIV high-prevalence states. The number of PLWHA interviewed was higher at 2,385, since wherever there were more than one adult PLWHA in a family, an additional person was interviewed. The number of female and male respondents, were 1,043 and 1,342 respectively.

The challenge of conducting a survey of this nature lies in identifying Persons Living with HIV and AIDS (PLWHA) and securing their consent for an interview. The list of PLWHA attending VCTC at government hospitals was not provided to the NCAER team for reasons of confidentiality and to respect the rights of the PLWHA. Keeping in mind the ethical issues and the directions of the Institutional Review Board at NCAER, support was enlisted from the counsellors of the State AIDS Control Societies and representatives of the NGOs working in this field. By virtue of working with the PLWHA directly, the counsellors and NGOs were sensitive to their needs and were also able to gain the trust of the PLWHA. Moreover, they were also well qualified for conducting the interviews. These counsellors and NGOs approached the HIV households with whom they were in touch and conducted the interviews

subsequent to receiving consent from the PLWHA.

For the larger states such as Andhra Pradesh, Karnataka, Tamil Nadu and Maharashtra, 400 HIV households were drawn per state. Since Nagaland and Manipur are smaller states, 450 HIV households were drawn for both states. For the non-HIV households, a listing of households in the locality/village was used to select the sample. A maximum of 150 households were listed in each selected village and in urban areas, around 100 households were listed in each block.

Nine case studies and six Focus Group Discussions (FGDs) were conducted in order to collect information that would supplement the findings of the quantitative survey. The six FGDs (one FGD in each state) were conducted with the members of the Network of Positive People. While the case studies helped in capturing problems like stigma and discrimination, the findings from FGDs were useful in confirming quantitative findings and to further analyse data from the household survey.

Profile of the sample

The sample mostly included households that had low income and educational levels. Though the HIV and non-HIV households shared similar socio-economic characteristics, in comparison, the non-HIV household heads were better educated and also had a marginally high average annual income. The average annual household income was Rs. 47,260 for the sample HIV households in comparison to Rs. 48,900 for the non-HIV households. In terms of education, 27.8 percent of heads of the HIV households were illiterate as compared to 19.9 percent of the heads of the non-HIV households.

While the case studies helped in capturing problems like stigma and discrimination, the findings from FGDs were useful in confirming quantitative findings

Since the sample of non-HIV households was drawn in such a way that they matched the income and occupational categories of the HIV households, the percentage distribution of household heads by their occupational categories was almost the same for both types of households. A sizeable number of the heads of the households were working as wage earners either in the agricultural sectors or in other sectors. Nearly one-fourth of the HIV and non-HIV household heads were wage earners, while about 22 percent of the heads of HIV households and 25 percent of the heads of non-HIV households were salary earners. 28 percent of women were working as labourers either in agriculture, in construction sector or in other non-agricultural activities.

Nearly 60 percent of the households heads in HIV households were in the age group of 20-50 years, and for non-HIV households, this proportion was lower at 53 percent.

In the PLWHA sample, 70 percent of the men were currently married while this was the case for 49 percent of women PLWHA. Significantly, more than were third of the sample female PLWHA are widows. While 54 percent of the male sample PLWHA were in Stages I or II, in the case of females, as many as two-thirds of the sample were in Stages I or II. The level of education of the sample PLWHA was also quite low, as 24 percent of men and 30 percent of women were illiterate.

Employment and income

For sample HIV households, the Work Force Participation Rate (WFPR) was higher than the rate for non-HIV sample households in both rural and urban areas in all age groups. The main reason behind

this is likely to be the increased financial burden due to illness of persons infected with HIV.

The WFPR of non-HIV children (0-14 years) or elderly (60 and above years) in the HIV households is higher than that of the same age group in non-HIV households. This confirms the view expressed in literature that non-HIV persons in the HIV households, especially the elderly, are put under considerable burden to look after the needs of the household.

In general, the female child WFPR is higher than the male child participation rate, thus showing a greater burden on the female child. Specifically, among female children, the WFPR is virtually the same whether they are affected by HIV or not. However, no HIV positive male child was found to be working. Clearly, the gender inequality among children is accentuated by HIV and AIDS.

The pattern of change in occupational distribution and sectoral distribution due to HIV and AIDS for people in the age group 18-60 years shows a decline in employment of PLWHA in all occupation groups. There is an increase in percentage of 'unemployed' PLWHA from 3.61 percent (before test) to 9.80 percent (after test).

HIV and AIDS also have an impact on the income levels of the household. The total loss in income was found to be 9.24 percent of the total household income of all HIV households in the sample. The loss of income for HIV households can be either due to loss of job of the PLWHA or due to leave/absence from work. This can further be compounded by the loss of job of the caregivers or their leave/absence from work. The findings indicate that the loss due to leave/absence has more

The WFPR of non-HIV children (0-14 years) or elderly (60 and above years) in the HIV households is higher than that of the same age group in non-HIV households

of an impact since it represents a greater proportion of total households in the sample (36.48%) in comparison to the proportion of households reporting loss of income due to loss of a job (6%).

However, despite the smaller proportion of households reporting loss of income due to loss of a job, for the households affected this is not a trivial issue. It gains importance particularly because the loss of income as a proportion of current household income is very high, coming to around 66 percent of the total current income of the HIV households reporting losses. In terms of the monetary loss, the average income lost due to leave/absence in the last one year was Rs. 3,736 while the average income lost for PLWHA currently not working was found to be Rs. 27,421 in the last one year in the sample. If left unchecked, the resultant could have a disastrous effect on the economy of these households.

The caregivers can also be under tremendous pressure vis-a-vis the time devoted to work and the need to take care of the PLWHA. The income lost due to absence from work of caregivers is around 3.5 percent of the current income of the households so affected. Coupled with the loss of income of the PLWHA, this can be an additional burden and it can have severe consequences for the households at a lower level of income.

This, however, was not seen to be a very important channel for loss of income of the caregiver. The figures suggest that only those who are working on the margins at low wage rates withdraw from the labour force. This may be expected since those who earn high incomes would be the last to withdraw from the labour force, given the additional burden of expenditure imposed on the household due to a PLWHA member.

If the loss of income through all channels is combined, nearly 9.1 percent of the total current income of the HIV households is the resultant loss. Since there is excess supply of labour in the Indian economy with the possibilities of substitution of labour by capital as well as low prevalence rate, this impact may not be much in terms of value added in the economy due to HIV and AIDS at this point in time. However for the affected households the impact is severe.

Consumption and savings

There are a number of ways in which HIV and AIDS can influence the level and pattern of consumption and savings of the households and ultimately have a deleterious impact on individual sectors and national economies. Even though the proportion of food expenditure is much lower for the HIV households, the per capita per month expenditure on food of these households is slightly higher than that of the non-HIV households. The difference in per capita expenditure on food between the two types of households is mainly due to the expenditure on "other food" items, which may be related to the HIV status of these households, especially the need to have nutritious and balanced food. Medical expenses of the HIV households are almost four times higher than the per capita per month medical expenses of the non-HIV households.

A notable feature about savings is the lower average household saving of HIV households as compared to non-HIV households in both rural and urban areas. The study empirically validates the assumption that HIV and AIDS result in a decline in savings and assets of the households affected by it. This is largely indicated by the large and negative savings in jewellery and agricultural

A notable feature about savings is the lower average household saving of HIV households as compared to non-HIV households in both rural and urban areas

land by the HIV households, even as savings in these forms are positive in the case of non-HIV households. Another very important feature of the savings pattern of HIV households is that the bulk of savings are kept in the form of cash/bank deposits, i.e. the most liquid form of savings. The non-HIV households allocate a larger share of their savings to other financial assets, which are relatively illiquid. The asset position of HIV households is weaker compared to non-HIV households and across all income groups, HIV households spend more on house rent than non-HIV households.

One of the methods of coping with the financial burden/loss of income due to the infection could be liquidation of assets or borrowings. Interestingly, almost 43 percent of the HIV households had either borrowed or liquidated assets for this purpose, from the time when a member of the household was detected to be HIV-positive. The average amount generated due to this has been estimated at Rs. 24,558. The percentage of such households, however, was very high for the lowest income group (56%), going down with the level of income of the households.

In the last one year, nearly 46 percent of HIV households had borrowed as compared to around 27 percent of non-HIV households. The percentage of households that borrowed is higher in the case of HIV households at all levels of income. Many of the relatively poor households are dependent on borrowings to meet their consumption needs. The combination of greater need for borrowings and possible dependence on non-formal sources of funds can wreak havoc on the economy of these households.

The head count of poverty ratio from the sample data has been estimated in order to see the difference between non-HIV and HIV households in the sample. The head count ratio for HIV households is higher than the head count ratio among non-HIV households. However, this is mainly because of the higher ratio of poor population among HIV households in rural areas. A striking feature is the contrast seen in terms of rate of savings between poor HIV and poor non-HIV households. The former group has a very high negative rate of savings while the same is positive for the latter. Clearly, the poor among HIV households are under a greater burden of trying to meet their consumption expenditure.

In terms of consumption, it is seen that the head count ratio of poverty is lower in the case of HIV households in urban areas, even though the same level of income poverty for both HIV and non-HIV households in urban areas had been observed. The reason must lie in greater emphasis placed by HIV households on consumption and this is linked with the negative savings rate seen in the case of poor HIV households. Despite greater focus on consumption by poor HIV households, their per capita consumption expenditure turns out to be lower than that of non-HIV households. This is just the opposite of households above the poverty line, where the per capita expenditure of HIV households is higher than its counterpart. This suggests that the poor are put under unbearable stress due to HIV and AIDS, including the HIV negative household members. The irony that the HIV households face is twofold: not only are they pushed into poverty due to HIV and AIDS, but they are also required to spend more in order to sustain themselves for a longer period.

In the last one year, nearly 46 percent of HIV households had borrowed as compared to around 27 percent of non-HIV households

Education

While there is evidence to support the argument that education helps prevent HIV transmission, it has also been shown that in the worst affected countries, AIDS is seriously undercutting the education sector by affecting the demand, supply and quality of education. This study measured the impact of HIV and AIDS on the schooling of children by comparing ever and current enrolment rates, type of school attended, school attendance rate and similar dimensions. This was also done comparatively across HIV and non-HIV households.

The differences between HIV and non-HIV households are more marked in current enrolment percentages than in ever enrolment percentages, indicating that the dropout rates are higher in HIV households. This difference in ever and current enrolment percentages between the HIV and non-HIV households persists even after controlling the household income. For both types of households, the dropout rates are lower for the urban children.

There is a gender difference in the current enrolment percentages, especially in the case of rural children belonging to HIV households, which suggests that in the HIV households, girls are more likely to be withdrawn from school. This is not surprising since girls are often forced to drop their education in favour of domestic and care related activities, which are obviously heightened in a situation of HIV. The reason for discontinuation of schooling is largely unaffordability.

Interestingly, no HIV household has reported stigma or discrimination as reasons for non-enrolment or discontinuation of schooling. But this

is mainly because their HIV status is not disclosed in the schools.

The per capita expenditure of HIV households on education of children is lower than that of the non-HIV households, especially at higher levels of income. This is due to a combination of lower current enrolment rate and a higher proportion of children enrolled in government schools where the fees are lower.

The average number of days absent from school during the last academic year was higher for the children of HIV households. In both types of households, interestingly, 'child refused to attend school' seems to be an important reason for being absent from school, along with the child's own ill – health. A higher percentage of HIV households reported the ill health of the parents as a reason for absenteeism. On the other hand, a much higher percentage of children from non-HIV households reported to be absent for fun i.e. for reasons like going out of station or attending social functions.

Impact on health status

The most visible impact of HIV and AIDS at the household level is the financial burden on the families of the infected persons resulting from increased expenditure on medical treatment. The survey showed that the burden of non-hospitalised as well as hospitalised illnesses, the prevalence of which is substantial in HIV households, is very heavy on HIV households as compared to non-HIV households. The survey also showed that for the PLWHA, the prevalence rates of both non-hospitalised and hospitalised illnesses increases with the advance in the stage of infection. The jump in the rates is more marked after Stage II, clearly indicating the

The differences between HIV and non-HIV households are more marked in current enrolment percentages than in ever enrolment percentages, indicating that the dropout rates are higher in HIV households

deteriorating health status of the infected persons in Stage III and IV. More than 80 percent of the PLWHA in Stage IV had reported hospitalisation.

As far as non-hospitalised illness episodes are concerned, as high as 22 percent reported that they were frequently ill during the last one year and 16 percent reported frequently falling ill during the last one month. Another two to four percent reported that they were almost continuously ill. As expected, diseases like tuberculosis, diarrhoea and fever account for a fairly high percentage of the illness episodes reported by the PLWHA, during the one-month reference period. Alongside, providing treatment for the curable infections is essential to enable the PLWHA to lead a better and active life. The survey results show that not all illness episodes were treated. 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.

Interestingly, the percentage of sample PLWHA reporting hospitalisation since they were tested positive is only marginally higher than the percentage reporting hospitalisation in the last one year; 43 to 44 percent of the PLWHA who were interviewed have reported hospitalisation. The percentage reporting hospitalisation is much higher for men as compared to women.

The PLWHA seem to rely more on the public health services for the treatment of non-hospitalised illness episodes. While 44 percent of the non-hospitalised illness episodes had been treated at the government health facilities, the percentage of illness episodes for which treatment had been sought in the

private facilities is lower at 37 percent. Additionally, compared to the general population, the PLWHA also relied on the NGO sector for provision of health services, with nearly 16 percent reporting that the episodes were treated by the health facilities run by NGOs. This is understandable since there are a number of NGOs providing treatment, care and support.

Similarly in the case of hospitalisation, in 50 percent of the cases the PLWHA had gone to government hospitals and for 21 percent of the cases they had sought admission in care and support homes run by NGOs. Another 28 percent of the cases sought treatment from private nursing homes. There are interesting gender differences in the source of treatment for hospitalisation. More women (57.2%) sought treatment in a government hospital as compared to men (46.6%) but the opposite holds true when seeking treatment at private nursing homes.

It was noted that with the increase in the household income, the dependence on the government hospital and NGOs comes down and utilisation of private nursing homes/hospitals increases. Only a small percentage of PLWHA belonging to the lowest income category had gone to the private hospital.

The HIV households seem to incur a huge out-of-pocket expenditure for the treatment of non-hospitalised illness episodes as well as for hospitalisation. Even if the treatment has been sought from the government health facilities and NGOs, the households have incurred a substantial expenditure. On an average, the out-of-pocket expenditure has been Rs. 676 per illness episode; the highest being Rs. 1,070 per episode when the treatment is sought from a private clinic

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

and Rs. 322 when the PLWHA had gone to an NGO for treatment.

The average expenditure per hospitalisation is Rs. 2,672 and there is a substantial gender gap in the average cost of hospitalisation; while the average household expenditure per hospitalisation is Rs. 2,994 for men, this average is much lower at Rs. 1,953 for women. All the households, irrespective of their income level, have resorted to borrowings and liquidation of assets to meet hospitalisation expenses, although the percentage of cases where the households resorted to liquidation of assets has also been the highest for the lowest income category. The data source of financing hospitalisation by stage of infection shows that at the initial stage, more households are able to finance the hospitalisation from their past savings. But as the stage of infection advances, they seem to end up liquidating their assets, in addition to borrowings.

Nearly one-fourth of the sample PLWHA has not disclosed their HIV-positive status in the community, fearing stigma and discrimination

Stigma and discrimination

Stigma is not new to public health, nor is it unique to HIV and AIDS. In the context of stigma and discrimination, two important indicators are the reaction of the family and that of the larger community. In most cases, the initial reaction of the family members was that of shock and disappointment. However, for about 42 percent male PLWHA and (surprisingly) 45 percent of female PLWHA, the family was supportive. The support to females came mostly from the natal family.

Though shock could be an expected natural reaction on learning about the positive status, their reaction after the news settled in is more relevant. 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 positive respondents have reported that their families are quite supportive in spite of there being slight initial hesitations. In the case of females, family support mostly means support from the natal family. However, more women are supportive of their HIV-positive husbands (12.4%) than men are of their HIV-positive wives (8.5%).

Nearly one-fourth of the sample PLWHA has not disclosed their HIV-positive status in the community, fearing stigma and discrimination. Of those who have disclosed their status in the community, about ten 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, not allowing their children inanganwadi centres etc. The presence of an HIV-positive individual also affects the marriage and job prospects of other family members to some extent. While in the case of marriage prospects, the female PLWHA seem to be more discriminated, for employment prospects, both seem to be equally affected although it was reported by a small percentage.

While 84 percent of women in the sample informed their spouses about their HIV status immediately, the percentage of men who did the same is lower at 69 percent. It is seen that while nearly 55 percent of the men who had tested HIV-positive had gone in for a test after prolonged illness, this percentage was only 26 percent in case of women. A higher percentage of women had gone in for voluntary testing, while around 12 percent of women discovered their status during pregnancy.

Since a working person spends most part of his day in the workplace, it is essential

that the atmosphere is conducive to work. It is seen that a majority of PLWHA who are employed (74%) have not disclosed their status at their workplace. Three reasons have emerged for their not disclosing the status, the most common being fear of losing the job (45%). Social discrimination and lowering of prestige are the other reasons for not revealing their status. Of the 26 percent who have disclosed their status, 10.3 percent have reported facing discrimination at the hands of the employer. During the survey, it was also found that most of those who had revealed their status were those who were working in NGOs in the field of HIV and AIDS.

The impact of stigma and discrimination in healthcare settings is also marked. PLWHA, being prone to many opportunistic infections have to seek medical care very often. While one expects that they would be treated with care and consideration, the healthcare setting has emerged as the most frequent place of discrimination, followed by familial and community contexts. 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.

Because of the stigma attached to HIV, not only are PLWHA discriminated against during their lifetime, but this discrimination continues even after death. Out of all the households that were considered for the study in the six states, 502 cases of AIDS death were observed. Although the number of deaths that occurred in hospitals is not available, there have been cases where people have faced discrimination in hospitals when a family member has died due to AIDS. Respondents also reported facing discrimination at the time of cremating the body. While in some cases they

were unable to obtain transport to take the body to the cremation ground, in a large number of cases, the community would not allow them to perform the last rites. In a small percentage of cases there was non-cooperation from the staff of the cremation ground. It has been observed that social boycott was much higher in rural areas as compared to urban areas.

Knowledge and awareness about HIV and AIDS

Through the survey of non-HIV households, an attempt was made to gauge the knowledge and awareness about HIV and AIDS from a sample of 3299 men and 2925 women in the age-group of 20 to 60 years. A very high percentage of the respondents reported having heard about HIV and AIDS. Media, especially television and radio, seem to have played a key role in creating this awareness. Although everyone has heard about HIV and AIDS, not all of them have the knowledge about other details like whether HIV and AIDS transmission could be prevented and where one should go for voluntary testing. Women appear to be less knowledgeable about information related to HIV and AIDS as compared to men. The survey of general population clearly indicates that there is a gender gap in not only knowledge about the infection, but also in the attitude towards PLWHA.

A little more than 50 percent of the sample could mention all the modes of transmission of HIV. The percentage of people not knowing even a single mode of transmission is very small, although it is found to be higher in case of women respondents.

Although a fair percentage of respondents knew the various modes

The survey indicates that there is a gender gap in knowledge about the infection and also in the attitude towards PLWHA

of transmission, many of them also had misconceptions about them. These myths and misconceptions about the modes of transmission accentuate the stigma and discrimination against HIV infected persons. The most common misconceptions seem to be that sharing of razors (more than 75%) and mosquito bites (about 36%) could spread AIDS. A few of them believed that hugging and kissing a PLWHA or sharing food and utensils and touching or shaking hands with the HIV-positive person could infect them as well. Knowledge and awareness about condoms assumes significance in the context of preventing HIV infection. While maximum number of people were aware of the use of condoms for avoiding pregnancy, a lesser number were aware that it could be used for prevention of HIV and people were least knowledgeable about its use in prevention of STI (26.5 percent for men and 21.5 percent for women).

Around 5.5 percent of female PLWHA have been asked to leave home, compared to 1.9 percent of the male PLWHA

Misconceptions regarding the spread of the infection have led to high-prevalence of discrimination and negative responses and attitudes of people towards PLWHA. As compared to men, women were more prejudiced and had a negative attitude towards such persons since they are more likely to have lesser knowledge and awareness. People were generally more hesitant to avail the health facilities used by PLWHA, to allow their children to mingle with children belonging to HIV households and to send their children to a school where HIV-positive children were studying.

Women and girls

As mentioned in the earlier sections, women and girls seem to bear the brunt and the infection disproportionately

affects them, psychologically, socially and economically. The present survey also shows that women constitute 70 percent of the caregivers and nearly 21 percent of these caregivers themselves are HIV-positive. Nearly one-third of the female caregivers are also employed and thus bear the burden of multiple responsibilities of caregiving and employment and household chores.

There are gender differences in the health-seeking behaviour and out-of-pocket expenditure on healthcare. As compared to men, in the case of women, a higher percentage of illnesses are left untreated, clearly indicating a gender gap in the treatment-seeking behaviour. The female PLWHA seem to have experienced more stigma and discrimination within the family even though this percentage is quite a marginal proportion of the total sample. Around 5.5 percent of female PLWHA have been asked to leave home, compared to 1.9 percent of the male PLWHA.

HIV widows are fairly young, mostly in the age group of 20 to 30 years and their households are economically and socially worse off than the other HIV households - their household income, availability of amenities as well as ownership of assets and consumer durables is much lower. A comparison of the HIV-widow households with the other HIV households also reveals that their savings are lower, percentage of households which have either borrowed or liquidated assets after a family member became HIV-positive is higher, as also were the borrowings in the last one year. Further, a higher percentage of these widow households are below the poverty line as compared to the others.

Policy implications

The findings of this study call for urgent policy action in order to mitigate the negative impact generated by HIV and AIDS. This response needs to be multi-pronged as the issues are diverse and complicated. In addition to the scaling up of national poverty reduction strategies, special social protection programmes are required to support the people, households and communities that are hardest hit by the epidemic. The scale of impact is likely to increase in the future as the number of households affected would increase. Greater number of currently working PLWHA would withdraw from labour force due to illness. This is accompanied by reduced

income and savings, liquidation of assets and increased indebtedness of HIV households. Reduction of human capital not only due to death and morbidity of PLWHA but also due to reduced investment in education of children will only increase the impact of the epidemic.

The study clearly brings out the deplorable condition of HIV-positive widows. In the absence of the bread-earner, the widow households are much worse off than the other HIV households, in terms of household income, expenditure, borrowings and liquidation of assets. Denial of share in the property and lack of any other avenue of income could push these widows into risky behaviour.

Introduction

1.1 Background

AIDS has emerged as a serious challenge for the developing as well as the developed world. The number of people reported to be living with HIV across the globe is estimated to have doubled from 19.9 million in 1995 to 40.3 million in 2005 (UNAIDS and WHO, 2005). More than 94 percent affected are reported to be adults (over 15 years) and 43 percent are women. Since it mainly affects the adults in their prime working age, individuals and households face severe social and economic consequences of this growing pandemic. The potentially negative impact of HIV and AIDS on real GDP, savings, skill formation, labour productivity and life expectancy has to be seen in the light of the large scale of the AIDS epidemic. In 2005, close to 3.1 million died of AIDS and nearly five million new cases of HIV infections have occurred. AIDS has become the fourth most crucial cause of death across the world and a leading cause of death in Africa. It is estimated that every minute one in every five youth (15-24 years) is infected with HIV. Next to sub-Saharan Africa (which accounts for nearly 60 percent of People Living With HIV and AIDS), South and the South-East Asian region accounts for 18 percent of the world's HIV infection as on December 2005. India – with 5.206 million people

living with HIV in 2005 (NACO, 2005) – accounts for nearly 69 percent of the HIV infections in the South and South-East Asian region.

Within a short period of 15 years, the HIV epidemic has emerged as a serious public health problems in India and across many parts of the globe. It is

Table 1.1
Global summary of the AIDS epidemic, December 2005

Number of PLWHA in 2005
Total: 40.3 million (36.7–45.3 million)
Adults 38.0 million (34.5–42.6 million)
Women 17.5 million (16.2–19.3 million)
Children under 15 years 2.3 million (2.1–2.8 million)
People newly infected with HIV in 2005
Total 4.9 million (4.3–6.6 million)
Adults 4.2 million (3.6–5.8 million)
Children under 15 years 7,00,000 (6,30,000–8,20,000)
AIDS deaths in 2005
Total 3.1 million (2.8–3.6 million)
Adults 2.6 million (2.3–2.9 million)
Children under 15 years (5,10,000–6,70,000)

Note: The ranges around the estimates in this table define the scale for the actual numbers based on the best available information.

Source: UNAIDS and WHO, 2005

The aptness of the policy action depends on a thorough research into: channels of influence of HIV and AIDS on individuals, sectors and national economies and its quantification

estimated that the number of People Living With HIV and AIDS (PLWHA) in India increased from 0.2 million in 1990 to 5.206 million in 2005. India remains a low prevalence country with overall HIV prevalence of 0.91 percent. The prevalence rate of the infection for India, though lower than the rates for other countries like Thailand and Myanmar, is higher than the rate for all the South-East Asian countries (WHO, 1999). The available surveillance data indicates that in India, HIV is prevalent in almost all parts of the country, although the prevalence is higher in states like Tamil Nadu, Maharashtra, Andhra Pradesh, Karnataka, Manipur and Nagaland. Further, in recent years the infection has spread from urban to rural population and from high-risk behaviour groups to the general population. Migration of males from rural to urban areas in search of employment is partly responsible for this trend. While these six states have the highest prevalence rates, there are places in other states that require immediate attention.

As noted above, the problem of HIV and AIDS has deep social and economic roots and hence its impact reaches far beyond the health sector with severe socio-economic consequences. A number of direct and indirect costs to the individuals as well as to the national health system can emerge as a result of HIV and AIDS. It is essential, therefore, to step up the current efforts. However, the *aptness* of the policy action depends on a thorough research into:

- (1) channels of influence of HIV and AIDS on individuals, sectors and national economies and its quantification;
- (2) knowledge of individual and societal behaviour which may negate the effects of policy;
- (3) costs of non-intervention compared with the net benefits (or costs) of

(alternative) policy interventions. The main focus of this study is on the first two questions, with particular reference to the six high-prevalence states in India mentioned above. Regarding the second question, it is felt that social stigma attached to the infection is the major inhibiting factor in controlling the spread of the infection. This study intends to deal with this aspect in detail.

Bloom and Mahal (1997) have classified the research, focusing on the negative impact of AIDS in national economies, into two groups:

- (a) One group of researchers have focused on the high estimated costs of medical care for PLWHA and depletion of labour force in critical sectors and their implication for indicators of macro-economic performance such as GNP per capita and growth rate (World Bank, 1993; Philipson and Posner, 1993) and even for sectors which are relatively labour intensive such as agriculture and transport (Kanjilal and Forsythe, 1997). The high personal medical costs of testing, for HIV and HIV-related illnesses and treating opportunistic infections such as TB are examples of direct costs to the individual. The direct costs to the health system include care and treatment of opportunistic infections and other costs like screening all blood prior to transfusion, costs of IEC and AIDS research. Significant indirect costs also emerge as a result of lost production and incomes due to HIV and AIDS related illnesses and deaths.

Research studies tend to show that income lost as a result of death due to AIDS related illnesses is usually the most important economic cost, since those that die from AIDS related illnesses are

generally in the most productive years of their life. The economic impact of the AIDS epidemic is most significant at the level of family and community—especially among the poor and marginalised groups – rather than at national, macro-levels, particularly in South Asia (UNDP, 2003).

However, these studies have certain drawbacks. It is difficult to predict the future impact of the AIDS epidemic based on present costs. Firstly, they cannot account for all the indirect costs of the epidemic. The reasons for reduction in labour supply and skill shortages influencing long-term growth and specific sectors are difficult to predict on the basis of partial equilibrium models. The problem is compounded by the lack of knowledge on the conversion from sero-prevalence to AIDS and further, to mortality rates. It is also not known how fast the epidemic may spread from the high-risk group to the general population and what impact it will have on different age groups and skill categories. Moreover, all the direct costs cannot be accounted for by scaling up the costs from the individual/ household level. Certain costs such as changes in food habits and resulting government subsidy on these items may not be accounted for. The rate of time preference of consumption for a PLWHA may be different and this itself may increase household expenditure. But it has to be noted that almost any study is open to some form of criticism and this should not stop the attempts to estimate the costs of the AIDS epidemic to the individual and the society and the most effective ways of meeting the challenge.

(b) The second group has drawn the implications of the AIDS epidemic on the long-term economic growth and on growth rates in particular sectors

based on CGE models (Kambou, Devarajan and Over, 1992; Arndt and Lewis, 2001; Bell, Devarajan and Gersbach, 2003). These allow the possibility of a number of assumptions with regard to transmission channels from HIV and AIDS to economic growth and well-being to be tested, the impact of which is otherwise difficult to predict. The channels of influence include depletion of labour stock due to AIDS-related death, reduced savings and reduced investment on children's education. There is a fair amount of consensus in the literature on the negative impact of HIV and AIDS on economic growth. However, these models tend to make some strong assumptions and hence, it may be argued, overstate the threat posed by AIDS to economic growth. They, for example, ignore surplus labour, most probably overstate the decline in educated labour force, ignore normal social and economic adjustments and tend to overstate reduction in expenditure on child education and savings.

A number of difficulties are encountered in making an assessment of the socio-economic impact of HIV and AIDS. While studies indicate a net negative effect on long-term economic growth, results are at best tentative (Becker, 1990). This is because a number of parameters are arbitrarily chosen due to lack of information. These include a few mentioned assumptions: (a) rate of growth of HIV infection; (b) the possibility of reduced rate of growth once the high risk group is saturated; (c) conversion rate from sero-prevalence to AIDS; (d) the variation across age groups and skill categories.

In the context of HIV and AIDS, stigma and discrimination hinder the effectiveness and accessibility of prevention, treatment

The channels of influence of HIV and AIDS include depletion of labour stock due to AIDS-related death, reduced savings and reduced investment on children's education

and care. Stigma refers to a negatively perceived defining characteristic used to set persons apart from the dominant majority. Discrimination acted upon through ostracising, shunning or rejecting others (Busza, 1999), has tended to fall into two basic categories – legislative and community-level. Societal-level discrimination such as through media constitutes a third level. Public health history is laden with examples of stigma and discrimination impeding individual health: individuals with leprosy, cholera and syphilis faced prejudice and discrimination similar to that seen today with HIV and AIDS (Valdiserri, 2002).

In India, since the first diagnosed case in 1986, perceptions of the epidemic have largely labelled it as a sickness of others: the marginalised, the poor and the vulnerable. Several states have proposed HIV protection bills that would require mandatory reporting or partner notification – actions deemed as potential violations of individual rights in many countries. Further, in 1998 the Supreme Court of India suspended the right of PLWHA to marry; after considerable activism, the right was restored in 2002 (Lawyers Collective, 2003). The National AIDS Control Programme recognises the obstacles caused by stigma and discrimination and emphasises the need for respondent measures.

The major causes of stigma are lack of depth in knowledge about HIV and AIDS, attitudes toward sexual behaviour and perception of immoral activities. Of the limited number of studies of the social reaction to AIDS, all document an overwhelmingly negative response to PLWHA in India (Bharat et al, 2001). The degree to which stigma is applied may vary based on perceived fault for contracting the infection. In the Indian context, sex workers and men who have

sex with men and injecting drug users may be branded as carriers of the virus. However, research has also shown bleak circumstances for women infected by spouses and children of HIV-positive parents.

Fear of prejudicial treatment can be a major reason for not being tested. Further, studies in India illustrate that PLWHA cite fear of discrimination as a primary barrier to disclosing their positive HIV status. A study in South India demonstrates that even among those who disclose their status, the majority limited it to immediate and to a lesser extent, extended family (Chandra et al, 2003), which is found to be the case in this survey too. Worldwide, studies in America and Africa reveal persistent attitudes of fear or discrimination towards HIV-positive individuals. One in five American adults *fears* persons with AIDS (Valdiserri, 2002). In Botswana – the country with the highest HIV prevalence – a majority of respondents expressed discrimination toward a teacher or shopkeeper with HIV, while not toward a family member (Letamo, 2003).

In India, research has documented discrimination in the family, hospitals, community and at the workplace. Notably, women face more discrimination than men (Bharat et al, 2001; ILO, 2003). The healthcare setting has emerged as the most often encountered place of discrimination, followed by familial and community contexts. Forms of discrimination in hospitals include refusal of treatment, discriminatory precautions and lack of confidentiality. Doctors often refuse to aid in the delivery of a positive pregnant woman despite minimal risk of contracting the infection (ILO, 2003). In a study in Mumbai and Bangalore, many healthcare providers and facilities were found to deny care, treat patients poorly

The major causes of stigma are lack of depth in HIV and AIDS knowledge, attitudes toward sexual behaviour and perception of immoral activities

and stipulate conditions for agreeing to treat patients (Bharat et al, 2001). Forms of discrimination included refusal to touch a patient, levying of additional charges and treatment only if the mode of infection was not sexual. All studied hospitals reported testing on patients with marker diseases such as tuberculosis and diarrhoea, mostly without consent. In some settings, healthcare providers were found to assume that all HIV-positive women clients were sex workers – and thus treated patients with a more casual attitude (Bharat et al, 2001). Stigma may also manifest in more subtle forms: for example, a physician may only provide information on heterosexual transmission of HIV, or not discuss sexual activity with adolescent patients (Valdiserri, 2003).

Gender is a strong determinant of response: 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 (Bharat et al, 2001; ILO, 2003; Point of View 2001). Married women respondents are forced to have intercourse with positive husbands, despite knowledge of the status. HIV-positive mothers also reported separation from children or being forced to give up their babies. Notably, research demonstrates that after initial discrimination in the family, most individuals receive eventual support (Bharat et al, 2001, ILO, 2003).

Community reactions to PLWHA include ostracism, differential treatment at death and discrimination in schools against children of infected parents (Bharat et al, 2001; ILO, 2003). Children also often face denial of basic amenities in the community (ILO, 2003). Schools

have refused admission to children of HIV-positive parents or expressed fear of the impact of the presence of an HIV-affected child on other students. In Mumbai, discrimination at death, in the form of mistreating the body or packing it in black plastic bags, was reported as a major source of distress (Bharat et al, 2001). Persons who die of AIDS related illnesses are also often denied traditional rituals at death.

Indian studies demonstrate mixed results regarding discrimination at the workplace. A majority of participants in the studies had not disclosed their status to employers. Limited information collected from employers has illustrated a pattern of denial of the need for HIV policies at the work place or the presence of discriminatory treatment in the workplace (Bharat et al, 2001; ILO, 2003). International experience does indicate significant discrimination at the workplace (Busza, 1999), and the experience in Indian courts confirms that this area will be of considerable concern. Currently, legislative provisions to prevent discrimination in employment are generally applicable to the state. The private sector – although governed by case law that has found it unlawful to dismiss a worker who is qualified and fit and does not pose a risk to others – is not held by strict legal standards currently (Lawyers Collective, 2003). The major impediments to testing and disclosure of HIV positive status are fears of isolation and of job loss. These are not unfounded concerns as Bharat et al (2001) reported employees being denied benefits, promotion or forced into retirement. Respondents who reported support from employers were primarily working with NGOs and Institutes in the field of. Overall, most individuals would not disclose their status to employees and colleagues while those who did

A majority of participants in the studies had not disclosed their status to employers

experienced hostility, poor treatment and job loss.

Stigma and discrimination contribute to the socio-economic vulnerability PLWHA. Early job loss, lost days due to illness and lack of insurance or benefits create increasingly difficult economic circumstances for individuals and households (Mahal, 2004). For employers, stigma can reduce labour supply, lead to lower workforce morale and threaten employee health and productivity (GBC, 2003). Most companies largely deny the need to address HIV and AIDS at the workplace: only 11 percent of Indian private firms maintain a written policy (Bloom et al, 2004). The ILO Code of Practice on HIV/AIDS advocates that at minimum, employers should implement non-discriminatory workplace policies. In the absence of clearly defined corporate policies in India and a lack of an overarching anti-discrimination legislation, PLWHA will continue to face economic vulnerability due to workplace discrimination. Currently, the Government of India is drafting non-discrimination legislation, a positive step to decrease stigma (Lawyers Collective, 2003).

The Indian Network of People Living with HIV (INP+) was constituted to raise awareness and advocate for the rights and needs of PLWHA. Increasingly, NACO and other agencies working in the field of HIV and AIDS address stigma and discrimination in prevention, treatment and care efforts. International research points to efforts such as awareness-raising seminars for healthcare providers, mobilisation of community leaders and additional research on stigma as a means to reduce its impact (Busza, 1999). UNAIDS and WHO have declared that eradicating stigma and discrimination is critical to expanding prevention and care: the World AIDS Campaign

(2002-2003), 'Live and Let Live' explores how individuals can eliminate these factors and improve the lives of PLWHA.

Research clearly illustrates that stigma and discrimination hinders prevention, treatment and care for PLWHA whose concerns for everyday life are strongly dictated by the level of discrimination. The likelihood of having economic security, childcare and insurance benefits is closely linked to the community response to AIDS. Stigma and discrimination disproportionately affect women and thus require specially tailored gendered strategies. Additional research in India is necessary, particularly at the household and community level, to understand the mechanisms and impacts of stigma. Clearer knowledge of the determinants of stigma and the pathways of discrimination will expand the potential to counter the negative impact and thus improve the lives of PLWHA.

1.2 HIV and AIDS scenario in the six high-prevalence states of India

The impact study has been undertaken by National Council of Applied Economic Research (NCAER) in six high-prevalence states namely Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland. When HIV prevalence in any state is five percent or more among high risk groups (like commercial sex workers, MSMs and those attending Sexually Transmitted Diseases (STD) clinics) and 1 percent or more among the low risk population (like women attending antenatal clinics), then the state is considered to be in *high-prevalence*. All the six states have prevalence rates much higher than the threshold limits defined above, particularly with respect to prevalence rates seen in STD clinic attendees. The situation is most serious

The likelihood of economic security, childcare and insurance benefits is closely linked to community response to AIDS

in Andhra Pradesh. Of the six states considered for this study, Andhra Pradesh has recorded the highest prevalence of 2.00 percent among the antenatal clinic attendees and 22.8 percent among STD clinic attendees in 2005 (Table 1.2).

These six states together (as may be calculated from Table 1.3) accounted for nearly 83 percent of the AIDS cases in India as on 31 July 2005. Nearly 56 percent of the cases were in the age group of 30-49 years. If the age group 15-29 years is also included, then nearly 89 percent of the cases belonged to the age group 15-49 years, which are the most productive years. Since most HIV infected individuals are in their prime productive years, HIV is considered to be a serious threat to economic growth.

NACO estimates show that the mode of HIV transmission in 86 percent of the AIDS cases reported has been sexual while 2.4 percent of the cases were due to Injecting Drug Use (IDU). However, there are region-wise differences in the dominance of a particular mode of transmission. While the main mode of transmission is unprotected sex in the southern states, in the North-East of

India, it is mainly due to injecting drug use. This is especially true in the states of Manipur and Nagaland, which lie adjacent to the drug-trafficking 'Golden Triangle' zone (Solomon et al, 2004).

The important factors responsible for the higher prevalence rate of HIV in the southern states have been assessed by NACO on the basis of the Behavioural Surveillance Survey (BSS) 2001. These factors comprise of relatively high-prevalence of sex with non-regular partners, high-prevalence of Sexually Transmitted Infections (STIs), low condom use, high trafficking of girls and women, and a large number of national highways. These hold especially true in the case of Andhra Pradesh as revealed by the Andhra Pradesh State AIDS Control Society's (APSACS) report on Situation and Response (APSACS, 2005). According to the Behavioural Surveillance Report (2001), 19 percent of men and seven percent of women reported sex with non-regular partners even as the national averages were 12 percent and 2 percent respectively. It has been noted that the women commercial sex workers are generally from lower economic strata, often from remote rural areas, are poorly educated and have little knowledge of HIV and AIDS. This makes it difficult to implement programmes targeted at increasing the use of condoms among sex workers. Reza-Paul (2005) found that 26 percent of sex workers in the city of Mysore (Karnataka) were HIV-positive. While 14 percent of the women used condoms consistently with clients, 91 percent of them never used condoms during sex with their regular partners.

IDU was emphasised to be the main channel of transmission in the focus group discussion conducted by the NCAER team in Manipur. The participants argued that the major reason for ID users

In 2001, the important factors for higher prevalence in the southern states are: high-prevalence of sex with non-regular partners, high-prevalence of Sexually Transmitted Infections (STIs), low condom use, high trafficking of girls and women, and a number of national highways

Table 1.2
HIV prevalence rates for
high-prevalence states-2005
(in Percentages)

States	STD clinics	ANC clinics
Andhra Pradesh	22.8	2.00
Karnataka	12.0	1.25
Maharashtra	10.4	1.25
Tamil Nadu	8.4	0.50
Manipur	7.2	1.50
Nagaland	1.7	1.43

Source: NACO (www.nacoonline.org)

not using safe syringes was the fear of being caught by the police who would treat them as criminals since IDU is a criminal offence. Pisani (2003), in his study on epidemiology of, has noted that most drug injectors knew where to get sterile needles but still nearly 88 percent of them chose to use non-sterile needles. There also seems to be an overlap between the IDU and commercial sex in the North-Eastern states, as was hinted by some participants in the focus group discussion at Manipur. This is also brought out by available statistics on this issue, with Behavioural Surveillance Studies showing that nearly 20 percent of the sex workers in Manipur were also injecting drugs. IDU is also emerging as a problem in other states, especially Tamil Nadu.

Studies of this nature are of importance at this juncture because this is a critical time for India's response to the epidemic. Of particular concern is the spread

Table 1.3
AIDS cases in India
(Reported by NACO)
(From 1986 to 31 July 2005)

S. No.	State/UT	AIDS Cases
1	Andhra Pradesh	12,349
2	Assam	225
3	Arunachal Pradesh	0
4	A and N Islands	33
5	Bihar	155
6	Chhattisgarh	0
7	Chandigarh (UT)	1,260
8	Delhi	970
9	Daman and Diu	1
10	Dadra and Nagar Haveli	0
11	Goa	567
12	Gujarat	5,636
13	Haryana	486

14	Himachal Pradesh	252
15	Jharkhand	0
16	Jammu and Kashmir	2
17	Karnataka	2,896
18	Kerala	1,769
19	Lakshadweep	0
20	Madhya Pradesh	1,396
21	Maharashtra	13,747
22	Orissa	467
23	Nagaland	736
24	Manipur	2,866
25	Mizoram	106
26	Meghalaya	8
27	Pondicherry	302
28	Punjab	292
29	Rajasthan	1,153
30	Sikkim	8
31	Tamil Nadu	52,036
32	Tripura	5
33	Uttaranchal	0
34	Uttar Pradesh	1,383
35	West Bengal	2,397
36	Ahmedabad M.C.	621
37	Chennai M.C.	0
38	Mumbai M.C.	7,484
	Total:	1,11,608

Source: NACO (www.nacoonline.org)

of infection to low risk population especially in rural areas. As per the latest NACO statistics, 58.57 percent of the HIV infected population is in rural areas, even though the HIV infection first started and spread in urban areas. Women are particularly vulnerable due to their lower social status and lack of control over decisions that affect their lives. This increases the possibility of spread of infection from HIV-positive males to their spouses. Since the level of literacy among women in India is very low, they also lack awareness about modes of transmission of HIV. This further increases their vulnerability

to HIV. While the rate of prevalence in India is low at present, it is possible to overlook crucial areas. Given India's size and the mobility of its population, the risk of these sensitive areas erupting into large-scale crisis affecting the general population with little or no notice is real. In this context, it is important to know what the costs of such oversight can be as well as determine the proper social and economic response to this epidemic. The financial demands of providing Anti Retroviral Therapy (ART) and treating Opportunistic Infections (OI) are only beginning. Given the levels of HIV and AIDS already present in India, the cost of drugs will be a major issue, apart from the increased pressure it is likely to put on the public health system. Due to the large population of India even a small rate of prevalence translates into large absolute numbers. Of particular concern is the stage of HIV prevalence and incidence in some large states like Uttar Pradesh and Bihar, where current rates of prevalence are low but any rise can have a considerable impact. These states are highly vulnerable due to the presence of large illiterate population, which is also mobile as migrant workers temporarily move out to other states in search of employment. According to the 2001 Census, the low prevalence states of Uttar Pradesh and Bihar have the largest number of net migrants moving out of the state (2.6 million and 1.7 million respectively). The 2005 AIDS epidemic update warns that even relatively minor increases in HIV transmission in the densely populated states of Uttar Pradesh and Bihar could translate into large numbers of people becoming infected.

1.3 Objectives of this study

The main focus of this study is:
Analyse the nature and type of socio-economic impact of HIV and AIDS on

households with focus on the relationship between and distribution of income and wealth, changes in the structure of employment and social security.

This research is based on the data collected from an independent primary survey by NCAER. The survey was supplemented with information gathered through focus group discussions and case studies. This study contains a review of levels and patterns of income and expenditure of the HIV affected households and a comparison with those, which are not affected by it. An important consideration here is the difference between HIV households and non-HIV households with respect to health expenditure. This is important in India especially because the cost of treatment is mostly borne by the households. Increased burden of coping with the health expenditure along with decline in household income due to an earning member falling sick can cause a variety of problems like liquidation of assets, a debt trap, reduction in savings and even lower investment in education of children.

In terms of the impact on education, while some assume that parents would weigh the returns to education including the probability of child survival (Bell, Devarajan and Gersbach, 2003), others have assumed that parents are altruistic with respect to a child's education (Basu, 1998). The prevalence rate in India is not high enough to make those households who have not been affected by HIV to weigh the probability of child survival before investing in children's education. However, if HIV households invest less on children's education, then one may expect that with greater spread of the infection, skilled labour force would decline more than would be expected, based on the decline in labour supply of

This study contains a review of the levels and patterns of income and expenditure of HIV affected households and a comparison with those, which are not affected by it

those who are directly affected by it. The analysis shows that HIV households do spend less on the education of children and this is linked to lower rates of enrolment among these households as compared to non-HIV households.

The direct impact of HIV on poverty and inequality has not been demonstrated empirically at the national or state-level for any country (UNDP, 2003). is likely to push households into the poverty trap, thus undoing the hard-earned achievements in this regard in a developing economy. The most important economic impact of is assumed to be reduced labour supply due to morbidity and death. This may be measured by looking at the difference between work participation rates of HIV households and non-HIV households. Household-level analysis is important because reduces the labour supply not only of the infected person but also of those who have to take care of the infected person.

It was deemed necessary to place greater emphasis on stigma and its quantification. However, it was also noted that it may not be possible to quantify all the channels and impacts of social stigma. Certain impacts such as being thrown out of job or school or shift in place of residence due to discrimination in the neighbourhood can be captured in a general survey through a structured questionnaire. But, more important implications and channels of social stigma may come only through in-depth interviews and group discussions. This may particularly be true of the problems faced by women. For example, some 40 percent of the women tested at the Osmania Hospital in Hyderabad did not turn up to learn the results of their tests (CSIS, 2004). There may be a number of reasons for this, but an important one reason could be that they fear the social consequences

if the result turned out to be positive. Discrimination against women within the household may be the most important form of social stigma which increases the obstacles to fighting the infection. This is however especially difficult to tackle through a structured/semi-structured questionnaire. Hence, the emphasis was placed on case studies, in-depth interviews and group discussions.

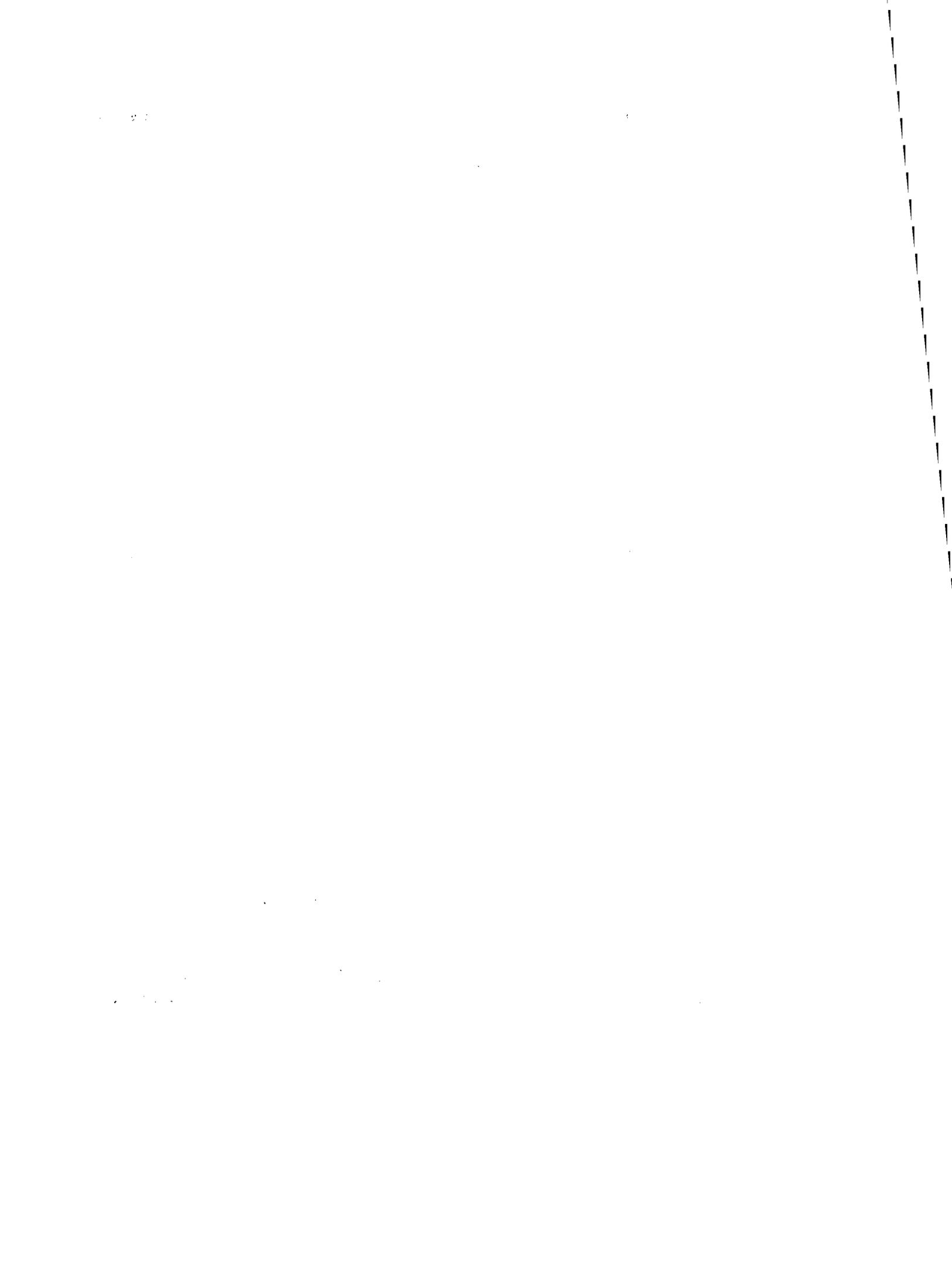
This report is divided into ten chapters. In the following chapter the methodology used for conducting the household survey and the qualitative research methods used for gathering information are discussed. Chapter three presents background characteristics of the sample households and a brief profile of the PLWHA who were interviewed for the study. Chapter four studies the impact of HIV status on income and employment of the PLWHA and their caregivers followed by a detailed analysis of the pattern of consumption and savings of the households in Chapter five. The presence of an HIV-positive person can affect the schooling of the children due to various reasons. Chapter six attempts to measure the impact of on the schooling of the children in terms of school enrolment, reasons for non-enrolment and dropout, type of school attended and school attendance.

The HIV households face tremendous financial burden due to medical cost of treating the opportunistic infections (OIs). In Chapter seven, the pattern of morbidity and the health seeking behaviour of the sample PLWHA and the out-of-pocket expenditure incurred on treatment of OIs are discussed. The social stigma attached with is the major inhibiting factor in controlling the spread of the infection. Chapter eight not only tries to capture the magnitude of stigma and discrimination faced by PLWHA at various social settings,

The most important economic impact of HIV and AIDS is assumed to be reduced labour supply due to morbidity and death

but also attempts to assess the knowledge and awareness about the infection among the general population and attitude of the people towards PLWHA. The impact of on girls and women has been discussed in Chapter nine. Since women and girls are more vulnerable to HIV because of their

low socio-economic status in the society, it was considered pertinent to detail the nature and patterns of the impact on them. The concluding Chapter ten, offers some broad conclusions based on the findings and suggests certain policy measures.



Data and Methodology

As already outlined in Chapter one, the principal objective of this study is to assess the socio-economic impact of HIV and AIDS on the infected/affected individuals and households. This assessment is based on a household survey conducted by NCAER. The methodology and data sources for the study of socio-economic impact on households have been outlined below.

The survey was conducted in the six high-prevalence states of Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra, Manipur and Nagaland covering both rural and urban areas. Keeping in mind the objectives of the study, NCAER conducted a survey of both HIV and non-HIV households. The purpose of surveying both HIV and non-HIV households (control group) is to compare their socio-economic characteristics, pattern of consumption and saving and borrowing of the households, prevalence of morbidity and differences in enrolment and dropout rates of children. In addition, case studies and Focus Group Discussions were also conducted to supplement the quantitative study. The survey of the non-HIV and HIV households commenced in October 2004 and was completed in May 2005.

2.1 Sample design for the household survey

2.1.1 Sample size

The survey covered more than 8,000 households in the six states. Out of this, one-fourth of households (around 2000) are those which have PLWHA, spread across all the six states. This number is large enough considering the difficulties involved were in identifying PLWHA and their households and more importantly in securing their consent for the interview.

For a state-level analysis, a minimum sample of 400 households are required. Therefore, around 400 HIV-positive households per state were drawn from Andhra Pradesh, Karnataka, Tamil Nadu and Maharashtra. A sample of around 450 HIV households from both the states of Nagaland and Manipur was drawn since they are much smaller in size in terms of their population.

In terms of disaggregation, the sample was drawn from both the rural and urban areas but contained more of urban households. The bias towards urban households happened inadvertently to ensure confidentiality of the PLWHA respondents. To ensure this, NCAER did

The selection of the districts depended upon the concentration/distribution of HIV and AIDS cases

not access the HIV households directly but depended on the Voluntary Counselling and Testing Centres (VCTC) counsellors who had knowledge of the address of the PLWHA households and therefore acted as field investigators for this survey. The VCTC counsellors drew the sample mainly from the various government health facilities and the care and support homes run by the NGOs that are located in urban areas. They interviewed all the PLWHA who gave their consent to be interviewed and in the process there was a bias towards urban households.

Further, specifically selecting rural HIV households is difficult, time consuming and would have increased the cost. It would have meant covering a much larger geographical area without any guarantee of an interview. Even after identifying and visiting households in villages, there was always a possibility that the households would not give consent to be interviewed.

Even after taking the estimates of NACO which indicate that 59 percent of PLWHA are from the rural areas, the prevalence rate in urban areas is likely to be higher since the urban population size is substantially lower than the rural. Since

the HIV epidemic started to spread from urban areas, given the higher prevalence rate in these areas, the selection of a bigger urban sample is justifiable.

2.1.2 Selection of districts

Based on the Sentinel Surveillance reports of the respective State AIDS Control Societies (SACS), the 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 SACS. The districts selected for the survey in the six HIV high-prevalence states are given in Table 2.1.

2.1.3 Criteria for selection

The state capital, which also happens to be one of the high-prevalence districts, was purposively selected as one of the sample sites from each state and most of the urban sample was drawn from capital city. 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.

The selection of the districts also depended upon the concentration/

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 and West, Chandel, Thoubal, Bishnupur, Churachandpur
Nagaland	Dimapur, Kohima, Tuensang
Tamil Nadu	Chennai, Namakkal, Tiruchirappali, Theni, Erode, Tirunelveli

distribution of HIV and AIDS cases. Districts where the concentration of HIV and AIDS cases was higher were selected to make the survey more cost-effective and less time consuming. A related concern was that if the district does not have enough number of cases, the required number of HIV households might not be captured.

2.1.4 Selection of HIV households

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 VCTCs situated at some of the government hospitals maintain a register with the addresses of those who have tested positive, but the VCTCs could not provide the list

to NCAER research team due to the confidentiality clause in conducting the HIV test. 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 not get access to the addresses of PLWHA. Instead it was decided to 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.

These persons were provided training by the NCAER team and were 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 (GH), Tuberculosis (TB) hospitals, care and support homes and drop in centres run by NGOs, VCTCs, Networks of Positive People and the residences of PLWHA. Table 2.2 presents

The HIV household sample was drawn mainly from the various government health facilities and care and support homes run by NGOs

Table 2.2
Distribution of sample HIV households by place of interview

(in Percentages)

Place of interview	Rural	Urban	Total
VCTC	17.4	11.7	14.2
TB hospital	6.2	3.3	4.6
Care and support home, community care centre and drop in centres	13.8	11.9	12.7
General hospital	11.2	9.8	10.4
Antenatal and maternity ward	3.2	3.3	3.3
ARV collection centre	1.3	2.5	2.0
Network of positive people's office	5.8	6.3	6.1
NGO office	4.5	7.6	6.3
Residence	35.5	42.0	39.2
Others	0.90	1.53	1.26
Total	100	100	100

the percentage distribution of sample HIV households by the place where they were interviewed.

More than 40 percent of the urban and 36 percent of the rural households were interviewed at their residences. Since the survey was mostly conducted through the VCTC counsellors, nearly 14 percent of the households were interviewed at the various VCTCs across the states. The care and support homes and the GH respectively accounted for 13 and 10 percent of the households interviewed.

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, which is not likely to affect those in Stage I could be assessed. However due to practical difficulties in contacting/interviewing many PLWHA in Stage III and IV, the sample had more of PLWHA in Stage I and II. While 43 percent of PLWHA were in Stage III and IV, 37 percent were in Stage II and 20 percent in Stage I.

Also, an attempt was made to select the sample from people belonging to different economic strata of society. However, in spite of their best efforts, the VCTC counsellors who acted as the field investigators, could not get access to the upper middle class and rich households since they drew their sample mainly from the public health facilities and the NGOs, which mostly cater to poor/low-income households. The middle class/rich PLWHA would generally approach 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 them, it was learnt that PLWHA visit them for the treatment

of opportunistic infections 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 did not live in a household set-up (eg, sex workers, persons living in shelter homes, hostels) were excluded from the sample, as the focus of the study was to examine the impact of HIV and AIDS on the households.

2.1.5 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 was to make comparisons with the HIV households, three households belonging to similar socio-economic strata were selected for the study. The ratio of 1:3 was arrived at as a compromise between two conflicting objectives. The first was to select a large number of non-HIV households with matching characteristics to each HIV household. This was to reduce the variance in the non-HIV sample and in order to get as close a match as possible. Second was not to overshoot the budget. Keeping in mind these two objectives, the ratio of 1:3 was taken to be the best possible option. 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 localities 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 (control group), a listing of the households in the locality/village was undertaken. In

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

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 was gathered which consisted mainly of the income of the household and occupational and educational status of the head of the household. 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 the variation in the sample was being captured. The respondents from non-HIV households were adult men or women in the age group of 20-60 years since it is the most relevant group to answer questions on knowledge and awareness about HIV and AIDS. Accordingly, any household that did not have a member in this age group was not selected for the survey.

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 was more than one adult PLWHA in a family, an attempt was made to interview the second person also. The state-wise distribution of the sample households is presented in Table 2.3.

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

Table 2.3
State-wise distribution of sample HIV households

State	Number of sample HIV HHs			Number of sample non-HIV HHs		
	Rural	Urban	Total	Rural	Urban	Total
Andhra Pradesh	189	211	400	528	718	1,246
Karnataka	199	202	401	580	622	1,202
Maharashtra	147	256	403	439	769	1,208
Tamil Nadu	223	187	410	650	553	1,203
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	1,341	2,386	--	--	--

2.1.6 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, differences in enrolment and dropout of children and time-use pattern of all the household members. In addition to this, 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.

Similarly, the questionnaire for the HIV households was designed to collect additional information about the 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 from the HIV households.

2.2 Qualitative techniques

The NCAER research team which was well trained in qualitative research techniques, decided to conduct case studies and Focus Group Discussions (FGDs) by themselves in order to collect information that would supplement the findings of quantitative survey and probe into the qualitative aspects such as how and why.

2.2.1 Case studies

Case studies were conducted to capture in-depth information on PLWHA as they are a better tool to capture problems like stigma and discrimination within the household. Chatting and using semi-structured in-depth interview schedules

with the PLWHA make them feel more relaxed and give them confidence to reveal facts more comfortably. For the purpose of conducting case studies, unique/typical cases of PLWHA were selected with the help of field investigators, NGOs and key informants of the locality. Two or three case studies were conducted in each of the states.

2.2.2 Focus group discussions

A total of six FGDs, one in each state, were conducted with the members of the Network of Positive Persons. The main purpose of the FGDs was to understand the social and economic problems faced by the network and the legal and other related issues taken up by them. The findings from FGDs are of help in complementing the analysis and interpretation of data collected by the household survey.

2.3 Field investigators

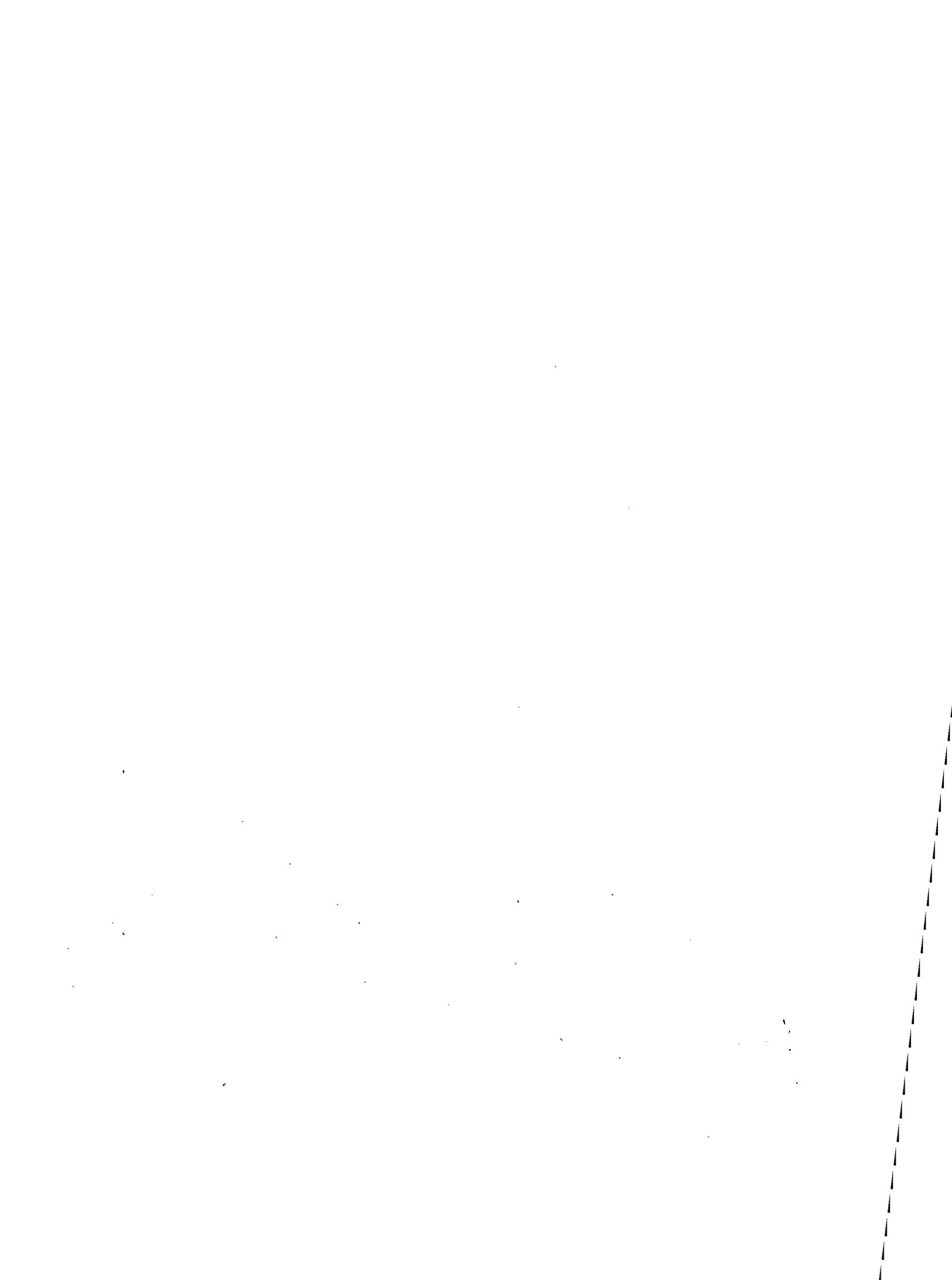
The survey team comprised of both male and female field investigators from the selected sample districts of the respective states. In the states of Karnataka, Maharashtra and Tamil Nadu, the VCTC/Prevention of Parent to Child Transmission (PPTCT) counsellors located at the respective district hospitals and other government health facilities were used for conducting the survey. In Manipur, along with the counsellors of the Manipur State AIDS Control Society, persons working with NGOs providing care and support services to PLWHA were also used to select the sample and conduct the survey. In Nagaland, as suggested by the State AIDS Control Society, NEDHIV, the NGO located at Dimapur conducted the survey with the help of the counsellors and outreach workers working for the various NGOs located in Dimapur, Kohima and Tuensang. In Andhra Pradesh, some of

the PLWHA trained by the APSACS to do counselling and outreach work were utilised for canvassing the questionnaire. They could easily access the households affected by HIV and AIDS and even visit their homes to fill up the questionnaire.

With the exception of Andhra Pradesh, in all the other states the persons who worked as Field Investigators were mostly postgraduates in subjects like Social Work or Psychology and a few were graduates. In Andhra Pradesh, of the ten Field Investigators, only four were graduates and others had studied only upto high school level. However all of them had sufficient training to work as counsellors and to do outreach work for the PLWHA. The questionnaires were translated into regional languages and those who were fluent in the local languages were selected for conducting the survey.

2.4 Training of field investigators

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 told 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 respondent to answer all the questions.



Profile of

for the HIV households and nearly one-third for the non-HIV households.

Nearly 60 percent of the household heads in HIV households were in the age group of 20 to 50 years and in the case of non-HIV households, this percentage was lower at 53 percent (Table 3.2). While about eight percent of the heads of HIV households belonged to the 51-60 age group, only six percent of the heads of non-HIV households were in

this age group. Only a small percentage was above 60 years. 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 better educated than the HIV household heads. About 28 percent of the HIV and 20 percent of the non-HIV household heads

Table 3.2
Occupation and level of education of head of the households

	HIV households			Non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
(in Percentages)						
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
Upto primary	17.5	14.9	16.0	20.9	15.7	17.9
Upto middle	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

were illiterate (Table 3.2). Of the sample households about 29 percent of the HIV household heads and 32 percent of the non-HIV household heads had completed high school or senior secondary level. The percentage of heads who have studied beyond senior secondary level was 11 in the case of HIV 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 has been more or less same for both types of households (the pattern of distribution of household heads by their income categories is shown in Table 3.3). A sizeable number of the heads of the households were seen to be working as wage labourers, either in the agricultural sector or in the 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.

3.1.2 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 did not work out to be exactly same. While nearly 24 percent of HIV households were from the lowest income group of less than Rs. 20,000 per annum, only about 10 percent of non-HIV households belonged to this group. While 35 percent of HIV households were found to be in the income range between Rs. 20,001 and Rs. 30,000, the non-HIV households in this range accounted for 29 percent of the sample. However, the percentage of households in the annual income categories Rs. 30,001-41,000 and Rs. 41,000 and above were almost similar for both types of households.

Most of the sample HIV households belonged to low economic and educational strata of society

The average household income was 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 belonged to low economic and educational strata of society. Although enough evidence shows that it is the poor people who are more vulnerable to

Table 3.3
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. Upto 20,000	32.9	17.3	24.0	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 and 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

HIV (UNDP, 2003), in the present sample there are more households from the poor and low-income categories due to lack of accessibility of the field investigators to the middle, upper middle and rich households. This happened because the sample was drawn mainly from the public health facilities and the NGOs mostly catering to poor/low-income households. As compared to non-HIV households, lesser percentage of HIV households seem to have basic amenities like electricity, own toilet and private tap/pump etc. (Table 3.4)

The data shows that only 30 percent of the sample HIV households and one-third of the non-HIV households are living in pucca houses; only 31 percent of the HIV and 37 percent of the non-HIV households have a tap or a hand pump in their house, indicating the poor standard of living of these households.

Sanitary facility is also an indicator of the standard of living of the households. Only 57 percent of HIV and 59 percent of non-HIV households have toilet facility in their homes and as expected this

Table 3.4
Distribution of sample households by the availability of basic amenities

(in Percentages)

Characteristics	HIV households			Non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Type of house						
Pucca	22.9	36.2	30.4	32.3	34.4	33.5
Semi-pucca	45.4	42.2	43.6	48.2	46.6	47.2
Kuchha	31.7	21.6	26.0	19.5	19.0	19.2
Drinking water						
Private tap/hand pump	20.4	39.3	31.2	26.1	45.1	37.2
Public tap/hand pump	54.4	41.7	47.1	57.9	41.7	48.5
Tubewell	7.2	5.4	6.2	5.1	4.9	4.9
Supply tanker	1.6	4.2	3.1	0.4	1.5	1.0
Well/river/pond	14	8.1	10.7	10.0	6.3	7.8
Any other	2.4	1.2	1.7	0.5	0.5	0.5
Sanitation facility						
Household having toilet	42.0	68.8	57.2	43.2	70.2	58.9
Electricity at home						
Household having electricity	85.1	91.6	88.8	91.2	95.1	93.4
Type of fuel for cooking						
Firewood	60.4	31.8	44.1	63.8	26.9	42.3
Coal	1.1	1.6	1.4	1.8	2.7	2.3
Kerosene	9.4	18.5	14.6	5.9	14.2	10.7
(LPG) gas	28.4	47.8	39.5	28.0	56.1	44.3
Others	0.6	0.2	0.4	0.5	0.1	0.3
Total	890	1,178	2,068	2,603	3,621	6,224

percentage has been much lower for the rural households. Not all the houses have electricity; 89 percent of the sample HIV households and 93 percent of the non-HIV households have electricity. As compared to sample HIV households, the percentage of households having electricity has been higher for the non-HIV households and expectedly higher for the urban households as compared to the rural households.

For cooking, a high percentage of both HIV (44%) and non-HIV (42%) households are using firewood. Liquid Petroleum Gas (LPG) seems to be another popular mode

with 40 percent of HIV and 44 percent of non-HIV households using it. Kerosene users form a marginally higher percentage in HIV households (15%) as compared to non-HIV households (11%).

The ownership of assets and other consumer durables in the households also indicate that as compared to non-HIV households, the economic status of the HIV households is quite low (Table 3.5). Although a significant number of households own a house; these houses could be just huts. In the case of both HIV and non-HIV households, higher percentage of households own houses

Table 3.5
Distribution of sample households by ownership of assets
and other consumer durables

(in Percentages)

Characteristics	HIV households			Non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Owning agricultural land	32.2	11.2	20.3	34.0	8.1	18.9
Household having livestock	28.4	10.4	18.2	27.5	9.9	17.3
Owning house/flat/plot	62.9	47.7	54.3	85.1	64.1	72.9
Owning consumer durables						
Fan	62.8	69.3	66.5	66.3	77.2	72.6
Bicycle	48.1	40.9	44.0	57.0	49.0	52.4
Radio/transistor	42.4	43.8	43.2	47.9	47.9	47.9
Tape recorder	29.1	42.3	36.6	30.2	46.1	39.5
Television (b/w)	31.8	32.3	32.1	41.3	36.1	38.3
Television (colour)	17.3	34.7	27.2	25.8	47.5	38.4
Refrigerator	4.9	18.3	12.6	8.1	24.4	17.6
Telephone/mobile	12.9	27.3	21.1	16.9	31.1	25.2
Washing machine	1.3	5.8	3.9	1.0	8.0	5.1
Computer	0.8	1.8	1.4	0.8	2.2	1.6
Two wheeler	11.1	17.6	14.8	17.6	23.4	20.9
Car/jeep etc.	1.3	1.9	1.6	2.8	3.8	3.4
Bullock cart	5.2	0.8	2.7	5.5	0.4	2.5
Tractor	1.2	0.6	0.9	1.5	0.3	0.8
Thrasher	0.6	0.3	0.4	0.4	0.1	0.3
Tubewell	6.6	5.2	5.8	7.9	6.4	7.1
N	890	1,178	2,068	2,603	3,621	6,224

A higher percentage of non-HIV households own houses/flats whether in rural or urban areas

in the rural areas as compared to urban areas. A higher percentage of non-HIV households have their own houses/flats whether in rural or urban areas. While as high as 73 percent of the non-HIV households own a house, only 54 percent of the HIV households have a house of their own. It is quite possible that many of the HIV households could have sold their houses in order to meet the medical expenses or to cope up with the loss of income of the PLWHA. The percentage of households owning agricultural land and livestock is marginally higher in case of HIV households. Generally, the percentage of households having consumer durables like fans, bicycles, televisions, telephones, refrigerators, or two wheelers has also been lower for HIV households as compared to non-HIV households, since HIV households, as already seen, belong to a slightly poorer section than the non-HIV households in the sample.

3.2 Profile of the sample PLWHA

As expected, most of the sample PLWHA were in the age group of 20 to 40 years (Table 3.6). In fact the majority of men (48%) were in the age group of 30 to 40 years, while the majority of women (59%) were in the lower age group of 20 to 30 years.

While more than 70 percent of the men are currently married, in the case of women this percentage is lower at 49 percent. What is significant is that while only four percent of men are separated or divorced or abandoned, in the case of female PLWHA this percentage is higher at seven percent. Similarly, while more than one third of the sample female PLWHA are widows, the percentage of widowers among sample

Table 3.6
Profile of sample PLWHA

(in Percentages)

	Male	Female
Age		
< 20	6.4	9.5
20-30	31.6	59.2
31-40	48.0	25.9
> 40	14.0	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
Upto primary	15.2	17.1
Upto middle	16.5	15.7
High school	23.3	22.2
Senior secondary	8.1	6.9
Graduate/diploma	13.1	8.4
Stage of infection		
I	15.8	25.3
II	37.9	36.2
III	33.8	29.7
IV	12.5	8.8
N	1,342	1,043

male PLWHA is much lower at four percent. As expected, the percentage of unmarried women is seen to be 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 who have studied beyond high school level. Not only is the percentage of illiteracy higher among women, also generally at every level of education the

percentage of women is less than that of men.

While 54 percent of the male sample PLWHA are in Stages I or II, in the case of females, as many as two-thirds of the sample are in Stages I or II. Only 12.5 percent of male PLWHA and nine percent of female PLWHA captured in the sample are in Stage IV. As already mentioned in Chapter two, in spite of the efforts taken to select the sample from different stages of infection, due to practical difficulties, not many PLWHA who were in Stage IV could be interviewed. In fact in the case of female PLWHA, there are more samples from Stage I and II.

In Table 3.7, the pattern of occupation of the sample PLWHA at the time of the

survey is compared with the occupation pattern at the time of detection of HIV-status. The purpose of this table is to see whether there has been any change in the pattern of occupation of the sample population as a result of their HIV status. It is seen that in case of both men and women PLWHA, the percentage in most of the categories under occupation is less corresponding to the time of detection of their status. The striking observation is regarding the percentage that is currently unemployed. While only four percent of PLWHA were unemployed at the time of detection of their status, the percentage increased upto 14 percent. Similarly, in the case of women the percentage of unemployed increased from 2.9 to 4.5, the percentage of women as housewives also increased from 36.9 percent to the

While 54 percent of the male sample PLWHA are in Stages I or II, in the case of females, as many as two-thirds of the sample are in Stages I or II

Table 3.7
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	8.0	2.9	9.2	3.3
Agri. wage labour	10.4	10.7	11.1	12.2
Construction worker	5.1	1.9	6.0	2.4
Other non-agricultural labour	9.6	6.9	11.5	7.4
Salaried	22.6	13.3	24.7	13.6
Trade/business	11.0	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	0.1	0.9
Domestic servant	0.1	4.0	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

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

current 39.3 percent. These percentages clearly indicate that while there is some marginal change in the occupation of the PLWHA after discovery of their HIV-positive status, a number of them seem to have withdrawn from the labour force. Thus, the loss of employment for many seems to be the real problem.

The sample is generally spread over all occupations. The highest percentage of men is working as salaried employees (22.6%). 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.

Notes:-

1. The expression Scheduled Castes was coined by the British and embodied in the Government of India Act 1935

to refer to groups which were then known as the depressed classes. After Independence, the SCs are defined in Article 366(24) of the Indian Constitution and the statutory list of these castes is notified. Tribals are known as the adivasis, which means original inhabitants. Being disadvantaged groups, the Constitution granted the tribals preferential consideration after Independence. For this purpose, STs like SCs, are defined in orders issued and amended from time to time by the President. The statutory lists of the SCs and the STs are notified in pursuance of Article 341 and 342 of the Constitution of India.

2. Under Article 340 of the Constitution of India, the backward class commission was set up to identify socially and educationally backward classes for their upliftment. The groups that are identified belong to OBCs category.

Impact of HIV Status on

Impact of HIV Status on Income and Employment

4.1 Introduction

The toll of Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) on income and employment can be very severe. Since HIV affects individuals in their prime earning years, it can imply lost earnings due to morbidity or death of the earning members. The ILO estimates that at least 26 million people infected with HIV worldwide are workers, aged 15 to 49 years, in the prime of their working lives. This is about three-quarters of all adults living with HIV (Lisk, 2002). Persons infected and affected with HIV are often subjected to social stigma/discrimination in employment. In such cases, the lost earnings are greater as individuals are forced to withdraw from the labour force even though they have many productive years left in them. Other members of the household, apart from the PLWHA, may also suffer loss of income and employment, especially at later stages of the infection when the person requires special care.

In many cases, the presence of AIDS means that the household will dissolve, as parents die and children are sent to relatives for care and upbringing. A study in Zambia revealed that 65 percent of households in which the mother had died had dissolved. But a lot happens

to a family before this dissolution as the family becomes bereft of assets and income-earners, further impoverishing the poor. The long-term impact of this on employment, income and productivity can be disastrous. However, one also needs to note that, as emphasised by Basu, Gupta and Krishna (1997), the death of an adult of productive age inflicts a cost on the household that cannot be captured by any simple measures such as loss of income. They further note that the cost to such a household varies considerably, based on socio-economic status and socio-cultural factors such as the role of the family, type of employment and status of women.

In this chapter, the focus is mainly on the household level impact of HIV and AIDS on employment and income. The impact on income and earnings of the household are seen in terms of both (a) loss of employment and thus income due to sickness and death of the AIDS patient and (b) loss of income due to loss of job or absence from work of caregivers of AIDS patients. While an attempt has been made to present some broad indications of the impact these would have at the macro-level, it must be noted that these are tentative, mainly because of the nature of this survey. Given a complete lack of knowledge about the population parameters, it is not possible to present any robust estimates from

a sample of this nature, which is likely to suffer from both sampling and non-sampling errors.

4.2 Income and its distribution in the sample

Since the purpose of surveying non-HIV households is to make comparisons with the HIV households, the survey studied the non-HIV households belonging to similar socio-economic strata as HIV households. There is more or less similar percentage distribution of households, population and income by occupation groups¹ among non-HIV and HIV households. (Table 4.1)

Majority of both non-HIV and HIV households captured in the sample belong to 'Agriculture Wage Labour' group in rural areas (22.50% and 21.01% for non-HIV and HIV households respectively). Their share in income, as may be expected, is comparatively less (15.46 percent and 12.87 percent for non-HIV and HIV households respectively).

As far as urban areas are concerned, majority of non-HIV and HIV households captured in the sample belong to the 'salaried' group (32.95% and 29.46% for non-HIV and HIV households respectively) with their share of income even higher (41.46% and 38.05% for non-

Table 4.1

Distribution of sample households, population and income by occupation

Non-HIV households

(in Percentages)

Occupation	Rural			Urban			Total		
	HHs	Pop.	Income	HHs	Pop.	Income	HHs	Pop.	Income
Cultivation	21.82	24.27	24.38	2.84	3.06	2.55	10.78	11.90	10.19
Agri. wage labour	22.50	22.09	15.46	3.42	3.71	1.89	11.42	11.37	6.64
Non-agricultural wage	18.29	16.86	14.38	25.68	25.42	17.66	22.59	21.85	16.51
Self-employed non-agriculture	14.33	13.65	14.58	24.25	24.21	24.84	20.10	19.81	21.25
Salaried	14.79	14.53	21.29	32.95	32.66	41.46	25.35	25.10	34.40
Others	8.22	8.60	9.91	10.85	10.94	11.60	9.75	9.97	11.01
Total	100								

HIV households

Occupation	Rural			Urban			Total		
	HHs	Pop.	Income	HHs	Pop.	Income	HHs	Pop.	Income
Cultivation	18.20	20.38	19.83	2.89	3.19	2.31	9.48	10.66	8.21
Agri. wage labour	21.01	20.24	12.87	5.18	4.80	2.18	11.99	11.51	5.78
Non-agricultural wage	17.98	16.56	16.78	22.16	21.01	15.51	20.36	19.07	15.94
Self-employed non-agriculture	13.26	12.21	13.48	18.08	17.75	18.43	16.01	15.34	16.76
Salaried	12.47	12.02	20.76	29.46	29.09	38.05	22.15	21.67	32.22
Others	17.08	18.59	16.28	22.24	24.16	23.53	20.02	21.74	21.09
Total	100								

¹The occupation group of the household has been defined by the source of income of the head of the household.

HIV and HIV households respectively). In the rural areas, the agricultural wage labour group is the worst off economically, having a much lower share of income than its share in households and population. In urban areas, the non-agriculture wage labour group is in a similar situation. The cultivation and agriculture wage labour group constitutes a very small proportion

of the sample in the urban areas, which is to be expected.

Income distribution pattern as given by percentage distribution of households and their share in income by 'income classes' in the sample is again more or less similar for both non-HIV and HIV households. (Table 4.2).

Table 4.2
Distribution of households and their share in income by
income categories in the sample

Non-HIV households (in Percentages)

Annual income category	Rural		Urban		Total	
	HHs	Share in income	HHs	Share in income	HHs	Share in income
Upto Rs. 20,000	14.56	5.74	7.21	2.14	10.28	3.40
20,001-30,000	35.19	22.16	24.80	11.78	29.15	15.41
30,001-41,000	16.37	14.20	15.69	10.25	15.97	11.63
41,001-84,000	26.74	37.47	36.90	39.45	32.65	38.76
84,001-1,30,000	5.53	13.93	11.30	21.43	8.88	18.80
1,30,001-1,73,000	1.23	4.41	1.80	4.81	1.56	4.67
Above 1,73,000	0.38	2.10	2.32	10.14	1.51	7.32
Total	100	100	100	100	100	100
Average income per household	40,915		54,641		48,900	

HIV households

Annual income category	Rural		Urban		Total	
	HHs	Share in income	HHs	Share in income	HHs	Share in income
Upto Rs. 20,000	32.92	11.81	17.32	4.46	24.03	6.94
20,001-30,000	21.80	14.75	18.34	8.49	19.83	10.60
30,001-41,000	15.17	14.60	15.53	10.10	15.38	11.62
41,001-84,000	23.82	36.10	32.60	34.21	28.82	34.85
84,001-1,30,000	4.04	11.66	10.36	19.11	7.64	16.60
1,30,001-1,73,000	1.35	5.36	2.63	7.01	2.08	6.46
Above 1,73,000	0.90	5.72	3.23	16.62	2.22	12.95
Total	100	100	100	100	100	100
Average income per household	37,002		55,019		47,266	

The sample is biased towards the lower income groups. Majority of the HIV households in the sample belong to the lower income group of less than Rs. 30,000 per annum. Only about 3.07 percent non-HIV and 4.3 percent HIV households earn more than Rs. 1,30,000 per annum. Around 55 percent and 36 percent HIV households in the rural and urban sample respectively earn less than Rs. 30,000 per annum. For non-HIV households these figures are 50 percent (rural) and 32 percent (urban). It is important to note that the overall average income per household is marginally more for non-HIV households (Rs. 48,900) than for HIV households (Rs. 47,266). The average annual household income and average per capita income by occupation

categories for both non-HIV and HIV households is given in Table 4.3. It shows that the average annual income of HIV and non-HIV households is quite close across all occupational categories in both the rural and urban sample. Even the annual per capita incomes are quite close.

For both non-HIV and HIV sample households in rural and urban areas, the average annual household income and annual per capita income is maximum for the 'salaried' group. As expected, the average annual household income and annual per capita income is higher in urban areas than in rural areas both for non-HIV and HIV sample households, except for annual per capita income

Table 4.3

Average household and per capita annual income by occupational categories in the sample

Non-HIV households

(in Rupees)

Occupational category	Average annual household income			Annual per capita income		
	Rural	Urban	Total	Rural	Urban	Total
Cultivation	45,720	48,935	46,213	9,334	10,265	9,474
Agri. wage labour	28,048	30,172	28,418	6,502	6,288	6,461
Non-agricultural wage	32,166	37,577	35,745	7,921	8,573	8,363
Self-employed non-agriculture	41,630	55,985	51,705	9,928	12,662	11,877
Salaried	58,902	68,754	66,350	13,620	15,662	15,169
Others	49,309	58,385	55,185	10,702	13,074	12,220
Total	40,915	54,641	48,900	9,291	12,338	11,068

HIV households

(in Rupees)

Occupational category	Average annual household income			Annual per capita income		
	Rural	Urban	Total	Rural	Urban	Total
Cultivation	40,309	43,982	40,946	8,933	10,036	9,119
Agri. wage labour	22,670	23,124	22,782	5,839	6,297	5,947
Non-agricultural wage	34,529	38,516	37,001	9,300	10,257	9,896
Self-employed non-agriculture	37,628	56,079	49,501	10,137	14,426	12,942
Salaried	61,593	71,067	68,771	15,862	18,172	17,615
Others	35,267	58,202	49,781	8,036	13,530	11,488
Total	37,002	55,019	47,266	9,180	13,893	11,845

for non-HIV households in urban areas belonging to the 'agriculture wage labour' group. As noted above, the overall average annual household income for non-HIV households is marginally higher than for HIV households. The average annual household income is higher across occupation categories for non-HIV households than for HIV households in all occupation groups except for 'salaried' and 'non-agriculture wage' groups.

As far as overall annual per capita income is concerned, it is slightly higher for HIV households (Rs. 11,845) than for non-HIV households (Rs. 11,068). Comparing within occupation groups, the annual per capita income is found to be higher for HIV households only in the following three occupation categories: 'non-agriculture wage', 'salaried' and 'self-employed non-agriculture'. Both, average annual household income and annual per capita income is higher for HIV households belonging to 'salaried'

and 'non-agriculture wage' occupation groups. Per capita income for HIV households is also higher than for non-HIV households when households are classified by the number of earners per household (Table 4.4). The higher annual per capita income for HIV households is because of the smaller average size of HIV households. The average household size for HIV households is lower than it is for non-HIV households (Table 4.4).

The majority of both non-HIV and HIV households with only one earning member belong to the 'upto Rs. 20,000' annual household income group. The majority of households with three, four or greater than four earners belongs to 'Rs 84,001 and above' annual household income group. An important thing to note is that as the number of earners goes up, the average household income also rises. But the per capita income initially rises with the increase in the number of earners and then drops. The average household size increases

Overall average annual household income for non-HIV households is marginally higher than for HIV households

Table 4.4
Households by number of earners and annual household income in the sample

Annual household income	Percentage of households by number of earners				Total
	1	2	3	4 and above	
Upto Rs. 20,000	51.97	36.95	8.50	2.59	100
20,001-30,000	41.07	42.35	12.77	3.81	100
30,001-41,000	34.48	39.11	19.24	7.17	100
41,001-84,000	32.33	34.33	19.97	13.37	100
84,001 and above	17.75	41.95	24.88	15.42	100
Total	34.49	38.60	17.70	9.22	100
Average income per household	43,422	53,125	62,000	66,549	48,900
Per capita income	10,814	11,670	11,268	9,540	11,068
Average household size	4.0	4.6	5.5	7.0	4.4
Dependency ratio	4.2	2.3	1.8	1.6	2.8

HIV households

Annual household income	Percentage of households by number of earners				Total
	1	2	3	4 and above	
Upto Rs. 20,000	47.94	37.46	10.48	4.13	100
20,001-30,000	34.36	45.60	16.61	3.42	100
30,001-41,000	33.54	44.17	18.40	3.89	100
41,001-84,000	29.49	36.94	19.66	13.90	100
84,001 and above	18.05	41.49	23.65	16.80	100
Total	32.93	40.47	17.69	8.91	100
Average income per household	40,150	52,928	62,483	72,579	47,266
Per capita income	11,557	12,436	11,789	10,887	11,845
Average household size	3.5	4.3	5.3	6.7	4.0
Dependency ratio	3.8	2.1	1.8	1.5	2.6

and dependency ratio decreases, with an increase in number of earners. Dependency ratio has been taken as the number of persons dependent on the income earners.

$$\text{Dependency Ratio} = \frac{\text{Total population per household}}{\text{Total number of earners per household}}$$

Controlling for number of earners, the dependency ratio for non-HIV households is found to be marginally

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 physical-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. *

higher than for HIV households, again because of the smaller average size of HIV households.

The above description clearly shows that because of smaller average size of sample HIV households, the annual per capita income is higher and the dependency ratio is smaller for the sample HIV households. Despite the average annual income per household being higher for sample non-HIV households compared to sample HIV households, the smaller size of the family results in higher per capita income of the HIV households. This tends to confirm the findings of a number of macro-economic studies at household level in which simulations suggest that while aggregate real GDP is likely to fall due to AIDS epidemic, the impact on per capita GDP is not likely to be as pronounced. This is primarily because while the AIDS epidemic reduces the aggregate GDP, it also reduces the population size. For instance Kambou, Devarajan and Over (1992) find that the AIDS epidemic would reduce the growth of real GDP in Cameroon by nearly two percentage points but real income per capita would not be affected. Similarly, MacFarlane and Sgherri (2001) conclude that the direction of impact of HIV and AIDS on rate of growth of real per capita income is not clear and it could even increase faster than in a no-AIDS scenario depending on the specific scenario considered. However, the results need to be interpreted carefully. It should not imply that the long-term impact of the epidemic on per capita income is going to be insignificant. The impact will not be visible on households where the PLWHA members are still alive and working. It is likely to be a very different scenario for the household when these members are not alive or not able to work at all. It must also be kept in mind that the spread of the epidemic would further worsen the

scenario and the impact would not be visible, with the prevalence rate still not having reached the levels of some of the African economies.

Further, while the other studies have focused on the reduction in population due to AIDS related death, the small size of HIV households in the sample can be due to multiple reasons, such as, PLWHA generally seem to live in a nuclear family, PLWHA prefer not to have births in the family.

4.3 Work force participation rate among non-HIV and HIV households in the sample

Participation is defined as the extent to which the population is willing and able to work. This work may be full-time, part-time or casual. For sample HIV households, the Work Force Participation Rate (WFPR) is higher than non-HIV sample households in both rural and urban areas and in all age groups (Table 4.5 (a)). The main reason behind this is likely to be the increased financial burden due to illness of HIV patients in the HIV households. The epidemic puts additional burden on all the members of HIV households to earn more. As can be seen from Table 4.5 (a), the Work Force Participation Rate of non-HIV persons that are children (0-14 years) or elderly (60 and above years) in the HIV households is higher than that of the same age group in non-HIV households. This confirms the view expressed in the literature that the HIV negative persons in the HIV households, especially the elderly, are put under considerable burden to look after the needs of the household. For instance, Wachter et al (2003) found the chance of losing an adult child to be 70 percent higher than if there were no AIDS epidemic in Thailand. They note that although the overall prevalence

The Work Force Participation Rate of non-HIV persons that are children (0-14 years) or elderly (60 and above years) in the HIV households is higher than that of the same age group in non-HIV households

Table 4.5 (a)
Work force participation rate by age group and place of residence

(per 100)

Age group	HIV households									Non-HIV households		
	PLWHA			Non-HIV persons			All			Rural	Urban	Total
	Rural	Urban	Total	Rural	Urban	Total	Rural	Urban	Total			
0-14	1.64	0.00	0.71	2.34	0.97	1.59	2.30	0.92	1.54	0.94	0.37	0.60
15-60	70.51	70.00	70.21	52.70	42.20	46.60	61.01	54.83	57.45	56.32	47.22	51.06
60 and above	33.33	33.33	33.33	37.95	28.38	32.87	37.85	28.57	32.89	30.40	27.85	28.90

Table 4.5 (b)

Work force participation rate by age group and sex in HIV households

(per 100)

Age group	HIV households					
	PLWHA		Non-HIV persons		All	
	Male	Female	Male	Female	Male	Female
0-14	0.00	1.61	1.52	1.67	1.43	1.67
15-60	84.93	52.54	68.28	31.87	77.18	40
60 and above	40	25	44.72	18.32	44.57	18.51

PLWHA falling in the age group 15 to 60 years have a higher WFPR than non-HIV persons in both rural and urban areas

is two percent, upto 13 percent of These may lose adult children before their own deaths. Caregiving responsibilities also often lie with the older generation. The case study presented in Box 1 demonstrates this scenario in India as well.

PLWHA falling in the age group 15 to 60 years have a higher WFPR than non-HIV persons in both rural and urban areas. This shows that the epidemic mainly affects the working population and therefore can have a serious impact on the supply of labour force and through it on the growth prospects of the economy. The non-HIV persons in the age group 15 to 60 years in HIV households have a much lower participation rate than the same age group among non-HIV households.

Within the sample HIV households, children with HIV have a lower WFPR than that of non-HIV children as their health condition would not permit them to work. However, there is a vital difference between rural and urban areas. In urban areas, HIV-positive children do not enter the work force unlike in rural areas where they do. This could be related to the financial condition of the household apart from other things such as awareness. Those residing in rural areas may not be aware of the full implications of being HIV-positive and their precarious financial position may force them to push their children into the labour market. It is often stated that the burden of coping is more pronounced on women, as there is an increased demand for their income-earning labour coupled with household work, childcare

and care of the sick. Notably, the female child WFPR is higher than the male child participation rate (Table 4.5 (b)). This again points towards greater burden on the female child. But, more importantly among children infected by HIV, female children have almost the same WFPR as those children not affected by HIV, while no HIV-positive male child was found to be working. This reveals the stark gender gap.

WFPR of male PLWHA is around 85 percent as compared to 52 percent participation rate of female PLWHA. Even the WFPR for the non-HIV male is more than that for the non-HIV female. Till today, a majority of the Indian nuclear families have a male head as the chief 'bread winner' of the family. It then becomes the responsibility of the male head of the households, whether HIV or non-HIV, to be the main earner of the family. The lower WFPR for non-HIV persons in the age group 15 to 60 than PLWHA can be due to various reasons like – the need for non-HIV persons (especially women) to look after the HIV patients and thus leave their present job, the possibility that these non-HIV persons in the age group 15 to 60 have not yet entered the labour market as they could also be students. It

needs to be noted, however, that female PLWHA have a higher rate of work force participation than the women who are not HIV-positive within HIV households as well as women in non-HIV households. These women may also be involved in providing care within the family, and looking after the children, which implies extremely high levels of pressure on them. A study that assesses the psychological impact on mothers living with HIV, their home lives and how they function as caretakers shows that the study population presented an elevated mean level of depression (Murphy et al, 2002). This heightened level of depression was associated with lower ability to perform regular tasks and with increased responsibilities for children.

HIV-positive women have a higher rate of work force participation than the women who are not HIV-positive within HIV households as well as women in non-HIV households

4.4 Change of job/loss of employment of PLWHA and caregivers

Of the total 2,376 PLWHA in the age group 18 to 60 years who were interviewed for a possible change in their job profile, 1,713 reported to be currently working. In the sample, only 150 reported to have changed their jobs after being detected positive (Table 4.6)².

Table 4.6
Change in job due to HIV and AIDS

	Rural	Urban	Total
Number of workers who changed jobs after being detected positive	58	92	150
Average monthly income of those who changed jobs	2,660	3,322	3,066
Number that received any benefit	6	12	18
Average benefit received at the time of leaving the job for those who received benefit	56,667	70,608	65,961

²Table 4.6 gives information for people who have changed their job and not for people who completely stopped working due to HIV and AIDS.

There is an increase in percentage of 'unemployed' PLWHA from 3.61 percent (before test) to 9.80 percent (after test)

Out of 150 people in the sample who changed the job, only 18 received benefits at the time of leaving the job, with an average amount of benefit being Rs. 65,961. These benefits included provident fund, gratuity, compensation and pension. These benefits are found to be higher in urban areas. The sample estimates demonstrate that there is no proper mechanism of support for people who have to change the job due to HIV and AIDS. This issue is more serious in rural areas with little job opportunities and social security benefits from jobs as the majority are engaged in agriculture and allied activities.

The pattern of change in occupational distribution and sectoral distribution due to HIV and AIDS for people in age group 18 to 60 years is given in Table 4.7 and Table 4.8 respectively. Both the tables show the increase in unemployment after being detected as HIV-positive. The distribution of PLWHA shows the decline in employment of these people in all occupations groups (Table 4.7). There is

an increase in percentage of 'unemployed' PLWHA from 3.61 percent (before test) to 9.80 percent (after test). Group 'others' in Table 4.7 includes students, housewives and pensioners. The percentage share of 'others' also increases after the test. There is a much higher share of this group for non-HIV persons (36.23 %) as compared to PLWHA.

There is also a decrease in the percentage of PLWHA engaged in all sectors after the test except for 'health' and 'not available' sectors (Table 4.8). The term 'not available' refers to all those who are in labour force but unemployed as well as students and housewives. There is a shift of workers mainly from 'agriculture and allied', 'manufacturing and construction' and 'trade, transport, communication, hotels and restaurants' into 'not available' due to the increase in unemployment. Some of the PLWHA are currently working in NGOs providing services to other PLWHA and they have been grouped under the health sector. The decrease in percentage of people

Table 4.7
Change in occupational distribution due to HIV and AIDS (age group 18-60)

(in Percentages)

Occupational category	Distribution of PLWHA		Distribution of members from non-HIV households
	Before test	After test	
Cultivation	6.77	6.01	6.91
Agri. wage labour	11.61	10.56	8.34
Non-agricultural wage	23.69	20.11	13.45
Self-employed non-agriculture	17.67	16.75	11.56
Salaried	19.78	18.64	14.42
Unemployed	3.61	9.80	9.08
Others	16.83	18.09	36.23
Total	100	100	100
Number of persons	2,376	2,376	17,484

Table 4.8
Change in sectoral distribution due to HIV and AIDS (age group 18-60)

(in Percentages)

Sectoral category	Distribution of PLWHA		Distribution of members of non-HIV households
	Before test	After test	
Agriculture and allied	19.61	17.50	16.40
Manufacturing and construction	18.13	15.86	13.05
Trade, transport, comm, hotels and restaurant	21.84	19.61	11.12
Health	3.36	3.70	1.05
Other services	16.45	15.40	13.40
Not available	20.41	27.77	44.82
Others	0.16	0.12	0.16
Total	100	100	100
Number of persons	2,376	2,376	17,484

in 'agriculture and allied' sector can be seen from the decrease in percentage engaged in 'cultivation' and 'agriculture wage labour' occupation.

It is not only PLWHAs who suffer loss of income and employment, but also other members of HIV households. The caregivers have to perform twin functions, namely, to contribute to the income of the household and to look after the PLWHA. Not all the PLWHA need caregivers. It is only in the advanced stage of the infection that they need the help of caregivers. Out of the total 2376 PLWHA interviewed, 683 reported that they needed care, i.e. around 29 percent of the sample needed care (Table 4.9). In the sample, 882 persons were providing care to these AIDS patients. Out of total caregivers 39.4 percent were currently employed and 1.2 percent had to leave their jobs, as they were required to spend time looking after the PLWHA. Though these ratios cannot be taken as true population parameters, they may be taken as indicative of the impact on labour force due to HIV and AIDS.

Table 4.9
The situation with respect to provision of care to PLWHA

PLWHA who need care	683
Number of caregivers	882
Number of caregivers who are currently employed	348
Number of caregivers who gave up their job in order to provide care	11

Out of the total 2376 PLWHA interviewed, 683 reported that they needed care, i.e. around 29 percent of the sample needed care

Table 4.10
Occupational distribution of caregiver

Occupational category	Employment pattern of caregiver		
	Rural	Urban	Total
Cultivation	0	0	0
Agriculture wage labour	71	11	82
Non-agricultural wage	27	49	76
Self-employed non-agriculture	30	40	70
Salaried	24	48	72
Others	42	6	48
Total	194	154	348

It is interesting to see the distribution across occupation of the caregivers that are employed (Table 4.10). Out of a total 348 sample caregivers who are currently employed, the majority (around 56 %) belong to rural areas. As expected the majority of caregivers in rural areas are employed in 'Agriculture Wage labour' occupation group and in urban areas majority are employed in 'Non-agriculture wage' and 'Salaried' occupation groups. Households with a low income and no social security would depend on the family members providing care to the PLWHA in the household. So relatively a higher number of caregivers in the wage labour group does not come as a surprise.

4.5 Loss of income of PLWHA and the caregivers

The econometric results from various studies indicate that the epidemic's effect has been substantial in other countries. In Africa, the marginal impact on income per capita of a one percent increase in HIV prevalence rate is minus 0.59 percent (McDonald and Roberts, 2005). Loss of income of HIV patients can be looked for two categories of patients, one who are still working but suffer losses due to frequent absence from work and others who have stopped working (Table 4.11 and Table 4.12).

The total number of PLWHA who suffered loss of income due to leave/absence from the current job is 625 (Table 4.11). A total of 2,376 people in the age group 18 to 60 years were interviewed for the survey and interestingly, 1713 are reportedly still working. These figures show that only 36.48 percent of the total PLWHA currently employed suffered loss of income due to absence from work. This is despite the fact that a majority of the PLWHA in the sample are in Stage I

or Stage II and very few are in Stage III or IV of the infection. An estimate of the total number of persons who would have suffered a loss of income due to HIV and AIDS for the country cannot be given, since the sample is not proportionate to population. Due to the same reason, the loss of income due to absence from work is 9.24 percent of the total household income of all HIV households in the sample. The average income lost due to leave/absence in the last one year is Rs. 3,736. It is difficult to project this figure to predict the impact at the state level. Even to get a crude measure of the impact, the need is to know the share of the income of HIV households in the total income of all households. In trying to measure the loss in GDP there are further problems such as the possibility of substitution of PLWHA workers with other workers and substitution of labour by capital. Since the total number of PLWHA in India as per the estimates released by NACO were 5.206 million (a section would have never been employed) in 2005 and there were 402.5 million workers in 2001 as per the 2001 Census, scaling up the figure to the state or national level would not show a very dramatic impact on the economy or households. However, this is so at this juncture and as more and more PLWHA get diagnosed with AIDS, the impact is likely to become more visible. But it needs to be emphasised that the impact at the level of households is quite severe.

HIV households hire labour for cultivation purpose when PLWHA members are unable to do cultivation work. The extra amount spent on these hired labourers by these households is Rs. 96,510. However, it needs to be noted that this is only for those households where the PLWHA member is not able to work full time. Such households are relatively few in numbers. Some households that do not belong to

36.48 percent of the total PLWHA currently employed suffered loss of income due to absence from work

Table 4.11

Loss of income of HIV and AIDS workers due to absence/leave if currently working by occupational groups

Occupational category	Number of persons who suffered loss of income	Average income lost due to leave/absence in last one year (Rs.)	Extra amount spent on hired labourers by cultivators (Rs.)	Average fringe benefits lost during last one year (Rs.)	Income lost as a percentage of current household income
Rural					
Cultivation	12	6,484	76,250	0	24.19
Agriculture wage labour	89	2,376	1,000	0	9.36
Non-agricultural wage	75	3,142	0	83	8.17
Self-employed non-agriculture	40	2,838	0	25	8.60
Salaried	26	4,897	1,500	846	11.74
Others	1	3,000	0	0	41.66
Total	244	3,151	78,750	120	10.32
Urban					
Cultivation	3	4,667	4,500	0	9.78
Agriculture wage labour	30	3,031	0	0	9.69
Non-agricultural wage	159	3,464	2,000	137	8.40
Self-employed non-agriculture	103	4,378	260	132	7.52
Salaried	84	5,457	11,000	758	11.01
Others	2	600	0	0	0.55
Total	381	4,111	17,760	260	8.76
Both rural and urban					
Cultivation	15	6,121	80,750	0	20.89
Agriculture wage labour	119	2,541	1,000	0	9.45
Non-agricultural wage	234	3,361	2,000	120	8.33
Self-employed non-agriculture	143	3,948	260	102	7.72
Salaried	110	5,325	12,500	779	11.16
Others	3	1,400	0	0	1.88
Total	625	3,736	96,510	205	9.24

Table 4.12

Loss of income of PLWHA workers if currently not working by occupational groups

Occupational category	Persons	Average income lost due to loss of job (Rs.)	Extra amount spent on hired labourers by cultivators (Rs.)	Income lost as a percentage of current household income
Rural				
Cultivation	15	0	26,000	4.38
Agriculture wage labour	25	13,888	0	74.05
Non-agricultural wage	46	28,361	0	90.63
Self-employed non-agriculture	13	40,708	0	104.36
Salaried	16	37,500	0	81.30
Others	1	0	0	0
Total	116	23,974	26,000	74.63
Urban				
Cultivation	2	0	0	0
Agriculture wage labour	8	16,369	0	87.82
Non-agricultural wage	36	23,304	0	56.97
Self-employed non-agriculture	18	31,700	0	77.52
Salaried	28	49,363	0	55.21
Others	0	0	0	0
Total	92	31,768	0	59.79
Both rural and urban				
Cultivation	17	0	26,000	4.19
Agriculture wage labour	33	14,489	0	77.37
Non-agricultural wage	82	26,141	0	73.61
Self-employed non-agriculture	31	35,477	0	88.47
Salaried	44	45,049	0	61.15
Others	1	0	0	0
Total	208	27,421	26,000	66.25

cultivation group have also reported that they spent some amount on hired labourers. Cultivation is likely to be a supplementary source of income for these households. Among PLWHA currently working, people in 'cultivation' group are the main sufferers, with the loss being nearly 21 percent of the current household income.

The total number of people who suffered a loss of income due to loss of a job is 208 (Table 4.12). The average income lost for

PLWHA who are currently not working is Rs. 27,421 in the last one year in the sample. The average income lost is higher in urban areas than in rural areas, but this is expected due to higher wage rates in urban areas. The average fringe benefits that PLWHA currently not working lost during the last one year is about Rs. 205, with the main sufferers being the 'salaried' group. This again is probably due to the fact that other household groups are unlikely to have any privileges in terms of fringe benefits. The wage labour,

cultivation and non-agriculture self-employed group is unlikely to be entitled to any fringe benefits. The total income lost has been calculated as a percentage of current household income of those households that lost income. For the PLWHA who are currently not working, the income lost as a percentage of current household income is 66 percent, whereas 'Self-employed non-agriculture' people currently not working lost 88 percent of their current household income. It is observed that income lost as a percentage of current household income is very high for PLWHA who are unable to work. For some households, the total loss of income in the last one year is even more than the current household income (percentage being more than 100 percent for 'Self-employed in non-agriculture' household group in rural areas).

However, even though this represents only around 6 percent of the total current income of the HIV households in the sample, for those households that are

affected in such a manner, it is not a trivial issue, particularly since the loss of income as a proportion of current household income is very high. This can result in great misery at the household level and even increase the level of poverty. The scale of impact is likely to increase in the future as the number of households so affected would increase with greater number of currently working PLWHA withdrawing from the labour force due to illness. There would be a need to supplement the income of HIV households, find some form of employment for other members of the household or even the PLWHA so that the hard fought battle against poverty is not reversed.

It is not only the PLWHA who suffer the loss of income but also the caregivers who spend a majority of their time looking after the patients in the family (Table 4.13). The total number of caregivers in the sample who suffered loss of income is 348 and the average income lost due to

For the PLWHA who are currently not working, the income lost as a percentage of current household income is 66 percent

Table 4.13
Loss of income of caregiver if currently working by occupational groups

Occupational category	Rural		Urban		Total	
	Average income lost due to leave/absence from work (Rs.)	Income lost as a percentage of current household income	Average income lost due to leave/absence from work (Rs.)	Income lost as a percentage of current household income	Average income lost due to leave/absence from work (Rs.)	Income lost as a percentage of current household income
Cultivation	0	0	0	0	0	0.00
Agriculture wage labour	987	3.30	3,884	13.47	1,376	4.63
Non-agricultural wage	2,516	6.26	3,758	10.59	3,317	8.93
Self-employed non-agriculture	540	1.26	1,405	2.68	1,034	2.15
Salaried	2,073	2.86	663	0.72	1,133	1.33
Others	2,087	4.58	0	0	1,826	3.73
Total	1,503	3.58	2,045	3.50	1,743	3.54

On an average, 40 workdays are lost by PLWHA who had to take leave/be absent from work. For some in the rural 'Others' group, the average number of workdays lost is more than three months

leave/absence from work is Rs. 1,743. The income lost due to absence from work of caregivers is 3.5 percent of the current income of the households so affected, which is lower than that due to absence from work of PLWHA. The impact at the aggregate level will not amount to a big sum given the current prevalence rate. The overall impact of the loss of income due to leave/absence of caregivers from work, amounts to merely 0.6 percent of the current total household income of the HIV households. But it may have severe consequences for the households at low level of income. This is particularly true of the households whose major source of income is wage labour.

The income lost as a percentage of current household income is maximum for caregivers in 'Non-agriculture wage' group. In general, these figures support the observation made above that the loss of income can occur not only due to illness among household members, but also because of other members diverting time and effort away from income-generating activities towards taking care of the PLWHA. Taking care of a person sick with AIDS is not only an emotional strain for the household members, but also a strain on household resources. Loss of income, additional care-related expenses, the reduced ability of caregivers to work and mounting medical fees and funeral expenses together can push affected households deeper into poverty.

As mentioned above, the loss of income for the HIV household can also be due to the loss of job/withdrawal from work of the caregiver. This was not seen to be a very important channel for loss of income of the caregiver. As was seen in Table 4.9, only 11 caregivers in the sample reported to have withdrawn from the labour force even as the currently employed number was 348. The average income

lost for those who withdrew from labour force was Rs. 1,700. The income loss for the households in which the caregiver withdrew from the labour force was 3.1 percent of the current household income. These figures suggest that only those who are working on the margins at low wage rates withdraw from the labour force. And this may be expected since those who earn high incomes would be the last to withdraw from the labour force given the additional burden of expenditure imposed on the household due to a PLWHA member.

In order to predict some economy-wide effects of the impact of HIV and AIDS, the average number of workdays lost per PLWHA worker needs to be viewed. This would provide a hint of the amount of loss that would come due to depletion of manpower. HIV and AIDS destroys human capital built up over years and weakens the capacity of workers to produce goods and services for the economy. The loss of skilled labour together with the increase in care and treatment costs tends to depress production, hamper savings and impede investments in the long term. The average number of workdays lost by those who had to take leave/be absent from work of sample PLWHA is given in Table 4.14. These persons lose an average number of 40 workdays. For some in rural 'Others' group, the average number of workdays lost is more than three months. In 'Agriculture wage labour' group, the number of workdays lost is the maximum, which are large figures. If the epidemic is not controlled at this stage, it can have a deleterious impact on the economy in the long term.

Since India is a labour abundant country, labour replacement is easy. When using these figures to predict economy-wide

Table 4.14

Average number of workdays lost due to leave/absence from work of PLWHA

Occupation category	Average number of work days lost due to leave/absence in last one year		
	Rural	Urban	Both rural and urban
Cultivation	39	45	40
Agriculture wage labour	51	69	56
Non-agricultural wage	37	39	38
Self-employed non-agriculture	33	44	41
Salaried	26	35	33
Others	100	31	54
Total	38	41	40

effects, one has to keep in mind the possibility of substitution of PLWHA workers with other non-HIV workers. For instance, in agricultural households with the PLWHA still active, other family members or hired labourers replaced the PLWHA member in 96 cases (out of a total of 196 cultivation households in the sample), when the health of the PLWHA member did not allow him/her to work. In the case where the PLWHA was not working, 22 households reported that other family members had replaced him/her while only six households reported having spent extra amount on hired labourers. Even though at the household level, the economic impact may be overcome due to possibilities of substitution, it is however likely to be felt by the household members in terms of effort intensity and time-poverty. At the sectoral level, the impact is unlikely to be felt till the possibilities of substitution have been exhausted, which would be the case if the epidemic continues to spread without any checks and controls.

But it needs to be noted that replacement of skilled labour is not that easy. Labour market and workplace policies need to be adjusted to address the impact on availability of skilled workers, productivity and human resource development. Efforts are needed to support and protect the rights of workers living with HIV and AIDS, maximising their productivity through access to care and support and changes in work routine. For example, Volkswagen Brazil has implemented a successful prevention and treatment programme, preventing many new infections among its workers and reducing HIV and AIDS related absenteeism by 90 percent.³

If the loss of income through all channels is combined, nearly 9.1 percent of the total current income of the HIV households is the resultant loss. Because India is a labour surplus economy and there are wide possibilities of substitution of labour by capital, this could be seen as the outermost bound of loss in value added in the economy due to HIV and AIDS. However this is

In the case where the PLWHA was not working, 22 households reported that other family members had replaced him/her while only six households reported having spent extra amount on hired labourers

³ UNGASS Roundtable 3, "Social-economic impact of the epidemic and the strengthening of national capacities to combat HIV/AIDS", Final draft, 28 May 2001

so at the current point in time. However, the long-term impact may not remain muted. This is seen to be the case from the simulations conducted on the basis of the CGE model that has been constructed at NCAER to measure the long-term impact of the epidemic on Indian economy.

From a policy standpoint, it is desirable to know the reasons for PLWHA to withdraw from the labour force. The most important reason for leaving the job is their ill health. Any effort directed to keep them healthy would reduce the household level as well as macro-economic impact of HIV and AIDS.

4.6 Support from employer

An attempt was also made to find out whether the employers were providing some form of support to the PLWHA workers in the form of reimbursement of medical expenditure, paid leave or group insurance. The finding was that not a single person had received any form of support from the employer. While this might appear to be a bit callous on the part of the employers, it has also to be kept in mind that generally the PLWHA workers had not revealed their HIV status at the workplace. Further, this would be valid only for the households that are not self-employed. Nearly one-fourth of the HIV households in the sample belonged to the self-employed group.

4.7 Observations

The impact on employment and income due to HIV and AIDS is likely to vary with the number and stage of infection of people/households captured in the sample. While the per capita income levels are not that affected due to the small average size of the HIV household,

the impact of employment increases along with the progression in infection. For example, those working will face lesser impact than those who are unemployed.

The prevalence of HIV (within HIV households) is higher among the working people than among those who are not in the work force, as also seen in terms of the Work Force Participation Rate calculated from the sample. This is a matter of concern from the point of view of the economic impact of the epidemic on the household as well at a more aggregated level. For the HIV households, it has resulted in higher prevalence of child labour as compared to non-HIV households. There is also a higher Work Force Participation Rate among the elderly in the HIV households. This raises the question of old age security. Given these indicators, the long-term impact of the epidemic can be disastrous, if the incidence of HIV continues to rise.

The loss of income for the HIV households varies across occupational and income groups. Of particular concern is the status of wage labourers who do not have any social security and therefore are hit hard by any episode of HIV and AIDS. The main impact is felt through the loss of job or leave/absence from work of the PLWHA. These groups may need special support to tide over the crisis imposed by the HIV-related illness. The aggregate economic impact of the infection does not appear to be much, given a reduction in income of the HIV households by around nine percent of their current income in the sample. Given the current prevalence rate, extrapolation of this figure at the level of the state or the national economy may not show a large impact. But, it needs to be kept in mind that the sample is skewed towards lower income groups. Also, it comes out

The impact on employment and income due to HIV and AIDS is likely to vary with the number and stage of infection of people/households captured in the sample

clearly from the survey that the impact at the household level is serious. And this is something that cannot be ignored.

In addition to the scaling up of national poverty reduction strategies, special social protection programmes are required

to support the people, households and communities that are hardest hit by the epidemic. Given the heavy burden that the epidemic is putting on women as caretakers and income earners, social security arrangements are needed to respond to their needs.

Impact on the Level and Pattern of

Impact on the Level and Pattern of Consumption and Savings of the Households

5.1 Introduction

There are a number of ways in which HIV and AIDS can influence the level and pattern of consumption and savings of the households and ultimately, have a deleterious impact on individual sectors and national economies. The increase in medical expenses of the household due to HIV and AIDS is likely to be met by reduction in other expenses. For households that are below or close to poverty line, it can imply reduced expenditure on even essential needs like food and clothing. It can also imply reduced spending on education of children, which could reduce the future stock of human capital. Increased medical treatment costs coupled with reduction in household income due to economically productive members falling sick can imply reduced savings (see Cuddington, 1993; Over, 1992). This can have serious consequences for economic growth, particularly in developing economies. The ratio of treatment cost to per capita income was estimated to be nearly two in India in mid-1990s by Bloom and Mahal (1996) (as noted in Mahal, 2004). This clearly indicates that the treatment costs are very high and can place a huge economic burden on the households affected by HIV. The impact can also be in terms

of increased inequality and possible increase in poverty. The relatively richer households might have enough financial resources to meet the additional burden imposed by AIDS related illness, but for the relatively poor households, it might imply not only a decline in savings but reduction or elimination of what ever small assets they may possess (see Pitayanon, Kongsin and Janjaeron, 1997). The adverse financial implication of HIV and AIDS on households can cause increased indebtedness of these households. Since banks are unlikely to lend money for meeting the expenses associated with HIV and AIDS, the households affected by HIV may fall in the grip of the moneylenders who lend at exorbitant rates of interest.

5.2 Consumption patterns

Table 5.1 presents the pattern of expenditure for non-HIV and HIV households, separately for rural and urban areas. The HIV households spend a relatively lower proportion of their total consumption expenditure on food than the non-HIV households both in rural and urban areas. On the other hand, as may be expected, medical expenses constitute a much higher share of total consumption expenditure for the HIV households. Many studies in India have pointed out that

Table 5.1
Share of expenditure on some major items

(in Percentages)

Item	Non-HIV households			HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cereals	15.35	12.93	13.78	12.66	11.08	11.66
Pulses	2.62	2.08	2.27	2.43	2.06	2.19
Other food	31.77	28.68	29.77	29.66	28.38	28.85
Total food	49.74	43.69	45.82	44.75	41.51	42.70
Fuel and light	8.15	9.86	9.26	7.76	8.91	8.49
House rent	1.34	4.67	3.50	2.63	6.34	4.98
Clothing and footwear	5.69	5.13	5.33	4.84	4.58	4.68
Durables	2.22	1.79	1.94	1.32	1.24	1.27
Education of children	3.86	5.15	4.69	3.05	3.27	3.19
Medical	3.58	2.87	3.12	12.53	9.67	10.72
Other non-food	25.42	26.83	26.33	23.12	24.47	23.98
Total	100	100	100	100	100	100

In the sample, nearly 11 percent of the total consumption expenditure of HIV households is devoted to medical expenses as compared to a mere three percent in the case of non-HIV households

the main impact of HIV on households is through the increased medical expenses. This is because households have to cope with the medical expenses related with the epidemic on their own rather than receiving support from the government. In the sample, nearly 11 percent of the total consumption expenditure of HIV households is devoted to medical expenses as compared to a mere three percent in the case of non-HIV households. The HIV households also spend a higher proportion of their total consumption expenditure on rent, which suggests that these households have lower assets than the non-HIV households. With respect to education of children, it is seen that the HIV households, in both rural and urban areas, spend a lower proportion of their total consumption expenditure on education though the difference is larger in urban areas. This upholds the general idea in the literature that HIV and AIDS might affect the education of children. The long-term impact might be more acute, particularly when the children are orphaned.

Since nutritious and balanced food is important for ensuring a longer and healthier life for the PLWHA, it is important to see whether these households spend less on food even in absolute terms. Even though the proportion of expenditure on food is much lower for the HIV households, the per capita per month expenditure on food of these households is slightly higher than that of the non-HIV households (Table 5.2). The reason is a higher per capita consumption expenditure of the HIV households. It was noted in Chapter 4 that in urban areas, the per capita income of HIV households is higher in the sample. In rural areas the per capita income of the non-HIV households is slightly higher than that of HIV households in the sample. So, the higher per capita expenditure of HIV households may be explained in terms of higher per capita income of these households only in the case of urban sample but not for the rural sample. The difference in per capita expenditure on food between the

Table 5.2

Average per capita per month expenditure on some major items.

(in Rupees)

Item	Non-HIV households			HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cereals	110	122	117	104	121	114
Pulses	18	19	19	20	22	21
Other food	227	270	252	244	311	282
Total food	356	412	389	369	456	418
Fuel and light	58	93	78	64	97	83
House rent	9	44	29	21	69	48
Clothing and footwear	40	48	45	39	50	45
Durables	15	16	16	10	13	12
Education of children	27	48	39	25	35	31
Medical	25	27	26	103	106	105
Other non-food	182	253	223	190	268	234
Total	712	941	845	821	1,094	976

two types of households is mainly due to the expenditure on 'other food' items, such as vegetables, fruits, milk and milk products and oil which may be related to the HIV status of these households, especially the need to have nutritious and balanced food.

The HIV households have a higher share of medical expenditure in total expenditure despite the fact that their per capita expenditure is higher. Thus, the medical expenses of the HIV households are much higher than that of the non-HIV households, almost around four times of the per capita per month medical expenses of the non-HIV households. The per capita expenditure of HIV households on education of children is lower than that of the non-HIV households. This is due to a combination of lower current enrolment rate and a higher proportion of children enrolled in government schools where the fees are lower (see Chapter 6). HIV and AIDS do affect the education of children and therefore

may have an impact on future human capital stock of the country.

Tables 5.3 and 5.4 present the average annual household consumption expenditure and the per capita annual consumption expenditure pattern, respectively, of households by occupation groups. Comparing the average annual consumption expenditure of the households by various occupation groups, presented in Table 5.3, with their average annual income (Table 4.3), it was found that the average household expenditure is slightly higher than the average annual income in the case of HIV households, except for the salaried and self-employed in non-agriculture groups. While there is a tendency among the respondents to inflate consumption expenditure and to subdue the income figure, there was an effort made at the time of the survey to match the cash inflow of the households with the cash outflow. Given this, it may be surmised that the main reason for this discrepancy

The HIV households have a higher share of medical expenditure in total expenditure despite the fact that their per capita expenditure is higher

When comparing expenditure on education of children across HIV and non-HIV households by place of residence and occupation groups, it is seen that in general HIV households spend less than the non-HIV households

is withdrawal by households from past savings or net borrowings, which comes out to be a valid reason as may be seen from Table 5.14. However, this higher expenditure may be due to some excessive expenditure on a wedding or a social event. This does appear to be the case when seen that the average consumption expenditure on 'other non-food' category is very high and next only to the average annual expenditure on food. This is true for both HIV and non-HIV households. The salaried group has the highest consumption expenditure in the sample, which is related to the higher income of this group. But since a large part of the size and variation of consumption expenditure is dependent on one-off expenses on social events, it is not advisable to read too much into this.

One consistent pattern that emerges again is the much higher expenditure of HIV households under the head of medical expenditure. Across occupation groups, the salaried group spends the highest amount under this head. The reason is likely to be related to the paying capacity as well as access to information and health facilities. The agricultural wage and non-agricultural wage households are unlikely to be able to afford the required services of private health providers and also have poor access to public health facilities. With a much lower paying capacity and lower awareness levels, they are also likely to ignore some illnesses. The cultivation group may depend on private health facilities, particularly where hospitalisation is necessary and in some sense be able to afford it, given better income and wealth position of these households. Under duress, these households can raise resources by selling off their assets. Interestingly the salaried households in rural areas

show much higher medical expenditure than the salaried group in urban areas. This is likely to be due to households in urban areas having better access to public health facilities where costs are lower. Also, the nature of their illness, particularly the fear of being stigmatised if their HIV status is revealed to anyone, may force those located in rural areas to go to the private sector in urban areas. This would raise the indirect costs of treatment for these households, such as travel costs.

When comparing expenditure on education of children across HIV and non-HIV households by place of residence and occupation groups, it is seen that in general, HIV households spend less than the non-HIV households. It is only in the case of agriculture wage labour group in rural areas that the HIV households spend more on education. This tends to suggest that the impact of HIV and AIDS on the education of children is negative. In fact, this comes out clearly when enrolment rates for the two types of households are presented later in this report. Thus the assumption made in many studies (like Bell, Devarajan and Gersbach, 2003) that one of the channels of impact of HIV and AIDS is through reduced household expenditure on education appears to be empirically sustainable. Even if this impact is not visible at the macro-level at the current rate of prevalence of HIV, long-term impact is likely to be more visible when there is death of earning members due to AIDS and the rate of prevalence is not checked. Across occupation groups, the salaried households spend the highest amounts on education, both in per capita and per household terms. This is likely to be related to greater awareness as well as greater capacity to invest on the human capital formation of the child.

Table 5.3

Average annual consumption expenditure per household by occupation groups

Non-HIV households

(in Rupees)

	Expenditure per household						Total
	Cultivation	Agri. wage labour	Non-agri. wage labour	Self-employment non-agriculture	Salaried	Others	
Rural							
Cereals	6,359	5,294	5,020	5,711	6,536	6,430	5,813
Pulses	1,129	974	963	921	984	903	994
Other food	12,767	10,238	11,396	12,172	13,980	12,682	12,033
Total food	20,255	16,506	17,379	18,805	21,500	20,016	18,840
Fuel and light	3,080	1,911	2,826	3,716	4,154	3,909	3,088
House rent	62	185	709	832	1,011	673	509
Clothing and footwear	2,407	1,546	1,654	2,057	2,979	2,964	2,156
Durables	1,708	197	356	523	1,246	1,194	840
Education of children	1,319	512	966	1,682	3,149	2,136	1,462
Medical	1,362	1,113	1,124	1,040	2,209	1,554	1,357
Other non-food	10,587	6,098	6,787	11,140	14,895	10,975	9,628
Total	40,781	28,069	31,802	39,795	51,144	43,422	37,881
Urban							
Cereals	7,579	6,191	5,436	6,977	6,820	6,718	6,492
Pulses	975	840	1,043	1,063	1,058	10,38	1,043
Other food	12,085	10,417	11,993	14,834	16,412	14,818	14,393
Total food	20,640	17,448	18,472	22,874	24,290	22,574	21,928
Fuel and light	4,299	2,855	3,750	5,054	5,925	5,434	4,950
House rent	1,153	628	2,013	2,540	3,014	1,504	2,343
Clothing and footwear	2,861	1,621	1,861	2,487	3,113	3,068	2,577
Durables	1,165	134	597	720	1,229	1,172	898
Education of children	1,596	757	1,333	2,535	3,764	2,890	2,582
Medical	1,120	960	1,062	1,352	1,768	1,795	1,443
Other non-food	9,525	5,147	7,513	12,470	18,707	17,518	13,465
Total	42,359	29,549	36,601	50,031	61,810	55,954	50,186
All							
Cereals	6,546	5,450	5,295	6,600	6,750	6,616	6,208
Pulses	1,105	951	1,015	1,021	1,040	991	1,023
Other food	12,662	10,269	11,791	14,040	15,819	14,065	13,406
Total food	20,314	16,670	18,102	21,661	23,609	21,672	20,637
Fuel and light	3,267	2,075	3,437	4,655	5,493	4,896	4,171

(Contd....)

Table 5.3 (Contd....)

House rent	230	262	1,572	2,031	2,525	1,211	1,576
Clothing and footwear	2,477	1,559	1,791	2,359	3,081	3,031	2,400
Durables	1,625	186	515	662	1,233	1,179	874
Education of children	1,362	555	1,209	2,281	3,614	2,624	2,114
Medical	1,325	1,087	1,083	1,259	1,876	1,710	1,407
Other non-food	10,424	5,933	7,267	12,073	17,777	15,212	11,860
Total	41,023	28,327	34,976	46,979	59,208	51,536	45,040

HIV households

(in Rupees)

	Expenditure per household						Total
	Cultivation	Agri. wage labour	Non-agri. wage labour	Self-employment non-agriculture	Salaried	Others	
Rural							
Cereals	5,770	4,036	4,581	5,492	5,897	5,091	5,055
Pulses	1,258	815	882	994	943	936	968
Other food	13,695	8,999	11,229	12,213	15,225	11,246	11,841
Total food	20,723	13,850	16,692	18,699	22,065	17,273	17,864
Fuel and light	3,037	2,158	3,171	3,449	4,475	2,954	3,096
House rent	313	699	1,538	1,116	1,985	1,025	1,051
Clothing and footwear	2,270	1,505	1,778	1,767	2,418	2,042	1,934
Durables	749	149	530	797	551	533	528
Education of children	1,145	1,086	684	1,150	2,248	1,314	1,217
Medical	5,289	3,662	3,315	4,003	8,805	6,123	5,003
Other non-food	11,957	5,731	8,706	7,736	13,913	8,912	9,229
Total	45,483	28,841	36,413	38,716	56,461	40,174	39,921
Urban							
Cereals	7,120	4,234	4,588	5,706	6,563	6,205	5,786
Pulses	966	691	964	1,073	1,121	1,223	1,073
Other food	12,960	9,024	12,425	14,842	16,878	16,054	14,820
Total food	21,045	13,949	17,977	21,621	24,561	23,481	21,680
Fuel and light	3,193	2,315	3,869	4,915	5,303	5,089	4,652
House rent	1,482	1,514	3,389	3,249	4,472	2,391	3,309
Clothing and footwear	2,044	1,448	1,807	2,330	2,904	2,616	2,393
Durables	1,796	189	264	648	987	539	648

(Contd....)

Table 5.3 (Contd....)

Education of children	1,096	410	972	1,999	2,311	1,786	1,708
Medical	5,245	1,927	3,817	3,692	6,638	5,989	5,052
Other non-food	15,025	5,710	9,319	13,025	15,456	13,843	12,781
Total	50,927	27,461	41,414	51,480	62,633	55,736	52,222
All							
Cereals	6,004	4,084	4,585	5,630	6,401	5,796	5,471
Pulses	1,208	784	933	1,045	1,078	1,117	1,028
Other food	13,567	9,006	11,971	13,905	16,477	14,289	13,538
Total food	20,779	13,874	17,489	20,579	23,956	21,202	20,037
Fuel and light	3,064	2,197	3,603	4,393	5,102	4,305	3,982
House rent	516	899	2,686	2,489	3,869	1,890	2,337
Clothing and footwear	2,231	1,491	1,796	2,129	2,786	2,405	2,195
Durables	931	159	365	701	881	537	596
Education of children	1,137	920	863	1,696	2,296	1,613	1,496
Medical	5,281	3,235	3,626	3,803	7,163	6,038	5,031
Other non-food	12,489	5,726	9,086	11,139	15,082	12,033	11,252
Total	46,427	28,502	39,513	46,929	61,137	50,022	46,928

Table 5.4

Per capita annual consumption expenditure per annum on various items by occupation groups

Non-HIV households

(in Rupees)

	Per capita expenditure						Total
	Cultivation	Agri. wage labour	Non agri. wage labour	Self-employment non-agriculture	Salaried	Others	
Rural							
Cereals	1,298	1,227	1,236	1,362	1,511	1,396	1,320
Pulses	231	226	237	220	228	196	226
Other food	2,607	2,373	2,806	2,903	3,233	2,753	2,733
Total food	4,135	3,827	4,280	4,485	4,971	4,344	4,279
Fuel and light	629	443	696	886	961	848	701
House rent	13	43	175	198	234	146	116
Clothing and footwear	491	358	407	491	689	643	490
Durables	349	46	88	125	288	259	191
Education of children	269	119	238	401	728	464	332

(Contd....)

Table 5.4 (Contd....)

Medical	278	258	277	248	511	337	308
Other non-food	2,162	1,414	1,671	2,657	3,444	2,382	2,187
Total	8,326	6,507	7,831	9,491	11,826	9,424	8,603
Urban							
Cereals	1,590	1,290	1,240	1,578	1,554	1,504	1,466
Pulses	205	175	238	240	241	232	236
Other food	2,535	2,171	2,736	3,355	3,739	3,318	3,250
Total food	4,330	3,636	4,215	5,173	5,533	5,055	4,951
Fuel and light	902	595	856	1,143	1,350	1,217	1,118
House rent	242	131	459	574	687	337	529
Clothing and footwear	600	338	425	562	709	687	582
Durables	244	28	136	163	280	262	203
Education of children	335	158	304	573	857	647	583
Medical	235	200	242	306	403	402	326
Other non-food	1,998	1,073	1,714	2,820	4,261	3,923	3,040
Total	8,886	6,158	8,351	11,316	14,080	12,530	11,332
All							
Cereals	1,342	1,239	1,239	1,516	1,543	1,465	1,405
Pulses	227	216	238	234	238	219	231
Other food	2,596	2,335	2,759	3,225	3,617	3,115	3,034
Total food	4,165	3,790	4,236	4,976	5,398	4,799	4,671
Fuel and light	670	472	804	1,069	1,256	1,084	944
House rent	47	60	368	466	577	268	357
Clothing and footwear	508	354	419	542	704	671	543
Durables	333	42	121	152	282	261	198
Education of children	279	126	283	524	826	581	478
Medical	272	247	253	289	429	379	318
Other non-food	2,137	1,349	1,700	2,773	4,064	3,369	2,685
Total	8,410	6,441	8,184	10,792	13,537	11,413	10,194

(Contd....)

Table 5.4 (Contd....)
HIV households

(in Rupees)

	Per capita expenditure						Total
	Cultivation	Agri. wage labour	Non agri. wage labour	Self-employment non-agriculture	Salaried	Others	
Rural							
Cereals	1,279	1,039	1,234	1,480	1,519	1,160	1,254
Pulses	279	210	238	268	243	213	240
Other food	3,035	2,318	3,025	3,290	3,921	2,563	2,938
Total food	4,592	3,567	4,496	5,038	5,683	3,936	4,432
Fuel and light	673	556	854	929	1,153	673	768
House rent	69	180	414	301	511	234	261
Clothing and footwear	503	388	479	476	623	465	480
Durables	166	39	143	215	142	121	131
Education of children	254	280	184	310	579	299	302
Medical	1,172	943	893	1,078	2,268	1,395	1,241
Other non-food	2,650	1,476	2,345	2,084	3,583	2,031	2,290
Total	10,080	7,429	9,808	10,430	14,541	9,155	9,905
Urban							
Cereals	1,625	1,153	1,222	1,468	1,678	1,442	1,461
Pulses	220	188	257	276	287	284	271
Other food	2,957	2,457	3,309	3,818	4,316	3,732	3,742
Total food	4,802	3,799	4,788	5,562	6,281	5,459	5,475
Fuel and light	729	630	1,030	1,264	1,356	1,183	1,175
House rent	338	412	903	836	1,144	556	836
Clothing and footwear	466	394	481	599	743	608	604
Durables	410	52	70	167	252	125	164
Education of children	250	112	259	514	591	415	431
Medical	1,197	525	1,017	950	1,698	1,392	1,276
Other non-food	3,428	1,555	2,482	3,351	3,952	3,218	3,227
Total	11,621	7,478	11,030	13,243	16,016	12,957	13,187
All							
Cereals	1,337	1,066	1,226	1,472	1,640	1,338	1,371
Pulses	269	205	249	273	276	258	258

(Contd....)

Table 5.4 (Contd....)

Other food	3,022	2,351	3,202	3,635	4,221	3,297	3,393
Total food	4,628	3,622	4,678	5,380	6,136	4,893	5,022
Fuel and light	682	573	964	1,149	1,307	993	998
House rent	115	235	718	651	991	436	586
Clothing and footwear	497	389	480	557	714	555	550
Durables	207	42	98	183	226	124	149
Education of children	253	240	231	443	588	372	375
Medical	1,176	845	970	994	1,835	1,393	1,261
Other non-food	2,782	1,495	2,430	2,912	3,863	2,777	2,820
Total	10,341	7,440	10,569	12,270	15,660	11,544	11,760

The HIV households engaged in wage labour devote a lower percentage of total expenditure to food as compared to the wage labour group among non-HIV households

In general, nearly half of the total expenditure is for food in all categories of households (Table 5.5). However, the salaried households spend a much lower proportion of their total consumption expenditure on food, the figure being nearly 40 percent in the case of non-HIV households and 39 percent in the case of HIV households. This is so despite the fact that in per capita terms they spend the highest amount on food in the sample. The result is not surprising considering the fact that elasticity of expenditure on food is generally less than one, i.e., as income goes up households tend to spend a lower percentage of this income on food. The lower proportion of consumption expenditure on food is mainly substituted by higher spending on other non-food, which relates to social events and likes. Not only is the per capita expenditure of salaried households and self-employed non-agricultural households on education high, relative to other groups, but even as a proportion of total spending it is higher relative to other household groups, particularly in urban areas. Clearly these households place a greater weight on education of children compared

to other groups. The HIV households engaged in wage labour devote a lower percentage of total expenditure to food as compared to the wage labour group among non-HIV households. This points to the need to pay special attention to the wage labour households who have to reallocate consumption expenditure to medical expenses. This is especially important as this is done out of a lower level of consumption expenditure, mainly by substituting away from food expenditure.

One of the important determinants of consumption expenditure is income. In the above tables it was seen that occupational groups which earned less were also in the habit of spending less and the pattern of expenditure also differed across these groups. Table 5.6 presents the pattern of expenditure by income groups. As was seen in the tables on income distribution, the sample is very sparse in the upper tail of income distribution. Hence these income groups have been combined in these tables. The proportion of expenditure devoted to food falls substantially, moving from the income group of

Table 5.5
Distribution of annual consumption expenditure across broad
groups of consumption items by occupation

Non-HIV households

(in Percentages)

	Cultivation	Agri. wage labour	Non agri. wage labour	Self employment non-agriculture	Salaried	Others	Total
Rural							
Cereals	15.59	18.86	15.79	14.35	12.78	14.81	15.35
Pulses	2.77	3.47	3.03	2.32	1.92	2.08	2.62
Other food	31.31	36.47	35.83	30.59	27.33	29.21	31.77
Total food	49.67	58.80	54.65	47.25	42.04	46.10	49.74
Fuel and light	7.55	6.81	8.89	9.34	8.12	9.00	8.15
House rent	0.15	0.66	2.23	2.09	1.98	1.55	1.34
Clothing and footwear	5.90	5.51	5.20	5.17	5.83	6.83	5.69
Durables	4.19	0.70	1.12	1.32	2.44	2.75	2.22
Education of children	3.24	1.83	3.04	4.23	6.16	4.92	3.86
Medical	3.34	3.97	3.53	2.61	4.32	3.58	3.58
Other non-food	25.96	21.73	21.34	27.99	29.12	25.28	25.42
Total	100	100	100	100	100	100	100
Urban							
Cereals	17.89	20.95	14.85	13.95	11.03	12.01	12.93
Pulses	2.30	2.84	2.85	2.12	1.71	1.86	2.08
Other food	28.53	35.25	32.77	29.65	26.55	26.48	28.68
Total food	48.73	59.05	50.47	45.72	39.30	40.34	43.69
Fuel and light	10.15	9.66	10.25	10.10	9.59	9.71	9.86
House rent	2.72	2.12	5.50	5.08	4.88	2.69	4.67
Clothing and footwear	6.75	5.49	5.09	4.97	5.04	5.48	5.13
Durables	2.75	0.45	1.63	1.44	1.99	2.09	1.79
Education of children	3.77	2.56	3.64	5.07	6.09	5.16	5.15
Medical	2.64	3.25	2.90	2.70	2.86	3.21	2.87
Other non-food	22.49	17.42	20.53	24.92	30.27	31.31	26.83
Total	100	100	100	100	100	100	100

(Contd....)

Table 5.5 (Contd....)

All							
Cereals	15.96	19.24	15.14	14.05	11.40	12.84	13.78
Pulses	2.69	3.36	2.90	2.17	1.76	1.92	2.27
Other food	30.87	36.25	33.71	29.89	26.72	27.29	29.77
Total food	49.52	58.85	51.76	46.11	39.88	42.05	45.82
Fuel and light	7.96	7.33	9.83	9.91	9.28	9.50	9.26
House rent	0.56	0.93	4.49	4.32	4.27	2.35	3.50
Clothing and footwear	6.04	5.50	5.12	5.02	5.20	5.88	5.33
Durables	3.96	0.66	1.47	1.41	2.08	2.29	1.94
Education of children	3.32	1.96	3.46	4.85	6.10	5.09	4.69
Medical	3.23	3.84	3.10	2.68	3.17	3.32	3.12
Other non-food	25.41	20.94	20.78	25.70	30.02	29.52	26.33
Total	100						

HIV households**(Percentages)**

	Cultivation	Agri. wage labour	Non agri. wage labour	Self employment non-agriculture	Salaried	Others	Total
Rural							
Cereals	12.69	13.99	12.58	14.19	10.44	12.67	13
Pulses	2.77	2.82	2.42	2.57	1.67	2.33	2
Other food	30.11	31.20	30.84	31.55	26.97	27.99	30
Total food	45.56	48.02	45.84	48.30	39.08	43.00	45
Fuel and light	6.68	7.48	8.71	8.91	7.93	7.35	8
House rent	0.69	2.42	4.22	2.88	3.52	2.55	3
Clothing and footwear	4.99	5.22	4.88	4.56	4.28	5.08	5
Durables	1.65	0.52	1.45	2.06	0.98	1.33	1
Education of children	2.52	3.77	1.88	2.97	3.98	3.27	3
Medical	11.63	12.70	9.10	10.34	15.59	15.24	13
Other non-food	26.29	19.87	23.91	19.98	24.64	22.18	23
Total	100	100	100	100	100	100	100
Urban							
Cereals	13.98	15.42	11.08	11.08	10.48	11.13	11
Pulses	1.90	2.52	2.33	2.08	1.79	2.19	2
Other food	25.45	32.86	30.00	28.83	26.95	28.80	28
Total food	41.32	50.80	43.41	42.00	39.21	42.13	42

Table 5.5 (Contd....)[‡]

Fuel and light	6.27	8.43	9.34	9.55	8.47	9.13	9
House rent	2.91	5.51	8.18	6.31	7.14	4.29	6
Clothing and footwear	4.01	5.27	4.36	4.53	4.64	4.69	5
Durables	3.53	0.69	0.64	1.26	1.58	0.97	1
Education of children	2.15	1.49	2.35	3.88	3.69	3.21	3
Medical	10.30	7.02	9.22	7.17	10.60	10.75	10
Other non-food	29.50	20.79	22.50	25.30	24.68	24.84	24
Total	100						
All							
Cereals	12.93	14.33	11.60	12.00	10.47	11.59	12
Pulses	2.60	2.75	2.36	2.23	1.76	2.23	2
Other food	29.22	31.60	30.30	29.63	26.95	28.56	29
Total food	44.76	48.68	44.26	43.85	39.18	42.39	43
Fuel and light	6.60	7.71	9.12	9.36	8.35	8.61	8
House rent	1.11	3.16	6.80	5.30	6.33	3.78	5
Clothing and footwear	4.81	5.23	4.54	4.54	4.56	4.81	5
Durables	2.01	0.56	0.92	1.49	1.44	1.07	1
Education of children	2.45	3.23	2.18	3.61	3.75	3.22	3
Medical	11.38	11.35	9.18	8.10	11.72	12.07	11
Other non-food	26.90	20.09	23.00	23.74	24.67	24.05	24
Total	100						

Rs. 41,000-Rs. 84,000 to the income group of Rs. 84,000 and above. This is true for both non-HIV and HIV households. But across non-HIV and HIV households, the proportion spent on food is lower among the latter. The shift again is mainly in medical expenditure for all income groups. Overall, while non-HIV households devote approximately two percent of consumption expenditure to medical needs, the HIV households spend approximately eight percent of total consumption expenditure on medicines and related items. Across all income groups, HIV households spend

more on house rent than the non-HIV households. Therefore it may be indicating that the asset position of the HIV households is weaker compared to non-HIV households.

As is to be expected, the average household consumption expenditure is higher for the higher income groups (Table 5.7). This rise in expenditure is much sharper for items other than cereals. This again is to be expected since expenditure on cereals is generally known to be income-inelastic. This is clearer looking at the per capita

Table 5.6
Distribution of annual consumption expenditure by income groups
and items of expenditure (Rural, Urban, Total)

Non-HIV households (in Percentages)

Item	Upto Rs. 20,000	20,001- 30,000	30,001- 41,000	41,001- 84,000	84,001 and above	Total
Rural						
Cereals	12	11	11	10	8	10
Pulses	2	2	2	2	1	2
Other food	24	23	22	21	18	21
Total food	38	36	35	32	27	33
Fuel and light	6	5	6	6	5	5
House rent	1	1	1	1	1	1
Clothing and footwear	3	4	4	4	4	4
Durables	0	0	1	2	2	1
Education of children	1	2	2	3	4	3
Medical	2	2	2	2	4	2
Other non- food	11	15	15	17	25	17
Total	100	100	100	100	100	100
Urban						
Cereals	12	11	10	9	7	9
Pulses	2	2	2	1	1	1
Other food	22	22	22	20	18	20
Total Food	36	35	34	31	26	30
Fuel and light	8	8	8	7	6	7
House Rent	3	3	4	3	3	3
Clothing and footwear	4	3	4	4	3	4
Durables	0	1	1	1	2	1
Education of children	1	2	3	4	5	4
Medical	2	2	2	2	2	2
Other non- food	10	11	12	17	28	19
Total	100	100	100	100	100	100
All						
Cereals	12	11	11	9	7	9
Pulses	2	2	2	1	1	2
Other food	23	22	22	20	18	20
Total Food	37	36	34	31	26	31

(Contd....)

Table 5.6. (Contd. ...)

Fuel and light	7	6	7	7	5	6
House Rent	2	2	3	3	2	2
Clothing and footwear	3	4	4	4	4	4
Durables	0	1	1	2	2	1
Education of children	1	2	2	3	5	3
Medical	2	2	2	2	2	2
Other non-food	10	13	13	17	27	18
Total	100	100	100	100	100	100

HIV households

(in Percentages)

Item	Upto Rs. 20,000	20,001-30,000	30,001-41,000	41,001-84,000	84,001 and above	Total
Rural						
Cereals	10	10	9	8	7	9
Pulses	2	2	2	2	1	2
Other food	21	22	21	20	19	20
Total food	33	34	31	30	28	31
Fuel and light	5	5	6	6	5	5
House rent	2	2	3	2	1	2
Clothing and footwear	4	3	3	3	3	3
Durables	0	1	0	1	2	1
Education of Children	2	1	2	2	3	2
Medical	9	7	10	10	7	9
Other non-food	14	13	14	17	23	16
Total	100	100	100	100	100	100
Urban						
Cereals	10	9	9	8	7	8
Pulses	2	2	2	1	1	1
Other food	21	22	21	21	18	20
Total food	32	32	31	30	26	29
Fuel and light	6	7	7	7	5	6
House rent	5	4	5	5	4	4
Clothing and footwear	3	3	3	3	3	3
Durables	0	0	0	1	2	1

(Contd....)

Table 5.6 (Contd....)

Education of children	2	2	2	2	3	2
Medical	6	8	6	7	7	7
Other non-food	13	12	14	16	23	17
Total	100	100	100	100	100	100
All						
Cereals	10	9	9	8	7	8
Pulses	2	2	2	2	1	2
Other food	21	22	21	20	19	20
Total food	33	33	31	30	27	30
Fuel and light	5	6	7	6	5	6
House rent	3	3	4	4	3	3
Clothing and footwear	3	3	3	3	3	3
Durables	0	0	0	1	2	1
Education of children	2	1	2	2	3	2
Medical	8	8	8	8	7	8
Other non-food	13	13	14	16	23	17
Total	100	100	100	100	100	100

Table 5.7

Average household annual consumption expenditure by income group

Non-HIV households

(in Rupees)

Item	Upto Rs. 20,000	20,001- 30,000	30,001- 41,000	41,001- 84,000	84,001 and above	Total
Rural						
Cereals	3,562	4,862	5,848	7,209	9,779	5,813
Pulses	653	908	1,029	1,158	1,417	994
Other food	7,190	9,779	11,799	15,269	21,428	12,033
Total food	11,406	15,549	18,677	23,637	32,624	18,840
Fuel and light	1,767	2,271	2,991	4,202	5,860	3,088
House rent	304	363	425	681	1,197	509
Clothing and footwear	1,031	1,544	2,027	2,909	4,931	2,156
Durables	115	202	483	1,764	2,821	840
Education of children	350	652	912	2,439	5,329	1,462
Medical	555	808	1,323	1,715	4,439	1,357
Other non-food	3,258	6,534	7,951	12,897	29,454	9,628

(Contd....)

Table 5.7 (Contd....)

(in Rupees)

Total	18,785	27,922	34,789	50,244	86,656	37,881
Urban						
Cereals	3,497	4,727	5,467	7,165	10,163	6,492
Pulses	614	858	961	1,136	1,404	1,043
Other food	6,720	9,347	11,599	16,030	25,029	14,393
Total food	10,831	14,932	18,027	24,331	36,597	21,928
Fuel and light	2,379	3,231	4,111	5,748	7,864	4,950
House rent	1,032	1,396	2,228	2,741	3,646	2,343
Clothing and footwear	1,060	1,472	1,933	2,904	4,936	2,577
Durables	76	285	309	849	2,983	898
Education of children	433	772	1,432	2,779	7,202	2,582
Medical	478	681	988	1,818	2,684	1,443
Other non-food	2,957	4,673	6,645	13,643	39,044	13,465
Total	19,247	27,442	35,673	54,812	1,04,955	50,186
All						
Cereals	3,536	4,795	5,630	7,180	10,067	6,208
Pulses	637	883	990	1,144	1,407	1,023
Other food	6,998	9,566	11,685	15,769	24,129	13,406
Total food	11,171	15,243	18,305	24,093	35,603	20,637
Fuel and light	2,016	2,746	3,631	5,218	7,363	4,171
House rent	601	874	1,456	2,036	3,034	1,576
Clothing and footwear	1,043	1,508	1,973	2,906	4,935	2,400
Durables	99	243	383	1,162	2,943	874
Education of children	384	711	1,209	2,662	6,733	2,114
Medical	524	745	1,132	1,782	3,122	1,407
Other non-food	3,135	5,613	7,205	13,388	36,646	11,860
Total	18,973	27,684	35,294	53,248	1,00,380	45,040

(Contd....)

Table 5.7 (Contd....)

HIV households

Item	Upto Rs. 20,000	20,001- 30,000	30,001- 41,000	41,001- 84,000	84,001 and above	Total
Rural						
Cereals	3,293	4,805	4,973	6,663	9,246	5,055
Pulses	627	902	1,040	1,299	1,556	968
Other food	7,036	10,284	12,189	16,314	24,606	11,841
Total food	10,956	15,991	18,202	24,276	35,408	17,864
Fuel and light	1,629	2,616	3,511	4,537	5,980	3,096
House rent	582	938	1,602	1,400	1,245	1,051
Clothing and footwear	1,207	1,609	1,910	2,609	4,357	1,934
Durables	117	309	259	787	3,112	528
Education of children	511	607	1,116	2,024	4,212	1,217
Medical	2,857	3,466	5,564	8,061	8,617	5,003
Other non-food	4,597	6,102	8,149	14,025	28,741	9,229
Total	22,456	31,639	40,313	57,718	91,670	39,921
Urban						
Cereals	3,009	4,124	5,096	6,433	9,993	5,786
Pulses	604	797	971	1,238	1,653	1,073
Other food	6,473	10,017	12,154	17,148	27,042	14,820
Total food	10,086	14,939	18,221	24,819	38,687	21,680
Fuel and light	2,013	3,144	4,099	5,528	7,943	4,652
House rent	1,601	1,898	2,879	4,251	5,247	3,309
Clothing and footwear	1,023	1,419	1,859	2,778	4,696	2,393
Durables	46	84	226	539	2,552	648
Education of children	488	700	1,120	1,923	4,280	1,708
Medical	1,926	3,570	3,536	5,724	10,168	5,052
Other non-food	4,091	5,672	8,270	13,007	33,970	12,781
Total	21,273	31,424	40,211	58,569	1,07,543	52,222
All						
Cereals	3,177	4,446	5,044	6,515	9,823	5,471

(Contd....)

Table 5.7 (Contd....)

Pulses	618	847	1,000	1,260	1,631	1,028
Other food	6,804	10,143	12,169	16,852	26,489	13,538
Total food	10,599	15,436	18,213	24,626	37,943	20,037
Fuel and light	1,787	2,894	3,850	5,175	7,498	3,982
House rent	1,000	1,444	2,337	3,237	4,340	2,337
Clothing and footwear	1,132	1,509	1,880	2,718	4,619	2,195
Durables	88	191	240	627	2,679	596
Education of children	501	656	1,119	1,959	4,264	1,496
Medical	2,475	3,521	4,397	6,555	9,817	5,031
Other non-food	4,389	5,875	8,219	13,369	32,784	11,252
Total	21,971	31,526	40,254	58,266	1,03,944	46,928

consumption expenditure shown in Table 5.8. There is relatively much smaller change in per capita expenditure on cereals and pulses across different income groups. Thus, the rise in average household expenditure on cereals with rise in income must be mainly due to rise in household size. This also implies that the rise in expenditure on other items of expenditure is due to two factors: rise in household size and rise in per capita consumption. The per capita expenditure rises very sharply in the case of 'other non-food' items which results in even sharper rise in average household expenditure on this item of expenditure. However, comparing the HIV and non-HIV households, it is seen that rise in per capita food expenditure is much higher for the former and hence the average household expenditure on food also rises more sharply in their case. This is truer of the expenditure on 'other food'. In general, the HIV households are required to spend more on special types of food such as vegetables, milk, fruits

and meat. The HIV households spend much more than non-HIV households on medicine in per capita terms. Moreover, the difference in spending on medical treatment between rural and urban households is much lower in the case of HIV households as compared to non-HIV households. Overall, the HIV households spend nearly four times the amount spent on medical treatment by the non-HIV households in per capita terms. The per capita and average household spending of the HIV households on education of children is very close to that of non-HIV households at lower level of household income. This might be due to the generally low capacity of these households, whether HIV or non-HIV to invest in education. However, at higher levels of income the gap widens with much lower expenditure of HIV households. While conducting case studies and group discussions, many HIV-positive parents had expressed their anxiety about the future of their children and great concern about providing

Table 5.8

Per capita item-wise annual consumption expenditure by income group

Non-HIV households

(in Rupees)

Item	Upto Rs. 20,000	20,001- 30,000	30,001- 41,000	41,001- 84v ,000	84,001- 1,30,000	Total
Rural						
Cereals	1,024	1,179	1,281	1,474	1,785	1,320
Pulses	188	220	226	237	259	226
Other food	2,066	2,372	2,586	3,122	3,911	2733
Total food	3,277	3,772	4,093	4,833	5,955	4,279
Fuel and light	508	551	656	859	1,070	701
House rent	87	88	93	139	218	116
Clothing and footwear	296	375	444	595	900	490
Durables	33	49	106	361	515	191
Education of children	101	158	200	499	973	332
Medical	160	196	290	351	810	308
Other non-food	936	1,585	1,742	2,637	5,376	2,187
Total	5,398	6,774	7,623	10,273	15,817	8,603
Number of persons	1,319	3,776	1,944	3,404	1,019	11,462
Urban						
Cereals	1,009	1,155	1,275	1,548	2,001	1,466
Pulses	177	210	224	245	276	236
Other food	1,938	2,283	2,704	3,463	4,928	3,250
Total food	3,124	3,648	4,203	5,256	7,206	4,951
Fuel and light	686	789	959	1,242	1,548	1,118
House rent	298	341	520	592	718	529
Clothing and footwear	306	360	451	627	972	582
Durables	22	70	72	183	587	203
Education of children	125	188	334	600	1,418	583
Medical	138	166	230	393	528	326
Other non-food	853	1,142	1,550	2,947	7,688	3,040
Total	5,551	6,704	8,318	11,840	20,665	11,332
Number of persons	905	3,676	2,436	6,185	2,834	16,036

(Contd....)

Table 5.8 (Contd....)

All						
Cereals	1,017	1,167	1,278	1,522	1,944	1,405
Pulses	183	215	225	242	272	231
Other food	2,014	2,328	2,652	3,342	4,659	3,034
Total food	3,215	3,711	4,154	5,106	6,875	4,671
Fuel and light	580	669	824	1,106	1,422	944
House rent	173	213	330	431	586	357
Clothing and footwear	300	367	448	616	953	543
Durables	28	59	87	246	568	198
Education of children	110	173	274	564	1,300	478
Medical	151	181	257	378	603	318
Other non-food	902	1,366	1,635	2,837	7,076	2,685
Total	5,460	6,739	8,010	11,284	19,383	10,194
Number of persons	2,224	7,452	4,380	9,589	3,853	27,498

HIV households

(in Rupees)

Item	Upto Rs 20,000	20,001- 30,000	30,001- 41,000	41,001- 84,000	84,001- 1,30,000	Total
Rural						
Cereals	933	1,190	1,236	1,499	1,817	1,254
Pulses	178	223	259	292	306	240
Other food	1,994	2,548	3,031	3,672	4,835	2,938
Total food	3,105	3,962	4,525	5,463	6,957	4,432
Fuel and light	462	648	873	1,021	1,175	768
House rent	165	232	398	315	245	261
Clothing and footwear	342	399	475	587	856	480
Durables	33	77	64	177	611	131
Education of children	145	150	278	455	828	302
Medical	810	859	1,383	1,814	1,693	1,241
Other non-food	1,303	1,512	2,026	3,156	5,647	2,290

(Contd....)

Table 5.8 (Contd....)

Total	6,363	7,839	10,023	12,990	18,012	9,905
Number of persons	1,034	783	543	942	285	3,587
Urban						
Cereals	930	1,162	1,355	1,517	2,070	1,461
Pulses	187	224	258	292	342	271
Other food	2,001	2,821	3,233	4,045	5,602	3,742
Total food	3,118	4,207	4,847	5,854	8,014	5,475
Fuel and light	622	885	1,090	1,304	1,646	1,175
House rent	495	534	766	1,003	1,087	836
Clothing and footwear	316	400	494	655	973	604
Durables	14	24	60	127	529	164
Education of children	151	197	298	454	887	431
Medical	595	1,005	941	1,350	2,106	1,276
Other non-food	1,265	1,597	2,200	3,068	7,037	3,227
Total	6,575	8,850	10,696	13,815	22,278	13,187
Number of persons	660	767	688	1,628	922	4,665
All						
Cereals	932	1,176	1,303	1,511	2,010	1,371
Pulses	181	224	258	292	334	258
Other food	1,996	2,683	3,144	3,908	5,421	3,393
Total food	3,110	4,083	4,705	5,711	7,765	5,022
Fuel and light	524	766	994	1,200	1,534	998
House rent	293	382	604	751	888	586
Clothing and footwear	332	399	486	630	945	550
Durables	26	50	62	145	548	149
Education of children	147	174	289	454	873	375
Medical	726	931	1,136	1,520	2,009	1,261
Other non-food	1,288	1,554	2,123	3,100	6,709	2,820
Total	6,446	8,339	10,399	13,512	21,271	11,760
Number of persons	326	470	585	829	1,419	670

them education. Still lower levels of expenditure by these households on education are seen which supports the assumption in literature that HIV and AIDS would result in lower investment on education of children (Bell, Devarajan and Gersbach, 2003). The reason for lower levels of expenditure by the HIV households, as has been noted above, may be linked to both lower levels of enrolment of children and greater proportion of children being enrolled in government schools. Apart from the destruction of human capital due to the death of those in their prime years and reduced investment on education of children, Bell, Devarajan and Gersbach (2003) also cite the possibility of decreased human capital due to parents with AIDS being less able to raise their own children. This mechanism however is difficult to quantify.

5.3 Savings

A notable feature about savings is the lower average household saving of HIV households as compared to non-HIV households in both rural and urban areas (Table 5.9). This is in spite of the fact that in the sample the average household income of the HIV households is quite close to that of the non-HIV households

and is higher in urban areas (Chapter 4). Another notable feature is that while among non-HIV households savings in the form of agricultural land are positive, the same among HIV households is a large negative figure. This points towards the vulnerability of the small farming households to any such exogenous shock such as the terminal illness of any of its members. This also confirms that the medical expenditure by the cultivation group may be met by the possibility of selling off agricultural land or such assets in order to meet this expenditure. The large and negative savings in jewellery and agricultural land by the HIV households, even as savings in these forms are positive in the case of non-HIV households, empirically validates the assumption in the literature that HIV and AIDS result in decline in savings and assets of the households affected by it. Another very important feature of the savings pattern of HIV households is that the bulk of savings are kept in the form of cash/bank deposits. The non-HIV households allocate a larger share of their savings to financial assets, less liquid form of savings but with higher returns. For instance, the HIV households in urban areas allocate nearly 99 percent of their savings to cash/bank deposits whereas the non-HIV households in

The medical expenditure by the cultivation groups among HIV households are met possibly by selling off agricultural land or such assets

Table 5.9
Average household savings during last one year by place of residence

(in Rupees)

	Non-HIV households			HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cash/bank deposit	2,618.54	3,863.63	3,342.91	3,025.74	5,189.62	4,258.36
Jewellery	800.67	757.93	775.81	-545.27	-532.47	-537.98
Agricultural land	13.32	223.60	135.66	-687.98	-699.49	-694.54
Assets (house/plot)	433.30	236.21	318.63	-272.81	797.11	336.65
Financial (shares etc)	727.04	1,074.19	929.01	184.55	483.94	355.09
Total	4,592.86	6,155.57	5,502.02	1,704.23	5,238.72	3,717.59

urban areas allocate only around 63 percent of their savings to this head. This again shows that HIV households are concerned about the expenditure they might be called upon to incur at any time. Hence, they might be shifting out of fixed assets into more liquid assets. In rural areas, the HIV households are net dissavers in terms of savings directed to house/plot. This movement away from fixed assets to relatively liquid assets has important long-term implications for these households as well as the economy. For the households it implies a loss of wealth and hence lower capacity to deal with exogenous shocks in the future. It can also reduce the long-term income by reducing the income earned in the form of interest and dividends, particularly from savings in financial assets. For the

economy, it implies reduced availability and institutionalisation of savings, which can result in reduced investment and economic growth. It must be noted that in the Indian case household sector is the major institutional source of savings.

The percentage of households that have negative savings is a mere 4.3 percent in the case of non-HIV households as compared to 18.1 percent of HIV households that are negative savers (Table 5.10). In keeping with this, the share of negative savers in income is 3.7 percent in the case of non-HIV households and 13.3 percent in the case of HIV households. Nearly 52 percent of HIV households in both rural and urban areas are zero savers. Compared to this 51 percent of rural non-HIV households and 46 percent of urban non-HIV

Table 5.10
Distribution of savers and non-savers

	Non-HIV households percent share in			HIV households percent share in		
	Household	Income	Savings	Household	Income	Savings
All						
Negative savers	4.31	3.66	-10.31	18.13	13.3	-70.01
Zero savers	48.02	33.42	0	52.13	36.35	0
Positive savers	47.67	62.92	110.31	29.74	50.34	170.01
Total	100	100	100	100	100	100
Rural						
Negative savers	3.42	3.07	-10.22	20.9	14.55	-173.86
Zero savers	50.52	36.57	0	52.25	39.25	0
Positive savers	46.06	60.36	110.22	26.85	46.19	273.86
Total	100	100	100	100	100	100
Urban						
Negative savers	4.94	3.98	-10.36	16.04	12.67	-44.48
Zero savers	46.23	31.73	0	52.04	34.88	0
Positive savers	48.83	64.3	110.36	31.92	52.45	144.48
Total	100	100	100	100	100	100

households are zero savers. The net result is that the percentage of HIV households that are positive savers are less than those among the non-HIV households. This results in much lower proportion of positive savers among HIV households as compared to non-HIV households. While only around 30 percent of the HIV households in the sample are positive savers, nearly 49 percent of the non-HIV households are positive savers. Since the sample was selected in such a way that the socio-economic profile of the HIV and non-HIV households are almost the same, the huge difference in savings pattern is attributable to the HIV status of the households.

The HIV households with negative savings dissave nearly 52.3 percent of the amount saved by the positive savers among these households. In comparison among the non-HIV households, the amount of dissaving by negative savers is only around 15.3 percent of the savings done by the positive savers. This shows that the long-term consequences of HIV and AIDS on total and household savings can be disastrous. The impact on savings at macro-level may not be

visible yet in the Indian case given the fact that the proportion of households affected by HIV is still quite low (even though in absolute terms the number is very high). However if the epidemic grows at the same alarming rate as in many African countries, then the impact on savings could become visible at the macro-level in a very short span of time, say a decade. Over, in his 1992 paper has assumed that 50 percent of the cost of medical treatment would be financed by reduced savings in sub-Saharan Africa and concluded that this would depress growth rates of real per capita GDP by roughly 0.15 percent. While it is not possible to assess with any reasonable degree of accuracy from this survey what the impact of this epidemic is at present on savings or what exactly it would be in future, the indications are that the impact on savings and hence on investment and growth could be very significant.

The main determinant of savings is the income of the household. The lowest income class of less than Rs. 20,000 has negative average household saving in both non-HIV and HIV households (Table 5.11). However the difference is

The percentage of HIV households that are positive savers are less than those among the non-HIV households

Table 5.11

Average annual household and per capita savings by level of income

Non-HIV households

Annual income category	Average household savings (Rs.)			Per capita savings (Rs.)			Rate of savings
	Rural	Urban	Total	Rural	Urban	Total	
Upto 20,000	-49	-54	-51	-14	-16	-15	-0.32
20,001-30,000	517	202	361	125	49	88	1.39
30,001-41,000	2,177	1,329	1,693	477	310	384	4.75
41,001-84,000	7554	5,047	5,906	1,545	1,090	1,251	10.17
84,001 and above	28,578	26,209	26,801	5,216	5,160	5,175	21.27
Total	4,593	6,156	5,502	1,043	1,390	1,245	11.25

(Contd....)

Table 5.11 (Contd....)

HIV households

Annual income category	Average household savings (Rs.)			Per capita savings (Rs.)			Rate of savings
	Rural	Urban	Total	Rural	Urban	Total	
Upto 20,000	-3,282.94	-3,073.47	-3,196.96	-930.27	-949.98	-937.95	-23.44
20,001-30,000	-1,340.53	-2,758.41	-2,087.51	-332.14	-776.81	-552.18	-8.26
30,001-41,000	-643.13	-148.40	-358.42	-159.89	-39.47	-92.59	-1.00
41,001-84,000	2,701.99	2,600.17	2,636.39	608.09	613.31	611.40	4.61
84,001 and above	40,227.32	33,626.72	35,123.21	7,904.32	6,966.06	7,187.60	24.66
Total	1,704.23	5,238.72	3,717.59	422.85	1,322.87	931.65	7.87

Almost 43 percent of HIV households had either borrowed or liquidated assets after one of the family members tested positive

the large value of average household dissaving in the case of HIV households resulting in very high rate of negative savings for them in absolute terms close to the rate of saving for the highest income group. The next two income groups of Rs. 20,001-30,000 and Rs. 30,001-41,000 have a slightly positive rate of saving in the case of non-HIV households. But in the case of HIV households, even these income groups have a negative savings rate of around - eight percent and - one percent. This shows that the lower income groups among the HIV households are able to cope only via the means of large dissaving, which raises concerns about the long-term impact of the epidemic on these groups. In the highest income group, the HIV households show a higher rate of savings than the non-HIV households. One reason is that in the sample the HIV households in these income groups have a much higher income compared to the non-HIV households. As was seen in Table 4.2, the percentage of households belonging to the income group of Rs. 1,30,000 and above is around three percent in the case of non-HIV households while it is slightly more than four percent in the case of HIV households. The share in income of this income group is around 19.4 percent in the case of HIV households whereas it is only around 12 percent in

the case of non-HIV households. Hence, it is not surprising that a much higher rate of savings for HIV households is found in this income group as well as a higher average household and per capita saving.

5.4 Coping mechanisms

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 member of the household turning out to be HIV-positive. It has been noted that the role of the state in mitigating the household impact of HIV and AIDS (or any other illness or premature death) is marginal (Basu, Gupta and Krishna, 1994). This is because the government sector covers a very small part of the population. Further it is not very clear how far the benefits offered by the government would help the employees in coping with the impact of the AIDS epidemic. While those working in the government sector might be better off, others especially those working in the unorganised sector, have no access to social security or employer support. Hence, the burden of coping with the impact of HIV and AIDS lies mainly on the households. In this context, it is important to note that the coping mechanisms used

Table 5.12

Liquidation of assets or borrowings to cope with financial burden of HIV and AIDS after being tested positive

Annual income category	Percentage of HH that borrowed or liquidated assets	Percent share in liquidation of assets or borrowings			Average borrowing or liquidation of assets per household (Rs.)
		Rural	Urban	Total	
Upto Rs. 20,000	56.14	33.54	16.03	23.71	18,702
20,001-30,000	47.07	25.30	13.59	18.73	21,351
30,001-41,000	45.60	17.92	15.31	16.45	24,967
41,001-84,000	37.25	18.45	43.55	32.53	32,243
84,001 and above	23.08	4.80	11.53	8.58	33,104
Total	43.33	100	100	100	24,558

Table 5.13

Liquidation of assets or borrowings to cope with financial burden of HIV and AIDS after being tested positive by occupational classes

Annual income category	Percentage of HH that borrowed or liquidated assets	Percent share in liquidation of assets or borrowings			Average borrowing or liquidation of assets per household (Rs.)
		Rural	Urban	Total	
Cultivation	39.80	21.59	2.89	11.09	31,295
Agri. wage labour	51.21	20.98	4.35	11.65	20,185
Non-agricultural wage	46.56	12.89	14.70	13.90	15,608
Self-employed non-agriculture	41.09	14.79	22.49	19.11	30,919
Salaried	32.53	12.81	24.44	19.34	28,559
Others	50.72	16.94	31.13	24.90	26,095
Total	43.33	100	100	100	24,558

by the households so that policies may be designed to complement existing household strategies as per the study.

One method of coping with the financial burden/loss of income due to the infection could be liquidation of

assets or borrowings. HIV households were specifically asked this question. They were asked whether they had to borrow or liquidate any assets in order to cope with the financial burden/loss of income after one of the family members tested positive. It needs to be

noted that this is not to be compared to the change in savings presented above. This question relates to the liquidation of assets/borrowings of HIV households since the time a person was first detected to be HIV-positive and therefore not linked to the tables on income, consumption, savings and borrowings, which relate to the last one year only. Also here a comparison with non-HIV households is, by definition, ruled out.

The response of HIV households in the survey to this question has been summarised by the income groups in Table 5.12. Almost 43 percent of the households had either borrowed or liquidated assets for this purpose, the average amount generated being Rs. 24,558. The percentage of such households, however, was very high for the lowest income group (56 percent), going down with the level of income of the households. The average amount borrowed or generated through liquidation of assets, however, is higher for higher income groups. Considering that the percentage of households declines with the rise in income, the higher average amount generated by the higher income groups is likely to be linked to greater credit-worthiness and better asset position of these households. It is also seen that the share of lower income groups in total borrowing/liquidation of assets is higher in rural areas rather than urban areas. While there can be a difference in needs between rural and urban households, it could also be linked to having assets to liquidate. Many rural households own assets in the form of land (however small) or farm animals, which can be sold off. This option may not be available to urban households, particularly from the lower income groups since the only asset they may possess is their labour.

On the other hand, the higher income classes in the urban areas are likely to have a higher credit-worthiness and also enjoy better access to institutional sources for borrowing, mainly banks. These households might be able to manage through borrowings rather than liquidation of assets, but this distinction is not available. In order to confirm the possibility of linkage between asset status and amount generated through borrowing or liquidation of assets, the latter is seen by occupational grouping of the households (Table 5.13). The highest average amounts are for the two self-employed groups namely the cultivators and the non-agriculture self-employed group. Clearly the asset position of the household does play an important role in taking recourse to borrowing or liquidation of assets. The worst position is that of the agriculture wage labour. The wage labour group therefore turns out to be the most vulnerable. Not only do they have lower income as compared to other occupational groups, they also lack access to borrowings and if they sell off any small assets that they may possess, their capacity to deal with any external economic shock goes down further.

Another aspect that needs to be looked into is the difference between HIV and non-HIV households in terms of their credit needs. The borrowings in the last one year by HIV and non-HIV households by level of income is presented in Table 5.14. The average borrowings presented here are only for those households that borrowed and not for all households. The borrowing per household is seen to go up with the income of the household. This is not surprising considering that the capacity of the household is dependent on the income and wealth available with the household. Nearly 46 percent of HIV households had borrowed in the last one

Table 5.14
Borrowings in last one year

Non-HIV households

Annual income category	Percentage of HH that borrowed	Percent share in borrowings			Average borrowing per household (Rs.)*
		Rural	Urban	Total	
Upto Rs. 20,000	53.59	15.49	8.57	11.47	5,246
20,001-30,000	33.46	30.23	19.46	23.97	6,195
30,001-41,000	23.74	13.08	12.66	12.84	8,532
41,001-84,000	19.24	23.82	43.28	35.13	14,092
84,001 and above	18.01	17.38	16.02	16.59	19,418
Total	27.49	100	100	100	9,167

HIV households

Annual income category	Percentage of HH that borrowed	Percent share in borrowings			Average borrowing per household (Rs.)*
		Rural	Urban	Total	
Upto Rs. 20,000	61.77	36.36	17.02	26.84	9,140
20,001-30,000	51.71	21.27	14.20	17.79	8,772
30,001-41,000	49.69	14.82	18.03	16.40	10,848
41,001-84,000	37.08	22.49	36.47	29.37	13,891
84,001 and above	21.46	5.07	14.29	9.60	18,942
Total	45.99	100	100	100	10,992

Note: *Figures are only for those households that borrowed. Also, lending by households have been ignored so these are not net borrowings.

The percent of households that borrowed during last one year is higher in the case of HIV households at all levels of income

year as compared to around 27 percent of non-HIV households. The percent of households that borrowed is higher in the case of HIV households at all levels of income. Further, in the case of non-HIV households, the lowest income group has the lowest share in borrowings. But in the case of HIV households, this income group has the second highest share in the total borrowings by all households. Many of the relatively poor households are dependent on borrowings not only for investment purposes but also to meet their consumption needs. This group of households often depends on the local moneylenders or friends and relatives for

their credit needs, since banks require collateral which these households do not possess. Given the HIV positive status of the earning members of the households, the requirement for consumption particularly medical treatment, is likely to be much higher for these households. The combination of greater need for borrowings and dependence on non-formal sources of funds can wreak havoc on the economy of these households. The average amount borrowed by the HIV household in this income group is also almost double that of the same household group in non-HIV households. The average amount borrowed by HIV households is

higher than the non-HIV households till the income group of Rs. 30,001-41,000. Beyond this income group the average borrowings are lower in the case of HIV households. The reason for lower average borrowing among HIV households might be linked to the fear of passing on the debt burden to future generations. They might look to restrict the loan amount so that they have some hope of being able to repay it and borrowings may be driven by necessity. The percentage share in total borrowings of households belonging to the income group of Rs. 41,001-84,000 is the highest. This is true in the case of both HIV and non-HIV households.

If the overall borrowings and lendings by the HIV households are taken, then the average borrowings come to Rs. 5,055 and the average lending comes to Rs. 1,458. Therefore, the net borrowing per household for the sample HIV households comes to Rs. 3,597 in the last one year.

The head count ratio for HIV households is higher than the head count ratio among non-HIV households in the sample

5.5 Poverty

The direct impact of HIV on poverty and inequality has not been demonstrated empirically at the national or state level for any country (UNDP, 2003). The head count ratio of poverty has been estimated from the sample data in order to see the difference between non-HIV and HIV households and whether HIV and AIDS have differential impact on poor and non-poor. One factor was defining the poverty line. The poverty line of 1999-00 obtained from Planning Commission for rural and urban areas has been updated by multiplying the growth of Consumer Price Index (CPI) in 2004-05 over 1999-00 of industrial workers in case of urban poverty line and agricultural labourers in case of rural poverty line. The updated poverty lines were Rs. 363.96 for rural areas, Rs. 551.72 for urban areas and Rs. 416.15 as the combined poverty line.

Table 5.15 presents the estimates in terms of income poverty. The head count ratio for HIV households is higher than the head count ratio among non-HIV households in the sample. However, this is mainly because of the higher ratio of poor population among HIV households in rural areas. In the sample, the per capita income of HIV households is higher than that of non-HIV households in urban areas and slightly lower than that of non-HIV households in rural areas. The difference in per capita income of HIV and non-HIV households does not appear large enough to merit such a big difference in incidence of poverty. But, it also depends on the elasticity of poverty to the definition of poverty line. If the distribution is highly concentrated around the poverty line, a slightly smaller average household or per capita income can result in large differences in estimates of poverty. This might be the reason for the difference observed in poverty. The poor households have higher household size than the non-poor, which is the reason for higher share of poor in population relative to their share in the number of households. But, the household size is lower among HIV households as compared to non-HIV households. This could be a reason why the former households show almost the same head count ratio as the latter in urban areas, as it would result in higher per capita income of these households. As was noted in Chapter 4, many studies have pointed out that even at the macro-level, the economic impact of HIV and AIDS is seen more in terms of GDP than per capita GDP, the latter being affected relatively less than the former due to decrease in population. But, a very stark contrast is seen in terms of rate of savings between poor HIV and poor non-HIV households. The former group has a very high negative rate of savings while this is positive for the latter. Clearly, the poor among HIV households are under

Table 5.15
Distribution of households by income poverty in the sample

Non-HIV households

	Percent share in			Average household		No. of households	Rate of saving	Family size
	Households	Income	Population	Saving	Income			
All				(Rs.)	(Rs.)		(Percent)	
BPL	16.97	8.18	19.49	211	23,584	1,056	0.89	5.08
APL	83.03	91.82	80.51	6,583	54,073	5,168	12.17	4.28
Total	100	100	100	5,502	48,900	6,224	11.25	4.42
Rural								
BPL	9.60	4.54	11.90	414	19,338	250	2.14	5.46
APL	90.40	95.46	88.10	5,037	43,208	2,353	11.66	4.29
Total	100	100	100	4,593	40,915	2,603	11.23	4.40
Urban								
BPL	22.26	10.14	24.92	148	2,490	806	0.59	4.96
APL	77.74	89.86	75.08	7,876	6,3156	2,815	12.47	4.28
Total	100	100	100	6,156	5,4641	3,621	11.27	4.43

HIV households

	Percent share in			Average household		No. of households	Rate of saving	Family size
	Households	Income	Population	Saving	Income			
All				(Rs.)	(Rs.)		(Percent)	
BPL	21.86	78.14	24.70	-4,004	17,062	452	-23.47	4.51
APL	7.89	92.11	75.30	5,877	55,714	1,616	10.55	3.85
Total	100	100	100	3,718	47,266	2,068	7.87	3.99
Rural								
BPL	21.35	8.05	24.81	-4,137	13,957	190	-29.64	4.68
APL	78.65	91.95	75.19	3,290	43,257	700	7.60	3.85
Total	100	100	100	1,704	37,002	890	4.61	4.03
Urban								
BPL	22.24	7.81	24.61	-3,908	19,314	262	-20.24	4.38
APL	77.76	92.19	75.39	7,855	65,233	916	12.04	3.84
Total	100	100	100	5,239	55,020	1,178	9.52	3.96

much serious constraint of trying to meet their consumption expenditure. The linkage could also be the other way, i.e., greater poverty could have driven these households into making some sub-optimal choices that were responsible for their being affected by HIV and AIDS. While this linkage is difficult to establish, or for that matter deny from this survey,

what does emerge is that the position of poor households affected by HIV is much more serious than that of non-HIV households.

Table 5.16 presents the share of the poor in the total population in terms of consumption poverty. Here, it is seen that head count ratio of poverty

Table 5.16

Consumption poverty in the sample

Non-HIV households

Poverty group	Percent share in			No. of households	Per capita expenditure	Family size
	Households	Income	Population			
All					(Rs.)	
BPL	16.47	8.86	19.39	1,025	4,827	5.20
APL	83.53	91.14	80.61	5,199	11,024	4.26
Total	100	100	100	6,224	9,822	4.42
Rural						
BPL	8.53	4.59	10.92	222	3,684	5.64
APL	91.47	95.41	89.08	2,381	8,967	4.29
Total	100	100	100	2,603	8,390	4.40
Urban						
BPL	22.18	11.16	25.45	803	5,177	5.08
APL	77.82	88.84	74.55	2,818	12,781	4.24
Total	100	100	100	3,621	10,846	4.43

HIV households

Poverty group	Percent share in			No. of households	Per capita expenditure	Family size
	Households	Income	Population			
All					(Rs.)	
BPL	14.07	33.69	16.46	291	4,250	12.33
APL	85.93	66.31	83.54	1,777	13,240	2.63
Total	100	100	100	2,068	11,761	3.99
Rural						
BPL	9.89	23.17	12.16	88	3,112	4.95
APL	90.11	76.83	87.84	802	10,845	3.93
Total	100	100	100	890	9,905	4.03
Urban						
BPL	17.23	34.32	19.76	203	4,787	4.54
APL	82.77	65.68	80.24	975	15,256	3.84
Total	100	100	100	1,178	13,187	3.96

is lower in the case of HIV households in urban areas, even though the same level of income poverty was observed for both HIV and non-HIV households in urban areas. In rural areas, the head count ratio in terms of income poverty was almost the double of non-HIV households for the HIV households. But in terms of consumption poverty, the

head count ratio is almost the same for HIV and non-HIV households in rural areas, the figures being approximately 12 and 11 percent, respectively. Clearly, the reason must lie in greater emphasis placed by HIV households on consumption and this is linked with the negative savings rate seen in the case of poor HIV households.

Despite greater focus on consumption by poor HIV households, their per capita consumption expenditure turns out to be lower than that of non-HIV households. This is just the opposite of households above poverty line where the per capita expenditure of HIV households is higher than that of non-HIV households. This suggests that the poor are put under greater stress due to the AIDS epidemic, including the members of the households who are not themselves HIV-positive.

Looking at poverty by occupation of the head of the household, it is seen that poverty among HIV households is much higher than non-HIV households, except in the case of non-agricultural wage households and self-employed in non-agriculture households (Table 5.17). Despite differences in incidence of poverty, the HIV households have higher per capita expenditure than non-HIV households. This brings out the strange dilemma that these households may face.

Table 5.17
Income poverty in the sample group by occupational categories

Non-HIV households

Occupation	Poverty head count ratio	No. of poor persons	No. of poor households	Annual per capita expenditure of poor (Rs.)
All				
Cultivation	15.06	493	83	4,293
Agri. wage labour	30.44	952	177	4,335
Non-agricultural wage	30.67	1,843	362	5,266
Self-employed non-agriculture	16.84	917	193	5,383
Salaried	9.35	645	133	5,885
Others	18.61	510	108	5,262
Total	19.49	5,360	1,056	5,106

HIV households

Occupation	Poverty head count ratio	No. of poor persons	No. of poor households	Annual per capita expenditure of poor (Rs.)
All				
Cultivation	20.45	180	35	7,521
Agri. wage labour	47.37	450	103	5,369
Non-agricultural wage	19.00	299	72	5,984
Self-employed non-agriculture	20.54	260	62	6,291
Salaried	11.91	213	46	6,807
Others	35.45	636	134	5,648
Total	24.70	2,038	452	6,004

They may be pushed into poverty due to AIDS but they are also required to spend more in order to sustain themselves for a longer period. But consumption poverty is lower among HIV households, except in the case of salaried and 'other' households (Table 5.18). Notably, head count ratio calculated in terms of consumption poverty is lower than that based on income poverty. The annual per capita expenditure of the consumption poor HIV households is lower than that of the consumption poor non-HIV households. This is contrary to the result related to income poverty.

There is likely to be a reverse linkage from poverty to HIV and AIDS as well. Poverty may be associated with sub-optimal choices that make the poor and marginal groups vulnerable to HIV infection. Poor households are characterised by high incidence of migration, low literacy levels and per capita income, and early age at marriage, which make them particularly vulnerable to the infection. This is particularly true in the case of women. This linkage may have been discerned by looking at the difference in prevalence rates between poor and non-poor households. However, this procedure

Table 5.18
Consumption poverty in the sample group by occupational categories

Non-HIV households

Occupation	Poverty head count ratio	No. of poor persons	No. of poor households	Annual per capita expenditure of poor (Rs.)
All				
Cultivation	16.83	551	92	4,112
Agriculture wage labour	27.98	875	164	4,163
Non-agricultural wage	30.50	1,833	352	4,973
Self-employed non-agriculture	17.17	935	191	5,172
Salaried	9.59	662	131	5,340
Others	17.40	477	95	4,916
Total	19.39	5,333	1,025	4,827

HIV households

Occupation	Poverty head count ratio	No. of poor persons	No. of poor households	Annual per capita expenditure of poor (Rs.)
All				
Cultivation	12.95	114	21	3,647
Agri. wage labour	27.16	258	59	3,900
Non-agricultural wage	14.42	227	53	4,838
Self-employed non-agriculture	13.90	176	41	4,635
Salaried	10.46	187	37	4,687
Others	22.07	396	80	3,936
Total	16.46	1,358	291	4,250

Case Study 2: 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.

cannot be adopted. A case study that clearly brings out this reverse linkage from poverty to HIV and AIDS in terms of its impact on women is presented here (*Case Study 2*).

5.6 Observations

The major difference in consumption expenditure of non-HIV and HIV households is that the medical expenses of the HIV households are much higher than that of the non-HIV households, almost around four times the per capita per month medical expenses of the non-HIV households. This is because households have to cope mostly with the medical expenses related with the epidemic on their own rather than receiving support from the government. These households need much greater support from the government in terms of access and affordability of medical

care. Special attention has to be directed at the wage labour households who have to reallocate consumption expenditure to medical expenses out of a lower level of consumption expenditure, mainly by substituting away from food expenditure.

The HIV households also spend a higher proportion of their total consumption expenditure on rent and energy, which suggests that these households have lower assets than the non-HIV households do. The HIV households, as was seen later, do liquidate their fixed assets in order to cope with the burden of the infection. The asset most likely to be liquidated is a house or a plot in the rural areas.

With respect to education of children, it is seen that the HIV households, in both rural and urban areas, spend a lower

Both the average household and per capita expenditure of the HIV households on education is less than that of the non-HIV households

proportion of their total consumption expenditure on education though the difference is larger in urban areas. This upholds the general idea in the literature that HIV and AIDS might affect the education of children. Both the average household and per capita expenditure of the HIV households on education is less than that of the non-HIV households. This is due to a combination of lower current enrolment rate and a higher proportion of children enrolled in government schools where the fee is lower. In fact, one of the coping mechanisms for these households may have been to continue investing on children's education in order to improve their human capital and future earning capacity. Many parents did express concern about continued education of their children. This suggests that even though parents are altruistic about investing in the education of their children, the financial burden imposed on them due to HIV and AIDS prevents them from doing so.

The percentage of households that have negative savings is a mere 4.3 percent in the case of non-HIV households as compared to 18.1 percent of HIV households. The negative savers among HIV households dissave nearly 52 percent of the amount saved by positive savers. In comparison among the non-HIV households, the amount of dissaving by negative savers is only around 15 percent of the savings done by the positive savers. Overall, the results show that not only is the average and per capita savings of HIV households lower than that of the non-HIV households for the lower income groups, it also results in a much larger negative impact on aggregate savings. This suggests that the long-term consequences of HIV and AIDS on total and household savings can be disastrous even though the impact

may not be visible yet in the Indian case given the fact that the proportion of households affected by HIV is still quite low.

This movement away from fixed assets to relatively liquid assets, observed in the sample in the case of HIV households has important long-term implications for these households as well as the economy. For the households it implies a loss of wealth and hence lower capacity to deal with exogenous shocks in the future. It can also reduce the long-term income by reducing the income earned in the form of interest and dividends, particularly for savings in financial assets. For the economy, it implies reduced availability and institutionalisation of savings, which can result in reduced investment and economic growth. This is particularly so since in the Indian case, households are the major institutional source of savings.

Almost 43 percent of the households had either borrowed or liquidated assets to cope with the financial burden after being detected to be HIV-positive. The percentage of such households was very high for the lowest income group, going down with the level of income of the households. The average amount borrowed or generated through liquidation of assets however is higher for higher income groups. This is likely to be linked to the asset position of the households, which would also determine their borrowing capacity.

The percentage of households that borrowed in the last one year is seen to rise continuously with the level of income of the household. The percentage of HIV households that borrowed is nearly double that of the non-HIV households. The lowest income group in the case of HIV households has the second highest share in the total borrowings by all

households, while this income group has the lowest share in total borrowings in the case of non-HIV households. The average amount borrowed by the HIV household in this income group is also almost double that of the same household group in non-HIV households. This brings out the vulnerable position of the HIV households, especially those at the bottom of the income pyramid. At the higher levels of income the HIV households do show smaller borrowings. The reason for this might be linked to the fear of passing on the debt burden to future generations. For the lower income groups, the factor could be lower capacity to borrow. This is another area that would require the attention of the state. Since the credit needs of these households could be a question of survival of the members of these households, borrowing for special purposes such as medical expenditure might be one issue that the state could take up. This issue, it is well known, is linked with the issue of return on investment for lending institutions and therefore, needs a more careful thought out intervention.

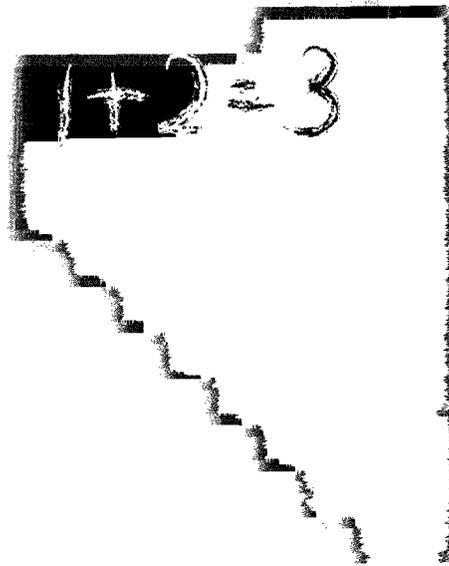
In rural areas, the head count ratio of poverty is higher among HIV households in the sample. A very stark contrast is seen in terms of rate of savings between poor HIV and poor non-HIV households. The former group has a negative rate of

savings while this is positive for the latter. In terms of consumption poverty, it is seen that head count ratio is lower in the case of HIV households in urban areas. In rural areas, it is almost the same as in the case of non-HIV households even though higher income poverty for HIV households in rural areas was observed. Clearly, the reason must lie in greater emphasis placed by HIV households on consumption and this is linked with the negative savings rate seen in the case of poor HIV households. The poor among HIV households are under much serious constraint of trying to meet their consumption expenditure. This suggests that the poor are put under greater stress due to the AIDS epidemic, including the members of the households who are not themselves HIV-positive.

While it does seem to be the case that HIV and AIDS could increase the incidence as well as severity of poverty, the linkage could also be the other way i.e. greater poverty could have driven these households into making some sub-optimal choices that were responsible for their being affected by HIV. While the latter linkage is difficult to quantify from this survey, there is evidence for it as seen in a case study. What does emerge clearly is that the position of poor households affected by HIV is much more serious than that of non-HIV households.

The poor are put under greater stress due to the AIDS epidemic, including the members of the households who are not themselves HIV-positive

Impact of HIV and AIDS on the



Impact of HIV and AIDS on the Education of Children

Now it is becoming common knowledge that a general foundation in formal education can serve as a protective barrier to HIV infection and hence there is an increased need for education in the context of HIV and AIDS. 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 education has been proved as a means to prevent HIV and AIDS (World Bank, 2002; Boler Tania and Kate Carroll, undated; Vandemoortele, Jan and Enrique Delamonica, 2000). However, while there is evidence to support the argument that education helps prevent HIV transmission, it has also been shown in the worst affected countries that AIDS is seriously undercutting the education sector by affecting the demand, supply and quality of education. Globally HIV and AIDS is seen as an immense challenge to the education sector and as an impediment to achieving the goal of education for all (EFA) by the year 2015. In worst affected areas, particularly in sub-Saharan Africa, the impact of AIDS on the education sector has been severe. (UNESCO, 2001; Wijngaarden Jan and Sheldon Shaeffer, 2004)

HIV and AIDS can have a large impact on the education of children by affecting the access to and demand, supply and quality of education. The children's

school enrolment may get affected and even if the children are enrolled, they may attend school intermittently. Eventually they may dropout if their parents cannot afford to pay their fees and related out-of-pocket expenses due to reduced family income or increased health expenditure. Children, especially girls, may be pulled out of school to take care of the sick family members or to supplement family income. Children born to HIV-positive parents or children infected with HIV may be denied access to schools due to fears and stigmatisation. Education may be affected because of higher levels of morbidity and mortality of teachers and finally the quality of education may suffer due to absenteeism from work by teachers as a result of their own illness or caring for the ill. Thus the impact of HIV and AIDS can ultimately lead to reduction in demand, supply and quality of education, leading to difficulties in increasing school enrolment, completion rates and overall learning achievements. Since most of the HIV affected persons are not only in their prime working age but are also often parents of young school-going children, the epidemic would have an adverse effect on many aspects of child welfare, including their education.

This chapter tries to examine the household impact of HIV and AIDS on the schooling of children. The household

impact is being measured not only by asking whether the child is going to school but also by finding out the child's school attendance, the type of school attended and reasons for dropping out. This chapter attempts to relate the presence of HIV and AIDS in a household to its ability to continue educating its children and tries to capture the gender differentials, if any. It also attempts a cross-sectional analysis of the differences in children's education in both HIV-positive households and non-HIV households, by keeping their socio-economic characteristics similar.

The number of reports published on this subject quote the empirical studies undertaken in African countries and Latin America on the impact of HIV and AIDS on enrolment rates and continuation of schooling of children orphaned by AIDS (Coombe 2002; Kelly 2000; World Bank 2000). Even the recent study undertaken in the Sangli district of Maharashtra, India, was also based on the data collected on orphans (Verma et al 2002). However, in the present study, the whole approach is different since the study is based on the interviews of PLWHA and as a result in these households, at least one of the parents is alive. This study tries to compare the schooling of children belonging to the two sets of households i.e. households with the presence of an HIV-positive individual and households without any such individual.

6.1 Ever and current enrolment of children

In this section, the household impact on enrolment and continuation of school education of children belonging to two sets of sample households namely HIV households and non-HIV households are assessed based on the survey results. The ever and current enrolment rates

for children in the age group of 6-14 years, which corresponds to class I-VIII and in the age group of 15-18 which corresponds to class IX-XII are presented in Table 6.1.

The ever enrolment ratio is calculated as, number of children in the age group 6-14 who were ever enrolled as a percentage of total number of children in that age group. 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.

The sample included 1562 children from the HIV households and 4861 children from the non-HIV households in the age group 6-14 years. Expectedly as compared to 6-14 age group, there were fewer children in the 15-18 age group; there were 360 children from HIV households and 1981 from the non-HIV households. The table reveals interesting differences between the schooling of children belonging to two types of households. First, the ever enrolment as well as current enrolment percentages are lower for the children of HIV households as compared to children of non-HIV households for both the age groups. Secondly, the difference between HIV and non-HIV households is more marked in current enrolment percentages than in ever enrolment percentages indicating that the dropout rates are higher in HIV households. Thirdly, though there is hardly any gender difference in the ever enrolment percentages, there are differences in the current enrolment percentages especially in the case of rural children belonging to HIV households. In fact, the gender gap is marginally more for the HIV households as compared to non-HIV households, suggesting that in the HIV household girls are more likely to be withdrawn from the school.

The differences between HIV and non-HIV households is more marked in current enrolment percentages than in ever enrolment percentages

Table 6.1

Ever and current enrolment of children in HIV and non-HIV households

(in Percentages)

Age 6-14 years	HIV household			Non-HIV household		
	Rural	Urban	Total	Rural	Urban	Total
Ever enrolled						
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
No. of children	811	751	1,562	2,661	2,200	4,861
Age 15-18 years	HIV household			Non-HIV household		
	Rural	Urban	Total	Rural	Urban	Total
Ever enrolled						
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
No. of children	198	162	360	1,033	948	1,981

These findings on the lower enrolment of children of HIV households are corroborated by the studies conducted in other countries like Botswana, South Africa, Swaziland, Zimbabwe and Zambia which already have evidences of stagnating or declining enrolment in schools that could be attributable to HIV and AIDS (Cornia G A, 2002)

6.1.1 Dropout rates and number of years of schooling

Table 6.2 compares the dropout rates among children of HIV households and non-HIV households and the average

number of years of schooling completed by the dropouts for both the age groups, that in 6-14 and 15-18 years. A number of observations are evident from the table. First, for both the age groups, the dropout rates are higher for the children of HIV households. Secondly, as expected, the dropout rates are higher for the 15-18 age group as compared to 6-14 age group for both HIV and non-HIV households. Thirdly, generally for both types of households, the dropout rates are lower for the urban children, the rural-urban difference is more marked in the case of 15-18 age group. While concluding it

Table 6.2

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		
	Rural	Urban	Total	Rural	Urban	Total
Percentage of children who dropped out of school						
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
No. of children	811	751	1,562	2,661	2,200	4,861
Age 15-18 years						
	HIV			Non-HIV		
	Rural	Urban	Total	Rural	Urban	Total
Percentage of children who dropped out of school						
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
No. of children	198	162	360	1,033	948	1,981

can be stated that as compared to boys, the dropout rates are generally higher among girls.

As compared to the children of non-HIV households, is the percentage of children dropping out of school and even the number of years of schooling completed by the dropout children is less for the children of HIV households. While the difference between HIV and non-HIV households is marginal in the case of 6-14 year age group, it is substantial in the case of older children. In the case of

older children while the girls of non-HIV households dropout of school earlier than the boys, among the children of HIV households, it is the other way round; boys are withdrawn from school earlier than the girls, probably to earn for the family.

The impact of HIV and AIDS on children's education as shown by this survey data may not sound very alarming. One of the reasons for this could be that the sample had more of households with PLWHA in the first and second stage of infection and fewer households with

persons in third or fourth stage. As more and more positive persons reach the higher stage of infection, the impact could be greater. Also, the impact would be much more on the children who are orphaned. This study includes only those children/households where at least one of the parents is alive. For instance it has been found in Mozambique that only 24 percent of orphans attend school as compared to 60 percent of those with living parents. (Coombe Carol 2002)

6.1.2 Ever and current enrolment of children by annual household income categories

Household income is one of the important demand side factors that determines the schooling of children. In order to see the influence of household income on the schooling of children, the ever and current enrolment percentages have been worked out for the children of HIV and non-HIV households by the annual

household income categories and these are presented in the following Table 6.3.

The ever and current enrolment percentages by the household income categories are worked out only for the 6-14 age group, since there are fewer children, (especially in the HIV households) in the higher age group. As compared to the children of non-HIV households, the ever and current enrolment percentages have been lower for the children of HIV households in the case of all the income categories. In other words even after controlling the household income, the differences in the ever and current enrolment percentages between the HIV and non-HIV households persist. However, this difference is most marked for the lowest income category and moving to higher household income categories, the difference between HIV and non-HIV households gets reduced and vanishes on reaching the highest income category. This implies that,

Household income is one of the important demand side factor that determines the schooling of children

Table 6.3
Ever and current enrolment rates for children (6-14 years)
by annual household income categories

(in Percentages)

Annual household income (Rs.)	HIV households			Non-HIV households		
	Boys	Girls	All	Boys	Girls	All
Ever enrolled						
Upto 20,000	91.83	90.09	90.95	96.00	95.65	95.84
20,001-30,000	94.97	90.68	92.81	96.60	97.02	96.79
30,001-41,000	95.49	88.68	92.47	97.70	95.24	96.61
41,001-84,000	93.19	95.90	94.42	97.91	96.31	97.19
Above 84,000	98.68	98.70	98.69	98.20	98.16	98.18
Currently enrolled						
Upto 20,000	87.02	85.38	86.19	94.00	93.24	93.65
20,001-30,000	92.45	86.34	89.38	93.71	92.95	93.37
30,001-41,000	93.23	85.85	89.96	96.65	94.71	95.79
41,001-84,000	92.77	92.31	92.56	96.98	95.60	96.36
Above 84,000	98.68	96.10	97.39	98.20	97.43	97.82
N	811	751	1,562	2,661	2,200	4,861

The difference between HIV and non-HIV households is most marked for the children belonging to the households where the head is illiterate

irrespective of the presence of an HIV-positive individual in a household, if the household is economically sound, the children are more likely to get educated. Also in the case of HIV households, the difference between ever and current enrolment percentages is very high for the lowest income category households and moving up, the gap gets narrowed down indicating a positive relationship between household income and continuation of schooling. For instance, for the children of HIV household belonging to the lowest income category of upto Rs. 20,000, the ever and current enrolment percentages are respectively 90.1 and 86.2 whereas the respective rates are 98.7 and 96.1 for the children belonging to the highest income category of Rs. 84,000 and above.

6.1.3 Ever and current enrolment rates by level of education of household head

The relationship between the level of education of the household head and the schooling of children has come out very clearly (Table 6.4).

Some important observations emerge from the Table 6.4. First, the ever as well as the current enrolment percentages for both types of households go up with the rise in the level of education of the household head. More importantly, at every level of education both the ever and current enrolment rates are lower for the children belonging to the HIV households as compared to non-HIV households. This again shows that even after controlling the level of education of the household, the difference between HIV and non-HIV households prevails. However the difference between HIV and non-HIV households is most marked for the children belonging to the households where the head is illiterate. With the rise in the level of education of the household head, the difference between HIV and non-HIV households gets reduced. This shows that irrespective of the presence of an HIV-positive individual in the family, the children belonging to educated families are likely to get at least a minimum level of education. Also in the case of households where the head is illiterate, there is a

Table 6.4
Ever and current enrolment rates for children (6-14 years)
by level of education of household head

(in Percentages)

Education of household head	HIV households			Non-HIV households		
	Boys	Girls	All	Boys	Girls	All
Ever enrolment rate						
Illiterate	90.57	88.44	89.55	95.47	94.63	95.08
Upto middle	92.12	91.24	91.69	97.31	96.56	96.97
High school/higher secondary	97.63	95.52	96.63	97.78	96.91	97.39
Graduate/diploma	97.06	96.87	96.97	98.82	97.93	98.41
Current enrolment rate						
Illiterate	84.84	82.22	83.58	91.14	88.79	90.06
Upto middle	90.64	87.11	88.92	95.64	95.00	95.35
High school/higher secondary	97.30	92.91	95.21	97.20	96.56	96.91
Graduate/diploma	97.06	96.88	96.97	98.82	97.24	98.09
N	811	751	1,562	2,661	2,200	4,861

substantial gender gap in both ever and current enrolment percentages, especially among the children of HIV households. However, moving to the most educated households where the household head is a graduate or a diploma holder, there is hardly any gender gap i.e. both girls and boys are provided with basic education. This indicates that the gender gap can be reduced as level of education of the parents increases.

6.2 Reasons for dropout

The survey results clearly show that

although there is not much difference between HIV and non-HIV households in the percentage of children, who were ever enrolled in school, there is a substantial difference in the current enrolment percentages, especially in the case of poor households and for older children. This indicates that most of the HIV households do enroll their children in school, but they are unable to continue their education. The survey tried to find out the reasons for discontinuation of schooling from both types of households and these findings are presented in Table 6.5.

Table 6.5
Reasons for dropout by type of households

(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

(Contd....)

Table 6.5 (Contd....)

15-18 years	HIV households			Non-HIV households		
	Boys	Girls	Total	Boys	Girls	Total
Could not afford	15.2	20.5	17.8	14.9	12.6	13.7
To take care of sick	6.5	2.3	4.4	0.7	-	0.3
To take care of younger sibling/take up other household work	2.2	22.8	12.3	2.7	6.6	4.6
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

It is not surprising that both HIV and non-HIV households have given 'could not afford' as a reason for discontinuation of schooling, as it has already been seen that the dropout percentages are very high among the children of poor households. However, other than this, there are differences between HIV and non-HIV households in the reported reasons for discontinuation of schooling. For instance, in the 6-14 age group, as high as 37 percent of the dropout children from the non-HIV households had discontinued their studies because they were not interested

whereas one-third of the children who had dropped out of school from the HIV households had done so because they had to take up a paid job. The ILO study also came out with similar findings in their survey of PLWHA (ILO, 2003). The study found that 17 percent of their children had to take up petty jobs to meet the financial requirements of the family. In the present study, another 22 percent had to take care of the younger siblings or other household work. This percentage is particularly high for the girls of HIV households who had given up studies. Thus the schooling of

children belonging to HIV households is discontinued, mainly because they are required to perform domestic chores/participate in paid work/take care of younger sibling/take care of the sick. These are reported as important reasons for dropout in the case of 53 percent of the boys and 64 percent of the girls in the 6-14 age group and 39 percent of the boys and 32 percent of the girls in 15-18 age group. The fact that a number of children from the HIV households have dropped out for taking up income-earning activities or to take care of younger siblings or household chores, shows that the opportunity costs also work as a great barrier to school participation for these children.

Surprisingly, no HIV household has reported stigma or discrimination as reasons for non-enrolment or discontinuation of schooling. Does this mean there is no discrimination in schools? The Focus Group Discussions conducted with the PLWHA provide some clue to this question. Most of the parents mentioned that as far as possible their HIV status is not disclosed in the schools, fearing discrimination and they do not think that there is any need to disclose their status. Hence the question of discrimination does not arise. Unless the child himself/herself is positive, the school authorities are not likely to know about the parents HIV status, especially in an urban set-up.

Box 3

Case Study 3: Children's dream of education shattered

Their father was a truck driver and earned on an average about Rs. 3,000 a month. This meant a comfortable existence for the entire family. About four to five years ago, due to the nature of his job and the loneliness of being away from home, he took to drinking, smoking and having extra-marital relationships.

Thereafter, after a spate of illnesses he was diagnosed HIV-positive. Since then, things have not been the same. In the last three years he has been hospitalised three times. Not only were all his savings spent on the hospital charges and medicines, but he also had to dispose of his wife's jewellery and borrow money from others. He was also forced to change his accommodation twice for he could not afford the rent and his family and he now live in a semi-pucca one-room accommodation with no separate kitchen, water tap or toilet. Although he is at present in the third stage of the infection, he is trying his best to earn and support his family. He is now employed as a driver and earns Rs. 1,500 per month.

During the last three years of financial struggle, his eldest son had to give up his studies after the

12th standard and start working to earn sufficient resources for the family. The boy, who dreamt of pursuing higher level education, is now shattered and embittered. He cannot understand how he is responsible for his father's illnesses and inability to work especially when all his friends are going to college and getting an education.

He blames his father and has adopted a very negative outlook. And his future also looks bleak. Even his relations with his father are strained as he seldom talks to his father and conveys his lack of respect and displeasure ever so often.

The second son, who is a good student, is at present studying in class X. He also wants to study further, but has no hope of doing so.

Due to these negative sentiments, a lot of blame is being put on the father. Even their mother feels that the father alone is responsible for all the misfortunes that the family is facing. The lack of emotional support for him ensures that he feels guilty and it prevents any kind of positive thinking and living.

6.3 Type of school attended

To a large extent the type of school attended by children is indicative of the economic status of the household. The percentage of children studying in government schools is much higher for the children of HIV households as compared to the non-HIV households (Table 6.6). While 63 percent of the children belonging to HIV households are studying in government school, 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. Since the expenses in government schools are comparatively lower, it is not surprising that more children from the HIV households are studying there.

It has already been seen in Chapter 5 that as compared to non-HIV households, the HIV households are spending much more on medical expenses. Since the sample of non-HIV households is taken

from similar economic background as HIV households, it may be reasonable to assume that the burden of medical expenses in the HIV households could be driving them to send their children to government schools. They are much cheaper if not free and also come with other benefits like free uniforms, mid-day meals and free books.

These findings are corroborated by the views expressed by the participants of the Focus Group Discussions conducted by the research team with 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 woman participant of the Focus Group Discussions lamented that since she needed money for the treatment of her husband, her child had to be shifted from an English

Table 6.6
Distribution of currently enrolled children by
type of school attended

(in Percentage)

Type of school	HIV Households			Non-HIV Households		
	Boys	Girls	All	Boys	Girls	All
6-14 age group						
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						
Government	60.51	66.87	63.29	51.48	50.27	50.91
Private*	38.97	33.11	36.42	48.28	49.73	48.97
Informal/others	0.51	--	0.29	0.24	--	0.13
Total	100	100	100	100	100	100

* Includes government aided private schools.

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 to English later, particularly in higher classes. Many of the HIV-positive persons who participated in the Focus Group Discussions conducted during the ILO study also talked about children being shifted to inexpensive schools due to economic constraints. (ILO, 2003).

In the case of HIV households, as compared to boys, the percentage attending government school works out to be higher for the girls; while 67 percent of the girls are attending government school, the percentage of boys going to government school works out to be lower at 60 percent. In the case of non-HIV households no such gender difference is seen. This again suggests that the HIV households are willing to spend more on the education of boys than on girls.

6.4 School attendance

The survey attempted to find out whether presence of an HIV-positive individual in the household affects the school attendance of children and the findings do suggest that to some extent it does. For both the age groups, the average number of days absent from school during the last academic year is higher for the children of HIV households. As far as 6-14 year age group children are concerned, the average number of days absent is 7.0 for the children of non-HIV households, while the same is higher at 10.5 for the children of HIV households. Similarly for the children in the higher age group, these averages are 6.7 and 9.6, respectively, for the children of non-HIV and HIV households.

There are interesting differences between the HIV and non-HIV households in the

Table 6.7
School attendance of children in the last academic year
by type of household

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	HIV households			Non-HIV households		
	Boys	Girls	All	Boys	Girls	All
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

reasons for absence as well. Although in both types of households, a high percentage of children had to absent themselves from school due to their own ill health, this percentage is higher for the children of non-HIV households. Expectedly, the percentage of households reporting ill health of the parents as a reason for children's absence is higher for the HIV households. While 28 percent of the children in the 6-14 age group and 36 percent of the children in 15-18 age group from the HIV households had to absent themselves due to their parents' ill health, in the case of children of non-HIV households these percentages are much lower at 6.6 and 10.3.

Another noticeable difference between the HIV and non-HIV households is that a much higher percentage of children from non-HIV households were absent for leisure or social activities i.e. for reasons like going out of station or attending social function. In the case of HIV households, the percentage of children giving these reasons has been much lower. Interestingly, 'child refused to attend school' seems to be an important reason for being absent from school in both types of households.

6.5 Impact on higher education

The survey tried to find out from the HIV-positive persons whether their HIV status is standing in the way of any of the family members getting higher education. The responses received from the PLWHA are presented in Table 6.8.

This question was not applicable to almost 60 percent of the PLWHA as the households did not have any one in that age group. Of the remaining 40 percent who responded to this question, 17 percent reported that the higher education of one of their family members was indeed getting affected. There is no rural-urban difference in the proportion reporting this impact. Given the gender bias in Indian society, it is not surprising that most of them are concerned about their sons' higher education getting affected. Nearly 13 percent of the urban respondents have mentioned that their siblings' higher education is being affected, although this percentage has been much lower at 2 percent in the case of rural PLWHA. The siblings' education could have been affected either due to the deteriorating financial condition of the

Table 6.8

Impact of HIV and AIDS on higher education of family members

(in Percentages)

	Rural	Urban	Total
People reporting that higher education getting affected	16.6	17.3	17.0
Affecting the Education of			
Sons	57.1	54.0	55.2
Daughters	17.9	13.7	15.3
Both	23.2	17.2	19.6
Siblings	1.8	12.6	8.3
Others	-	2.3	1.4
Total	100	100	100

Case Study 4: 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-sustaining 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.

HIV households as a result of increasing medical expenses or could be due to loss of income of the PLWHA. Also in India it is not uncommon to see older siblings educating their younger ones.

6.6 Ever and current enrolment of HIV-positive children

The sample captured 71 HIV-positive children in 6-14 age group and just four positive children in 15-18 age group. The details about the ever and current enrolment status of these children at the time of the survey are as follows.

It is heartening to note that majority of the children are studying in school i.e. 54 out of 71 are currently studying. But it is disturbing to know that in the case of

nine children, the parents had reported that their child did not get admission because of their HIV status.

Table 6.9

Ever and current enrolment of HIV-positive children (6-14 years of age)

	Boys	Girls	Total
Total number of children	41	30	71
Ever enrolled	35	23	58
Number never enrolled	6	7	13
Reasons for non-enrolment			
Admission denied because of HIV status	4	5	9
Child is too ill to study	2	2	4
Currently enrolled	34	20	54

6.7 Observations

The survey results do suggest that the presence of PLWHA in a household does affect the schooling of children. Though the enrolment of children in schools is affected only to some extent, continuation of schooling seems to be a greater problem for these children.

Both HIV and non-HIV households seem to have financial constraints in educating these children as 'could not afford' has been reported as an important reason for discontinuation of schooling. However, in the case of children of HIV households, 'had to take up a paid job/take care of younger siblings/the sick/look after household chores', have also emerged as important reasons for dropping out of school. This shows that for these children the opportunity cost is a great barrier to school participation.

A genuine concern for many of the HIV-positive parents is the future of their children. How long can they continue to educate their wards? Encouragingly most of the parents even if they themselves were not very well educated, seem very keen to educate their children, although they may not live to reap the benefit of their children's education. In fact, a number of PLWHA in the FGD, mostly widows, wanted to take good

care of themselves, so that they would be able to live till the time that their children become adults and are able to look after themselves. A few others were very positive in their attitude and were confident that they would survive till their children stand on their own feet.

However, the survey results show that not all can afford to educate their children beyond middle school. Given the strong family ties in India, a number of them, especially the widows, were confident that the grandparents or the uncles would take care of their children. Others hope that the government or an NGO would come to their rescue. In fact, often it is the grandparents who take care of the child orphaned by AIDS. However, a study conducted in Maharashtra found out that while the members of the extended family were providing shelter to the orphans, several of the orphans were not receiving continued education (Verma Ravi K. et al 2002).

There are also residential schools in which some of the children of PLWHA are studying. But these are few and far between and cannot cater to all. Some supportive system should be developed and simultaneously the families of PLWHA should be prepared to look after their children who lose both the parents.

The families of PLWHA are to be prepared to look after the children who lose both the parents

Impact of HIV and AIDS on



Impact of HIV and AIDS on Health

HIV and AIDS has emerged as one of the major public health challenges in India in recent years. At the macro-level it is increasing the burden on the already weak public health system of the country. At the household level, the most visible impact is the financial burden on the families of the infected persons resulting from increased expenditure on medical treatment. The financial implication could be quite severe, especially for the poor and low-income households. Since HIV-infected individuals are in their most productive years, the affected households are likely to suffer loss of earnings and income and the increased expenditure on medical treatment would further reduce the disposable income of the households. The impact on the individual and household could be further aggravated by the likelihood of multiple cases of HIV and AIDS within a household.

This chapter attempts to assess the burden of morbidity on the HIV affected households based on the data collected from the six HIV high-prevalence states. The details about the opportunistic infections suffered, the type of treatment sought and the out-of-pocket expenditure incurred on the treatment were gathered from a sample of 2,385 PLWHA. In addition, the survey also

collected information on the prevalence of non-hospitalised illnesses and the hospitalisation cases for all the members of HIV as well as non-HIV households (the controlled group), to compare the disease burden on the two types of households. The findings of the survey are presented in the following sections.

7.1 Prevalence rate of illness

7.1.1 Prevalence rates of illnesses—HIV and non-HIV households

The prevalence rates are calculated for both non-hospitalised illnesses and hospitalised cases from the information collected on all the members of the HIV and non-HIV households. In all, there was a sample of 2,068 HIV and 6,224 non-HIV households and the total number of persons was 8,252 for the HIV and 27,506 for the non-HIV households. The prevalence rate of non-hospitalised illnesses is calculated on the basis of 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 on the basis of the number of hospitalisation cases reported for the household members

Table 7.1
Prevalence rate of non-hospitalised illness for one month reference period by
type of households and age and sex

(Per'000 Population)

Age group	HIV households			Non-HIV households		
	Men	Women	Total	Men	Women	Total
0-14	306.0	323.1	314.1	320.4	307.1	314.3
15-59	1,041.6	731.7	877.5	232.1	235.0	233.5
60 +	749.0	800.0	774.1	647.2	660.4	653.8
All ages	794.2	625.6	708.0	276.4	274.7	275.6
(N) No. of persons	4,032	4,220	8,252	14,283	13,223	27,506

Table 7.2
Reported number of hospitalisation cases
in the reference year by type of households and sex

(Per'000 Population)

Age group	HIV households			Non-HIV households		
	Men	Women	Total	Men	Women	Total
0-14	50.9	56.3	53.5	53.9	52.8	53.4
15-59	462.6	225.4	337.0	58.2	73.2	65.6
60 and above	226.7	145.8	186.9	163.3	154.2	158.8
All Ages	319.7	175.4	245.9	61.8	71.8	66.6
(N) No. of persons	4,032	4,220	8,252	14,283	13,223	27,506

during the last one year preceding the date of interview. These are presented in Tables 7.1 and 7.2.

The tables clearly indicate that the burden of non-hospitalised as well as hospitalised illnesses is very heavy on HIV households as compared to non-HIV households. As expected in the 15-59 age group, men and women from HIV households have high-prevalence rate of both hospitalised and non-hospitalised illnesses since most of the PLWHA belong to this age group. What stands out is that in the 15-59 age group, the burden on HIV households is nearly four times that of non-HIV households with respect to non-hospitalised illnesses and is about five times in the case of hospitalised illnesses. While for the 0-14 age group,

the prevalence rate of non-hospitalised as well as hospitalised illnesses has been more or less same for both types of households, for the 60 and above age group the rates have been marginally higher for the HIV households.

In the HIV households, the prevalence rate of hospitalisation has been much lower for women, while no such trend is visible in the case of non-HIV households.

7.1.2 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 infection and the number of years back the infection was detected. The WHO classifies the HIV infection into four

clinical stages based on the infections and the performance scale. At Stage I, it is asymptomatic and the individual would be able to carry on normal activities. In the clinical Stage II, it is symptomatic (with symptoms like weight loss of <10 percent, 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 severe bacterial infection and/or would be bedridden for less than 50 percent of the days during the 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 the last one month.

The prevalence rates of both non-hospitalised and hospitalised illnesses go up with the increase in the stage of infection. The jump in the rates is much more marked after Stage II, clearly indicating the deteriorating health status of the infected persons in Stage III and IV.

While the stage-wise details have been given for 2,703 people, the prevalence rates on the basis of the number of years since HIV positive status was detected have been given only for 2,385 people. Of the 2,068 HIV households interviewed, there emerged 2,703 cases of PLWHA. These also included children in the age group of 0-14 and others who were less than 18 years 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 information could be collected only from 2,385 persons. Hence the difference in number of people for whom the results have been tabulated.

Table 7.3
Prevalence rate of illness and hospitalisation for PLWHA
by stage of infection and number of years since HIV status detected
(Per'000 Population)

	Non-hospitalised illnesses during last one month	Hospitalisation during last one year	Number of persons
Stage of infection			
Stage I	888.0	238.4	839
Stage II	1,471.9	504.4	1,015
Stage III	2,302.2	1,116.8	642
Stage IV	2,468.6	1,623.2	207
All	1,564.2	653.0	2,703
Number of years since detected			
Upto one year	1,538.0	637.4	1,208
2 to 5 years	1,615.5	700.7	1,069
> 5 years	1,592.6	713.0	108
All	1,575.7	669.2	2,385

The increase in the prevalence rates is not sharp if one goes by the number of years since the infection is detected. In fact, the prevalence rates have been fairly high even for those who had tested positive in the last one year. The reason for this could be that even if they were detected positive only a year back, they could have been infected many years ago. All that the survey instrument could gather was the number of years back the person was tested HIV-positive and there was no way of finding out when that individual caught the infection.

HIV virus causes chronic infection and the course of the infection would vary from individual to individual. Some persons may develop immune deficiency within two to three years and others may remain AIDS free for 10-15 years. The manifestation of infections in those diagnosed with AIDS depends on the level of immunity, which is reflected by CD4+T cell count.

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. It 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 Opportunistic Infections (OIs). These findings are presented below.

7.2 Details about non-hospitalised illness episodes

7.2.1 Frequency of illnesses (Non-hospitalised)

HIV weakens the body's immune system i.e., the ability to fight diseases and as a result, PLWHA can get many infections which are called Opportunistic Infection (OIs) because they take advantage of

the opportunity of infection offered by the weakened immune system. The prevention and treatment of OIs is an important component of management of HIV.

Table 7.4 shows the frequency at which the sample PLWHA were falling ill during the last one year and during the last one month. These illnesses include only those ailments for which they were not hospitalised. As high as 22 percent reported that they were frequently ill during the last one year and 16 percent of the PLWHA were frequently falling ill during the last one month. Another 2 to 4 percent reported that they were almost continuously ill. For the remaining persons, i.e., those who had not reported frequently or continuously ill, the average number of times they had fallen ill has been indicated. First, these percentages and averages are much lower for women PLWHA as compared to men. This gender difference in the reporting of illnesses could be either due to differences in the perception of illness between men and women or due to differences in the stage of HIV infection. Secondly, as the stage of infection increases, the percentage reporting frequently ill increases upto Stage III and comes down at Stage IV. However, the percentage reporting continuously ill goes up with the increase in the stage of infection and goes up very sharply after Stage III. As a result, the average number of times the person is ill comes down after Stage III. Thirdly, no clear trend emerges when the frequency of illness for PLWHA is calculated by number of years since they were detected HIV-positive. This again shows that year of detecting the infection may not be very accurate in judging the stage of infection.

More detailed information about the illnesses suffered by the PLWHA during

Table 7.4

**Frequency of illnesses 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							
Men	2.25	24.1	4.0	1.12	17.0	2.5	1,343
Women	1.90	20.0	3.0	0.93	15.3	2.1	1,044
By stage of infection							
Stage I	1.27	19.6	1.0	0.63	15.3	0.6	719
Stage II	2.23	22.3	2.8	1.04	18.0	1.2	887
Stage III	2.88	26.3	5.0	1.44	15.9	4.5	584
Stage IV	2.57	19.3	12.2	1.41	12.7	7.6	197
No. of years since detected							
Last one year	2.03	21.7	3.5	1.04	16.6	2.3	1,208
2-5 Years	2.18	24.1	3.7	1.04	16.6	2.3	1,069
>5 Years	1.95	11.1	2.8	1.00	8.3	2.8	108
All	2.09	22.3	3.6	1.03	16.3	2.3	2,385

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.

7.2.2 Nature of illnesses (Non-hospitalised illness episodes)

More than one fourth of the women and 55 percent men reported that they went for a HIV test because they had been suffering from prolonged illness.

Table 7.5 shows that undiagnosed fever has emerged as the most important reason for the PLWHA going in for the HIV test; 32 percent of men and 30 percent of women have mentioned this reason. Another one-fourth of men and 20 percent of women went in for a HIV test since they were suffering from Tuberculosis (TB). It is well known that tuberculosis is the most common OI among PLWHA and is the

Table 7.5

**Distribution of PLWHA reporting
prolonged illness as a reason for going in for HIV test**

(in Percentages)

Percent reporting prolonged illness	Men	Women
	55.0	26.7
Nature of illness		
Respiratory infection	4.6	3.0
Malaria	1.4	2.2
Fever	31.8	29.5
Headache, bodyache	2.4	3.4
Weakness	3.8	3.4
Loose motion/diarrhoea	17.1	18.7
Typhoid	0.7	1.1
Jaundice	1.4	1.1
TB (Tuberculosis)	24.4	20.1
Skin diseases	6.5	6.0
Gynaecological problem	--	3.4
Sexually transmitted diseases/RTI	1.6	3.0
Others	4.4	5.2
All	100	100
Number of persons	738	268

leading illness in general population in developing countries. In many countries HIV sentinel surveillance is carried out among TB patients to ascertain the level of HIV prevalence (Ahmed Zuber et al, 2003). Another common ailment associated with HIV and AIDS is diarrhoea and 17 percent of men and 19 percent of women had mentioned this as a reason.

Two percent of the women could not seek treatment due to lack of cooperation from the family

In Table 7.6 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.

In all 2,452 illness episodes were reported by PLWHA during the one month reference period. As expected diseases like tuberculosis, diarrhoea and fever account for a fairly high percentage of the illness episodes reported by the PLWHA, during the one month reference period.

Table 7.6
Distribution of non-hospitalised illness episodes by nature of illness reported

(in Percentages)

Nature of illnesses	Men	Women	Total
Respiratory infection	9.2	9.0	9.1
Malaria	1.4	0.8	1.2
Fever	32.8	35.7	34.0
Headache, bodyache	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
TB (Tuberculosis)	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

Tuberculosis is the most serious of all the opportunistic infections to which PLWHA are prone and in some areas of sub-Saharan Africa, as many as 50 percent of PLWHA also have Tuberculosis (TB). (Ekanem Ita I, 2005). It has also been found that the risk of death in HIV infected persons with tuberculosis is twice as high as in HIV infection without tuberculosis (as cited in Ahmed Zuber et al, 2003)

7.2.3 No treatment of illness

The Opportunistic Infections (OIs) result in more rapid decline in CD4 T-cells. Hence providing treatment for the opportunistic infections is essential for allowing PLWHA to lead an active life.

The survey results show that not all illness episodes got treated (Table 7.7). 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 gender gap in the treatment seeking behaviour. Though for both men and women, 'illness not considered serious' has been reported as a major reason for not seeking treatment, there is a substantial gender difference in the percentages. In as many as one-fourth of the cases women have not sought treatment due to financial constraints. 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 their husbands. Another two percent of the women could not seek treatment due to lack of cooperation from the family. This point was brought up in the Focus Group Discussions held in Mumbai. A few of the women participants mentioned that women generally do not get much family support for seeking treatment and even

Table 7.7
**Illness episodes receiving no treatment
 and reasons for no treatment for PLWHA**

(in Percentages)

	Men	Women	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

when they have to seek treatment, no one accompanies them.

7.2.4 Duration of illness episodes and treatment

For each of the illness episodes reported by the PLWHA during the one month reference period, detailed information on the number of days each episode lasted, the duration of treatment, number of days bed-ridden and number of days not going to work were obtained.

In the case of more than one-fourth

of the illness episodes, the illness continued for a long time or they had frequent bouts of the illnesses during the one month reference period. In the case of remaining illness episodes, on an average each illness episode lasted 8.7 days and the duration of treatment was marginally lower at 8.4 days. On an average the affected individual was bedridden for 3.8 days. The number of days not going to work i.e., mandays lost is calculated for those who are currently employed and this average works out to be 8.6 days.

Table 7.8
**Average number of days ill, bedridden and not going
 to work during each non-hospitalised illness episode in the last one month**

Stage of infection	Number of days ill	Percent reporting frequently/ continuously II	Duration of treatment (No. of days)	No. of days bedridden	No. of days not going to work	Number of episodes
Stage I	8.8	19.7	7.7	2.5	8.6	446
Stage II	8.6	25.4	8.0	3.1	8.2	854
Stage III	9.0	28.7	9.0	5.1	8.6	739
Stage IV	8.6	31.5	9.4	5.1	10.8	254
All	8.7	26.0	8.4	3.8	8.6	2,293

As expected, the percentage reporting frequently/continuously ill goes up with the rise in the stage of infection and at Stage IV in the case of more than 30 percent of the illness episodes, the affected person was reported to be continuously ill.

7.2.5 Source of treatment

The percentage distribution of illness episodes for which treatment was sought is presented in Table 7.9 by source of treatment.

The PLWHA seem to rely more on public health services for the treatment of non-hospitalised illness episodes

The PLWHA seem to rely more on public health services for the treatment of non-hospitalised illness episodes. While 44 percent of the illness episodes had been treated at the government health facilities, the percentage of illness episodes for which treatment had been sought in the private facilities is lower at 37 percent. In the case of male PLWHA, both government and private facilities had been utilised almost to the same extent. This could be due to the higher percentage of sample households in the lower economic strata. This is in contrast to the findings of a number of morbidity surveys in India which show a high dependence on private sector for the treatment of non-hospitalised illness episodes. For instance, the 52nd round of NSSO also points out that as many

as 55 percent of the non-hospitalised illness episodes had been treated in the private sector (NSSO, 1998). However, a study conducted among the slum dwellers of Delhi and Chennai found that for more than 40 percent of the illness episodes the households had sought treatment in a private health facility (Sundar et al 2002). However, as compared to the general population, the present survey shows that the PLWHA are relying more on the NGO sector. This is understandable since there are a number of NGOs working PLWHA. The NGOs seem to be playing an important role as nearly 16 percent of the episodes had been treated there. The 'others' category includes cases for which the affected persons directly purchased medicines from chemist shops or resorted to home remedies.

For only a small percentage of illness episodes, the PLWHA had gone to a faith healer or religious person. The participants of the FGD conducted with the members of Telugu Network of Positive People did mention that they had seen advertisements by 'Ayurvedic doctors' who claim to cure HIV. There are people who are carried away by such 'doctors' and do spend lot of money in the hope of getting cured (See Box 5). Even the ILO study came across PLWHA who had experimented with Siddha Therapy and spent Rs. 5,000 to Rs. 15,000 on the treatment, which ultimately proved to be of no benefit to them (ILO, 2003). In Tamil Nadu, the participants of the FGD said that although people used to believe in quacks and faith healers till recently, with increasing awareness they are no longer carried away by such persons.

The percentage of illness episodes for which treatment has been sought from private health facilities has worked out to be much lower for women. The women

Table 7.9
Distribution of non-hospitalised illness episodes
by source of treatment for male and female PLWHA

(in Percentages)

Source of treatment	Men	Women	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

Box 5

Case Study 5: Hoax Cure: The wonder cure for HIV and AIDS causes more harm than good

A number of PLWHA from the tribal areas and other parts of Andhra Pradesh seem to think that there is a wonder cure for HIV and AIDS! About 25 kms from Raichot in the Cuddapah district (bordering Chittoor district), there are small tribal villages (hamlets). In these villages, the religious persons and the faith healers are exploiting the ignorance of these PLWHA and are making them spend huge amounts of money on religious ceremonies to drive away the 'devil'. Many PLWHA have spent more than Rs. 15,000 on religious ceremonies with the hope that they would be cured. Although many of them do realise to their utter dismay that they had not been cured, people still flock to these religious persons hoping against hope for a cure.

Similarly, a number of PLWHA belonging to upper income category from the Krishna, Guntur and East Godavari districts of Coastal Andhra have been lured by the so-called Kerala medicine. This is supposed to be an Ayurvedic medicine and the advertisements in the local media claim that this medicine can completely cure HIV. In the name of Kerala medicine, ARV drugs are given. Since people do not consume the medicine continuously and the course regiment is not strictly followed, after some initial improvement their CD4 count improved, but ultimately their condition worsened.

PLWHA seem to rely more on government and NGO health facilities.

government and the NGOs comes down as the household income increases.

Table 7.10 shows that as the household income increases the percentage of episodes for which treatment is sought from the private doctors/clinics also increases since the higher income households can afford to spend on treatment. The percentage of episodes for which treatment is sought from

7.2.6 Out-of-pocket expenses incurred on treatment

The out-of-pocket expenditure incurred by the households includes amount spent on fees and medicine, clinical tests, transport cost and bribes and tips. In Table 7.11, the average expenditure incurred by the PLWHA on the treatment

Table 7.10
Distribution of non-hospitalised illness episodes by source of treatment and by annual household income groups

(in Percentages)

Source of treatment	Annual household income (Rs.)					All
	Upto 20,000	20,001-30,000	30,001-41,000	41,001-84,000	>8,40,000	
Government	50.1	44.0	42.1	42.5	35.3	43.7
Private	25.0	34.4	39.6	42.2	48.8	36.9
Charitable trust/NGO	19.2	18.0	16.2	12.5	12.8	15.9
Faith healer/religious person	0.2	--	--	0.3	--	0.1
Others	5.5	3.1	2.2	2.5	3.1	3.4
Total	100	100	100	100	100	100

of illness episodes is presented by source of treatment.

A few important observations emerge from the table. First, even if the treatment is sought from a government health facility, the households have incurred substantial expenditure, though less than the amount spent while seeking treatment from a private doctor/clinic. Secondly, the average expenditure per episode has been the least when the treatment is sought in an NGO. Thirdly, there is a big gender gap in the average expenditure incurred per illness episode, irrespective of the source of treatment. While for men, the average expenditure per episode is Rs. 796, for women, this average is much lower at Rs. 487. Finally, the rural-urban differences in the average out-of-pocket expenditure per episode are not very significant.

The average expenditure per episode has been the least when the treatment is sought in an NGO

7.3 Details about hospitalisation cases

7.3.1 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 in Table 7.12.

The average number and the percentage frequently hospitalised are calculated only for those reporting hospitalisation.

Interestingly the percentage of sample PLWHA reporting hospitalisation since they were tested positive is only marginally higher than the percentage reporting hospitalisation in the last one year; 43 to 44 percent of the PLWHA who were interviewed have reported hospitalisation. A few important observations are worth mentioning. First, the percentage reporting hospitalisation has been much 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 in-patient. Secondly, the percentage of PLWHA hospitalised as well as the average number of times hospitalised increases as the stage of infection advances. More than 80 percent of the PLWHA in Stage IV had reported hospitalisation. Thirdly, although the percentage hospitalised as well as average number of times hospitalised increase with the number of years since the PLWHA tested positive, the increase is

Table 7.11
Expenditure incurred by PLWHA for treatment
of non-hospitalised illness episodes by source of treatment (in Rupees)

(Average per illness episode)

Source of treatment	Rural		Urban		Total		
	Men	Women	Men	Women	Men	Women	All
Government	510	301	650	347	589	324	482
Private	1,179	759	1,225	803	1,202	781	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

Table 7.12
**Frequency of hospitalisation reported by PLWHA
 by stage of HIV infection and number of years since HIV status detected**

	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 frequently hospitalisation	Percent reporting hospitalisation	Average number of times	
By sex						
Men	54.6	1.75	0.55	53.3	1.53	1,343
Women	31.9	1.86	0.60	30.7	1.52	1,044
By stage of infection						
Stage I	20.7	1.45	--	20.4	1.30	719
Stage II	40.0	1.50	0.28	38.9	1.30	887
Stage III	68.5	1.94	0.78	65.9	1.62	584
Stage IV	82.2	2.33	1.23	81.7	1.98	197
By years back HIV status detected						
Upto 1 year	42.4	1.56	0.19	42.3	1.49	1,208
2-5 years	46.9	1.99	1.00	44.5	1.56	1,069
> 5 years	47.2	2.06	--	45.4	1.51	108
All	44.4	1.78	0.56	43.4	1.52	2,385

* Average has been calculated excluding those reporting frequently hospitalised.

not very sharp, rather it is very marginal. This once again reiterates that the number of years since testing HIV-positive may not be indicative of the stage of infection.

7.3.2 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 they had been hospitalised during the last one year reference period (Table 7.13). These three ailments respectively account for 18.2, 17.6 and 26.2 percent of the illnesses for which PLWHA were admitted in a hospital.

The average number of days admitted in a hospital at a time is 9.8; there is no gender difference in the average number of days admitted. The average number of days hospitalised has worked to be highest for tuberculosis (12.7 days), closely followed by meningitis and viral encephalitis, respiratory infection and malaria, in that order.

7.3.3 Source of treatment (Hospitalisation)

The percentage distribution of the hospitalisation cases by source of treatment is presented for men and women PLWHA in Table 7.14. For 50 percent of the cases the PLWHA had gone to government hospitals and another 21 percent of the cases they had sought admission in care and support homes run by NGOs. This again corroborates the general findings that even though

Table 7.13
Distribution of hospitalisation cases by nature of illnesses suffered
by PLWHA and number of days hospitalised

(in Percentages)

Nature of illness	Percentage of cases			Average no. of days hospitalised		
	Men	Women	Total	Men	Women	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
TB (tuberculosis)	18.8	15.0	17.6	12.5	13.1	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 7.14
Distribution of hospitalisation cases by source of treatment

(in Percentages)

Source of treatment	Men	Women	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

people prefer private healthcare for the treatment of non-hospitalised illnesses, when it comes to hospitalisation the government hospitals are preferred; since hospitalisation expenses in a private nursing home could be extremely prohibitive. The PLWHA do not have access to any health insurance cover either.

There are significant gender differences in the source of treatment. The percentage seeking treatment in a private nursing home/hospital as an in-patient has been much 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. For as many as 57 percent of

Table 7.15
Distribution of hospitalisation cases
by source of treatment and by annual household income groups

(in Percentages)

Source of treatment	Annual household income (Rs.)					All
	Upto 20,000	20,001- 30,000	30,001- 41,000	41,001- 84,000	Above 84,000	
Government	59.2	55.2	54.5	42.0	33.1	49.9
Private	18.6	25.2	23.5	35.1	44.2	28.2
Charitable trust/NGO	21.7	19.0	21.3	22.7	22.1	21.4
Faith healer/religious person	0.6	0.6	0.7	0.2	0.6	0.5
Total	100	100	100	100	100	100
No. of hospitalisation cases	360	306	268	462	154	1,550

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.

As the household income increases, the dependence on the government hospitals and NGOs comes down and utilisation of private nursing homes/hospitals increases. In fact, in the households belonging to the lowest income group, the government hospitals account for nearly 60 percent of the hospitalisation cases and the NGOs account for another 22 percent of the cases. This is understandable since any hospitalisation involves a huge expenditure which poor people can hardly afford. Hence only a small percentage of PLWHA belonging to the lowest income

category had gone to private hospital.

7.3.4 Household expenditure on hospitalisation

The direct cost of hospitalisation includes amount paid as room rent, doctor's fee and cost of medicine, clinical test, surgery and transport. In addition there could be expenses like special diet for the patients and lodging, food and travel costs for the care-givers. At times the households may have to pay tips/bribes to the hospital staff to get better care and attention. Table 7.16 shows the average amount spent by the household per hospitalisation case by source of treatment.

The average expenditure per hospitalisation is Rs. 2,687 and there is

As the household income increases, the dependence on the government hospitals and NGOs comes down and utilisation of private nursing homes/hospitals increases

Table 7.16
Average expenditure incurred per hospitalisation case
by PLWHA by source of treatment

(in Rupees)

Source of treatment	Men	Women	All
Government	1,533	1,270	1,440
Private	6,255	3,875	5,645
Charitable trust/NGO	1,701	1,836	1,738
Faith healer/religious person	1,600	600	1,267
All	3,001	1,984	2,687

Even when a PLWHA is hospitalised in a government hospital, the household seems to be incurring substantial out-of-pocket expenditure

a substantial gender gap in the average cost of hospitalisation. While the average household expenditure per hospitalisation is Rs. 3,001 for men, this average is much lower at Rs. 1,984 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 are more expensive. However, even after controlling the source of treatment, the average expenditure for women works out to be much lower than the expenses incurred on men.

The average expenditure per hospitalisation case is the highest when treatment is sought from a private health facility. Even when a PLWHA is hospitalised in a government hospital, the household seems to be incurring substantial out-of-pocket expenditure. Even the care and support homes run by NGOs are not absolutely free from the household's point of view. Even if room rent and medicines are free, the households may still spend in terms of transportation, boarding and lodging for the escort.

With the increase in the household

income, the average expenditure incurred per hospitalisation case generally seems to go up. In the highest income category, a patient has spent as much as Rs. 5,645 for the in-patient treatment in a private hospital. The table also points out that on an average the patient belonging to the lowest income category has spent Rs. 1,511. This expenditure could account for a very high proportion of the household income, which may be difficult to finance.

7.3.5 Source of financing hospitalisation

Any hospitalisation involves huge expenditure, which is difficult to finance for any household. A number of studies have shown that the households, especially the poor households are completely ruined. It has been estimated that more than 40 percent of individuals who are hospitalised in India borrow money or sell their assets to meet the cost of care. It has also been estimated that on an average hospitalised Indians spend 58 percent of their annual expenditure on hospitalisation. (see IIPM, 2005). The situation in HIV affected households could be worse since it is mostly the earning member of the family who is hospitalised. Hence, the survey

Table 7.17
Average expenditure incurred per hospitalisation case
by PLWHA by source of treatment and annual household income groups

(in Rupees)

Source of treatment	Annual household income					Total
	Upto 20,000	20,001-30,000	30,001-41,000	41,001-84,000	>84,000	
Government	695	1,064	1,437	1,916	3,986	1,440
Private	4,484	5,627	3,776	6,594	6,279	5,645
Charitable trust/NGO	1,175	1,309	1,301	2,143	3,241	1,738
Faith healer/religious person	1,800	600	675	500	1,840	1,267
All	1,511	2,256	1,952	3,605	4,820	2,687

tried to find out how the HIV-affected households financed the hospitalisation expenses.

In 36 percent of the cases the households could draw from their past savings to meet the expenses (Table 7.18). It can be seen that the percentage of hospitalisation cases that the households could manage with the past savings increases with the increase in the household income. As compared to households belonging to lower income categories, the households from the highest income category could rely more on the past savings; the percentage of hospitalisation cases where the households could draw from the past savings is fairly high at 52 percent.

However, all the households, irrespective of their income level, have resorted to borrowing and liquidation of assets, although the percentage of cases where the households resorted to liquidation of assets is the highest for the lowest income category.

The source of financing hospitalisation by stage of infection shows that at the initial stage more households are able to finance hospitalisation from their past savings and as the stage of infection advances, they seem to end up liquidating their assets, in addition to borrowing. (Table 7.19) This table again shows that the support the PLWHA receive from the NGOs is fairly significant.

7.4 Anti-retroviral therapy

Anti-retroviral therapy is one of the components of the comprehensive HIV and AIDS programme, which also includes prevention and other care and support activities. The availability of Highly Active Anti-retroviral Therapy (HAART) has greatly reduced AIDS-related mortality in advanced industrialised countries. Although there is no cure for HIV, ARV drugs can reduce mortality and prolong the life span of affected persons. In April 2004, the Government of India started providing free anti-retroviral therapy to some of the affected persons in the six HIV high-

The percentage of hospitalisation cases that the households could manage with the past savings increases with the increase in the household income

Table 7.18
Distribution of hospitalisation cases
by source of financing hospitalisation and annual household income groups

(in Percentages)

Source of financing	Annual household income (Rs.)					Total
	Upto 20,000	20,001-30,000	30,001-41,000	41,001-84,000	>84,000	
Past savings	20.0	31.2	38.0	44.4	52.4	35.9
Liquidation of assets	11.7	14.2	8.4	8.8	2.4	9.7
Borrow from money lender/other financial institutions	23.3	9.2	14.1	11.1	2.4	13.6
Loan from employer	--	2.8	2.1	1.4	2.4	1.6
Borrow from friends and relatives	27.2	28.4	29.6	24.1	26.2	26.9
NGO support	17.2	12.1	6.3	9.3	8.3	11.0
Others	0.6	2.1	1.4	0.9	2.4	1.3
Total	100	100	100	100	100	100

Table 7.19
**Distribution of hospitalisation cases
 by source of financing hospitalisation and stage of infection**

(in Percentages)

Source of financing	Stage I	Stage II	Stage III	Stage IV	All
Past savings	43.5	44.3	32.6	23.8	35.9
Liquidation of assets	8.7	7.9	7.7	17.0	9.7
Borrow from money lender/other financial institutions	17.4	9.2	15.1	15.6	13.6
Loan from employer	--	1.3	2.5	1.3	1.6
Borrow from friends and relatives	15.2	27.6	28.4	29.9	26.9
NGO support	14.1	6.7	13.0	12.2	11.0
Others	1.1	2.9	0.7	--	1.3
Total	100	100	100	100	100

prevalence states. The survey tried to find out how many of the sample PLWHA are on ARV therapy and their source of supply and the expenditure they incur on the ARV drugs.

Nearly 15 percent were on ARV therapy at the time of the survey, the percentage being higher in urban areas as compared to rural areas. It is worth mentioning here that another small percentage of PLWHA mentioned that though they were supposed to take ARV drugs, they are unable to do so because they cannot afford (See Box 6). The most important source seems to be the government

hospitals, as nearly 55 percent reported that they get the supply from government sources.

An important observation, which the survey team came across during the Focus Group Discussion, was that there are a few unscrupulous private practitioners who prescribe ARV drugs even if the patient does not need them and also without telling them that they were required to take these drugs life-long. In the process these practitioners make money by supplying the drug at a premium price. The patients take the drug for some time and obviously

Table 7.20
PLWHA on ART and source of getting ART

(in Percentages)

	Rural	Urban	Total
PLWHA on ART	10.3	17.7	14.5
Source of ART			
Government hospital	54.6	55.7	55.4
Private nursing home/doctors	25.0	15.2	18.3
NGO	6.5	4.6	5.2
Chemist shop	9.3	21.9	18.0
Others	4.6	1.7	2.6
Total	100	100	100

Case Study 6: ART still a far cry for many

He stays in a joint family of 22 members in west Imphal in Manipur and has a wife and two children. After completing his matriculation from a government school, he graduated in 1980 and four years later got a job as a class III employee in the PWD of Manipur Government. He earned a salary of Rs. 4,000 per month and things were looking good, except for the frequent illnesses he was suffering due to which he was forced to take leave from office. In 1990 he was suspended from his job for being frequently absent from office due to his sickness.

Since then it has been difficult for him to make both ends meet. He runs a petty trading business, from which he earns Rs. 3,000 per month. Despite the financial support he receives from other family members who contribute about Rs. 1,200 per month, he finds it difficult to manage. He is also burdened with a loan of Rs. 31,000 and has sold family jewellery for Rs. 5,000 in the last one year.

He needs the money to pay his mounting medical bills. He is HIV-positive and it was detected only in the second stage when he started getting sick. He could easily have been healthier and lead a better quality of life through the use of ART but the difficulty lies in access to these drugs. Even though ARV drugs are free of cost, he is unable to avail of them due

to non-availability of these drugs at the government facilities. As a result, he has to buy them from chemist shops which proves to be too costly. He therefore cannot afford to be on regular medication and this irregular and non-use of the drug has aggravated his condition further.

To make things worse, his wife is also HIV-positive. When he got married, he did not know that he was HIV-positive. By the time he found out, his wife had also been infected. Fortunately for the couple, their two kids are not positive since his wife was administered Nevropine during pregnancy.

This is a story that tells different tales. It demonstrates the mental, physical and psychological trauma he has to go through to meet his medical needs. The utter desperation of being unable to pay mounting medical bills is indeed immense. In the last one month, he spent Rs. 300 on medicines and fees and Rs. 700 for clinical tests for himself.

It is also a story that tells us how timely knowledge could have prevented this situation. When he started injecting drugs by sharing needles with others in 1984, he did not know the consequences of needle sharing in a group. Once he knew, he stopped sharing needles with others.

stop taking them when they see some improvement and when they can no longer afford to buy them. This has a disastrous effect on them.

As can be seen from Table 7.21, even when the PLWHA had obtained ART from the government source, they have incurred some expenditure. Maybe at times when they do not get the supply, they might have purchased from outside. As expected, the monthly expenditure on ART has been the highest when the individuals obtain from private doctors/clinic.

7.5 Observations

Many of the sample PLWHA had gone in for a HIV test after suffering from prolonged illnesses like undiagnosed fever, tuberculosis and diarrhoea.

- The prevalence rates of both non-hospitalised and hospitalised illnesses have been much higher for the HIV households as compared to non-HIV households mainly due the higher prevalence rates for the 15-59 age group upto which most of the PLWHA belong. The findings indicate a very heavy burden of diseases on HIV households.

Table 7.21
Average monthly expenditure on ART

	(in Rupees)		
	Rural	Urban	Total
Source of ARV			
Government hospital	79	321	246
Private nursing home/doctors	1,600	1,721	1,669
NGO	171	786	547
Chemist shop	1,380	1,095	1,141
Total	582	736	688

The borrowing and the liquidation, of assets increase as the stage of infection advances

- The burden of diseases increases, as the stage of infection advances causing tremendous financial burden on the family. The prevalence of non-hospitalised illnesses increases from 888 per thousand in Stage I to 2469 per thousand in Stage IV during the one month reference period. Similarly the prevalence of hospitalisation cases increases from 238 per thousand to 1623 per thousand during the last one year as the stage of HIV infection advances from Stage I to Stage IV.
- While the PLWHA seem to depend mostly on the health facilities provided by the government and the NGO as far as in-patient treatment is concerned, for the treatment of non-hospitalised illness episodes they are dependent on private doctors also and incur a lot of expenditure.
- Even if the treatment is sought from a government health facility, the PLWHA seems to be spending a lot of money. For instance, for the treatment of non-hospitalised illnesses, on an average the households have incurred an expenditure of Rs. 482 per illness episode. Similarly, the households have spent Rs. 1,434 per hospitalisation case when the PLWHA has sought admission in a government hospital.
- The HIV-affected families are resorting to borrowing and liquidation of assets to meet medical expenses. The borrowing and the liquidation of assets increase as the stage of infection advances. While 41 percent of the hospitalisation cases of PLWHA in Stage I are funded by borrowing and liquidation of assets in the case of PLWHA in Stage IV for 62 percent of the cases the households had to resort to liquidation of assets and borrowings.

Stigma and Discrimination, Knowledge and Awareness About HIV and AIDS

8.1 Stigma and discrimination

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.

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).

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

1. HIV is life-threatening and hence people are scared of contracting the virus.
2. The infection is associated with behaviours (such as sex between men and injecting drug use) that are already stigmatised in many societies.
3. People living with this infection 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.

The stigma has been compounded by fear arising from lack of knowledge about the modes of transmission of HIV. Because of the stigma attached to the infection, 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.

This chapter analyses the stigma and discrimination experienced by the sample of PLWHA in four different settings namely their family, community in which they live, at their workplace and at the healthcare facilities where they seek treatment. Discrimination faced by the HIV household at the time of AIDS related death in the family has also been discussed. This chapter also includes the views and attitudes of the general population (the

Table 8.1
Distribution of PLWHA by ways of discovering their HIV status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Discovering HIV status						
Voluntary testing	31.0	55.8	45.6	58.3	39.3	57.2
After prolonged illness	63.3	28.0	48.7	23.8	54.9	25.7
During pregnancy-spouse/self	0.9	11.5	0.5	12.3	0.7	12
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
No. of years since HIV was detected						
Less than a year	59.3	57.7	43.7	45.5	50.4	51.0
1-3 years	29.1	26.7	39.0	38.7	34.8	33.3
3--5 years	7.6	11.1	12.1	11.5	10.2	11.3
5+	4.0	4.5	5.1	4.3	4.6	4.4
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	5.0	4.1	3.8	6.1	4.3	5.2
N (Number of persons)	5,77	468	766	576	1,343	1,044

control group) about HIV and AIDS, since stigma and discrimination against PLWHA arise mostly due to lack of knowledge and awareness and misconceptions about the infection. Before discussing the stigma and discrimination experienced by the PLWHA, details about how the sample PLWHA discovered their HIV status and the disclosure of their status to their family members and others are presented.

8.2 Discovering HIV status

An HIV affected 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, 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 8.1 gives the percentage distribution of PLWHA by ways of discovering their HIV status. It is seen that while nearly 55 percent of the men who had tested HIV-positive had gone in for a test after prolonged illness, 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%). 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. A few people have also come to know of their status from the blood test conducted at the time of joining a job.

The sample consists mostly of those who had tested positive in the last three years. They account for nearly 85 percent of the sample PLWHA. About 56 percent men and 66 percent women had got the test done in government hospitals, and the remaining 44 percent men and 34 percent women from private hospitals/clinics.

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. For 71 percent men and 88 percent women, the mode of transmission of HIV is reported to be through heterosexual contact. While nearly 20 percent of men have contacted the infection through needle sharing, the percentage of women who have contacted it in a similar way is only about 3 percent. A few men and women have given blood transfusion/donation as the reason for getting infected.

A high percentage of the PLWHA (more than 65%) were shocked to know that they were positive

8.2.1 Initial reaction

The survey tried to find out how the affected/infected persons and their family members reacted as soon as the HIV status was discovered and Table 8.2 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

Table 8.2
Distribution of sample PLWHA by reaction to their HIV status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Initial reaction (Self)*						
Shocked	64.0	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	13.0	9.4
Decided to stay away from the family and spouse	4.9	1.5	3.4	2.3	4.02	1.9
Decided to keep HIV status secret	13.3	10.0	13.2	12.0	13.2	11.1
Others	0.4	0.4	0.7	1.2	0.5	0.9

(Contd....)

Table 8.2 (Contd....)

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
Empathised	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	2.0	5.4	1.9	5.5
All are supportive	61.9	55.1	55.6	55.0	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 response

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.

The initial reaction of the family members was also varied. As is to be expected, a considerable percentage of families/spouses were shocked and disappointed; some families empathised while some were embarrassed. However in case of about 42 percent men PLWHA and surprisingly 45 percent of female PLWHA they were supportive. Again surprisingly it is seen that in a larger

percentage of cases the family/spouse sympathised with the female PLWHA (19.8%) than the men PLWHA (15.5%). In case of female PLWHA, in all probability the family support may imply support from their natal family. However, as expected in our society, 6.4 percent of female PLWHA were disowned by their family in comparison with 1.3 percent of men PLWHA who were subjected to this. The percentage of female PLWHA deserted by their spouses is marginally higher than that of men PLWHA deserted.

8.2.2 Current attitude of spouse/family members

Although generally one expects that the spouse/family members of the PLWHA would be shocked when they first come to know about the positive status, what is more relevant is their reaction after the news settles in. The current attitude of the

family members as seen in the survey is quite encouraging, as 74 percent of men and 70 percent of women have reported that their families are quite supportive in spite of slight hesitation initially by a few. This speaks of the strong family ties in India. However, here there is a slight gender gap in the percentage receiving support from the family, although there is no rural-urban divide. The gender difference is more noticeable when seen that while nearly 5.5 percent of female PLWHA have been asked to leave home, only 1.9 percent of the men 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 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.

For both men and women, the contexts and forms of HIV related discrimination and stigmatisation would appear to be similar, but it is the context of 'relationship'

that sets apart the experiences of women from those of men. Discrimination like 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 men PLWHA, it is their discriminatory attitude towards women that is worse.

8.2.3 Coping with the situation

As seen earlier, when their HIV-positive status was detected, initially most of the people were either shocked or embarrassed or, could not believe. 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 8.3 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.

More women are supportive of their HIV-positive husbands (12.4%) than men of their HIV-positive wives (8.5%)

Table 8.3
Distribution of PLWHA by coping mechanism adopted to get over initial shock/disbelief

(in Percentages)

Characteristics	Men	Women
Counselling	39.7	32.0
Confidently	6.8	6.9
Family support	17.7	11.9
Friends support	1.6	3.8
Became alcoholic	--	0.4
Decided to keep HIV status secret	1.0	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

A small percentage of men and women (about 6.8%) decided to face the situation boldly. Some of them did receive moral and emotional support from their family and friends and also from NGOs. What is interesting is that after testing positive, nearly 35 percent of the respondents wanted to know more about the infection and the ways and means of leading a quality life in spite of their HIV status.

8.3 Disclosure of HIV status

Disclosure of HIV status, particularly to spouse and hospitals is linked to the spread of the infection. However, it is noticed that whether an individual who is affected 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 8.4 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 or keep her. This could be particularly true of the present sample which has been drawn from poor socio-economic background where the women would be totally dependent on their husbands economically.

Although a majority of the respondents have informed their spouses immediately, it is also seen that a few of them have taken a lot of time to inform. There are also those who have kept it a secret from their spouses. Nearly one-fourth of the sample PLWHA have not disclosed their HIV-positive status in the community, fearing, in all probability, the stigma and discrimination they will fall victim to.

8.4 Migration

Generally in the context of HIV and AIDS, migration is said to be one of the

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

Table 8.4
Distribution of PLWHA by disclosure of HIV status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Initially decided to keep HIV status a secret	13.3	10.0	13.2	12.0	13.2	11.1
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

causes for the spread of the infection. People who migrate from one place to another in search of jobs are usually separated from their families for long intervals of time. The poor among these, who also tend to live in groups, are more susceptible to HIV. However, what has been tried here is to find out as to how many people had to shift their residence after becoming HIV-positive, either because they did not want others to know about their infection, or, more importantly, they were forcibly made to leave their residence by house-owners because of the stigma attached to the infection.

It is seen from Table 8.5 that around 12 percent of the households had changed their place of residence after one of the family members was detected to be

HIV-positive. Of these nearly 50 percent had moved from one place to another within the same village/city. Percentage of households moving from village to city is nearly twice that of those moving from city to village. Inter-state migration has been very marginal.

While various reasons have come out for this change in residence, nearly 19 percent are because of the economic burden of the infection – either because they could not afford the earlier place of residence or because of loss of property. The effect of the stigma attached to the infection is revealed in two ways. Nearly 13 percent wanted to keep their HIV-positive status a secret and voluntarily changed their place of residence. In case of nearly 16 percent the affected were asked to vacate the house by the owners

Table 8.5
Distribution of PLWHA reporting change of residence and reasons
(in Percentages)

Characteristics	
Households reporting change of residence after detection of HIV	12.0
Type of movement	
Within the same city/village	48.4
From city to village	8.9
From village to city	16.1
From one city to another city	14.1
From one village to another village	8.9
One state to another state	3.6
Reasons for changing the residence*	
Search of employment	14.9
Could not afford earlier place of residence	16.9
To seek medical treatment	14.9
Loss of property	2.0
Reasons of anonymity	12.9
Asked to vacate the house because of HIV status	15.7
Others	22.6

*Multiple response

because of the stigma attached to the infection. Apart from these 15 percent each migrated to seek medical treatment and in search of employment.

8.5 Stigma and discrimination faced by PLWHA

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

8.5.1 Stigma and discrimination in the family and community

It has already been seen from Table 8.2 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. 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. But one thing that came out was that the daughters-in-law were treated much worse than the sons and there was no place in the family for them if the son died. 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 to 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).

The community's perception about the infection also influences the family's responses to the affected 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 8.6 presents stigma and discrimination faced by PLWHA in the community and neighbourhood. It has already been seen in Table 8.4 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, not allowing their children in anganwadi centres. In some cases they have also been refused houses for rent. In the present study gender differences or rural-urban divide is not seen. In the Focus Group Discussions (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. Other studies also give evidence of reactions like ostracism, differential treatment at death, and discrimination in schools towards children of PLWHA (Bharat et al, 2001; ILO, 2003).

The presence of an HIV-positive individual does seem to affect the marriage and job prospects of other family members to some extent. The female PLWHA seem to be more discriminated against as far as marriage prospects are concerned while both men and female PLWHA are equally affected in employment prospects.

The community's perception about the infection also influences the family's responses to the affected individual

Table 8.6

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

Percentage	Men	Women	Rural	Urban	All
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	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	30
Not allowed to participate in Mahila Mandals, Panchayats etc.	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 was affected	1.1	2.0	1.6	1.4	1.5
PLWHA whose family members' job prospect was affected	1.2	1.1	1.2	1.1	1.1

*Multiple response

8.5.2 Discrimination at workplace

Every person has a right to gainful employment and right to earn a living. Since a working person spends most part of his day in the workplace, it is also essential that the atmosphere is conducive to work. One is generally not likely to think of a 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, promotion practices, work allocation, establishment of unfair benefit packages and negative attitude of employers, co-workers and managers. In the present study, details about disclosure of the status in the workplace, discrimination/support by the employer were collected.

Out of the total of 2387 HIV-positive people who were interviewed during the survey, 1152 of them are working. It is seen that a vast majority of them (74%) have not

disclosed their status at their workplace. Three reasons have emerged for their not disclosing the status, the most common being fear of losing the job (45%). Social discrimination and lowering of prestige are the other reasons for not revealing their status.

As seen in Table 8.7, 74 percent of the employees have not disclosed their HIV-positive status in their workplace. Of the remaining 26 percent who have disclosed their status, it is seen from Table 8.8 that 10.3 percent have reported facing discrimination at the hands of the employer and their number is 31. Going by percentages, the discrimination is higher in the rural sample. While 16 percent are being forced to resign, nearly 10 percent are being forced to take up voluntary retirement. In case of about 20 percent benefits have not been given. Apart from these, promotion has been denied for about 29 percent. About 29 percent have been refused loan facilities. In all they have been discriminated against in all possible ways.

Table 8.7
Disclosure of HIV status at workplace

(in Percentages)

	Rural	Urban	Total
Who have not disclosed their HIV status at workplace	77.0	71.7	74.0
Reasons for not disclosing the HIV status			
Social discrimination	33.6	27.4	30.2
Lower prestige	22.8	27.0	25.1
Fear of losing job	43.6	45.6	44.7
Total	100	100	100
No. of persons who have an employer	495	657	1,152

Table 8.8
Discrimination at workplace

(in Percentages)

	Rural	Urban	Total
Who have disclosed the status	23.0	28.3	26.0
Facing discrimination (of those who have disclosed their HIV status)	13.2	8.6	10.3
Type of discrimination by employer*			
Promotion denied	46.7	12.5	29.0
Being forced to take up voluntary retirement	--	18.7	9.7
Benefits are not given	13.3	25.0	19.3
Being forced to resign	13.3	18.7	16.1
Refused loan facilities	26.7	31.2	29.0
Poor access to shared facilities, like canteen, toilet etc.	--	18.7	12.9
Others	26.7	18.7	22.6
Attitude of co-workers*			
Neglected, isolated, avoided	46.7	37.5	41.9
Verbally abused, teased	33.3	12.5	22.6
Labeling and name calling	26.7	31.2	29.0
Avoid sharing utensils and drinking water from the same glass	--	12.5	9.7
Avoid sitting in close proximity	66.7	31.2	25.8
Others	6.7	6.2	6.4
Number facing discrimination	15	16	31

*Multiple response

Case Study 7: Stigma at the workplace

Voluntary testing and ensuring confidentiality is an important tool in fighting stigma at the workplace. It ensures that the status of the individual is revealed only with his or her consent thereby protecting the rights of that person. Valuable support from the management can also be critical in influencing behaviour in the office environment.

However, this is still an ideal situation for India. There are hundreds of instances that point to the contrary. The story of an employee in the canteen of a chemical factory in Mangalore is a case in point. He was tested to detect the possibility of a mosquito-borne disease among canteen employees but under that guise a test for HIV was undertaken. Soon he was informed by the company doctor that he was HIV-positive and a western blot test done to confirm his HIV-positive status. But that was not before the clinic staff of the factory started avoiding him.

They even went as far as asking the officers of the

company to remove him from the job. To his good luck, the VCTC counsellor from Mangalore intervened and convinced the company's management to keep him. The company then offered him two options- either be transferred from the canteen to become a sweeper, or alternatively take voluntary retirement.

There are two lavatories in the area that have been allotted to him. Although his viral load is less and his CD4 count is good, the doctors have told him that it is not good for him to clean lavatories, since he might be exposed to Opportunistic Infections in the long term. In spite of the fact that the officers are aware of this and have also been told that by serving tea and washing vessels he will not be spreading infection to others, they are not transferring him back to the canteen. He feels that the company has cheated him by not taking his consent before the test. Although he has not lost monetarily by the change in the job, he feels that his self-esteem has been affected.

As has been seen a vast majority of the employees have not disclosed their status in their workplace. During the survey it was also found that most of those who had revealed their status were those who were working in NGOs in the field of HIV and AIDS. They also reported getting welcome support from their employers and also benefits like leave with pay and adjustable timings. Since the number of people who were not working with such NGOs, but getting support from the employers was negligible, no quantitative analysis of the data could be done.

Workers in the food business seem to be especially vulnerable to discrimination. This has been brought out by a number of case studies conducted on the subject of stigma and discrimination faced by PLWHA. A case study conducted by the research team in Mangalore, Karnataka,

showed how an employee working in the canteen as a tea-server in a chemical factory was treated once he was tested positive (See Box 7). A similar case study has been presented by Shalini Bharat in her work for UNAIDS – A food vendor in Mumbai, who sold Bhelpuri in an upper middle class residential area tested HIV-positive, and his doctor informed the police about it. The next day, police officers removed him, as according to them, he posed a risk to the health of his affluent customers. The police were not convinced by the vendor's explanation that he could not infect others by selling snack-foods (Bharat et al, 2001).

Even the attitude of the co-workers has been discriminatory. While 42 percent felt that they were neglected, isolated and avoided, nearly 23 percent have reported abuse and teasing. Nearly 29 percent have been subjected to name calling.

During the survey it was found that most of those who had revealed their status were those who were working in NGOs in the field of HIV and AIDS

Table 8.9
Discrimination at health facilities

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
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	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 physical abused, teased	30	28.9	31.9	26.0	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	29.0	24.0
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	5.0	7.7	7.1	11.0	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	4.0
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	8.0
Restrictions on movement	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	30.0	25.0	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 include refused access to facilities like toilets and common eating and drinking utensils, non-admission, shunting between wards/hospitals, doctor did not touch and gave wrong information.

Some have reported that co-workers avoid sitting in close proximity with them and sharing utensils and drinking water from the same glass.

8.5.3 Discrimination at health facilities

PLWHA are often prone to many opportunistic infections. They have to go to 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 8.9 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.

About 14.4 percent of men and 12 percent of women 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 men 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 7 on Health Status that only a smaller proportion of the PLWHA 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.

As regards the attitude of other patients, in about 34 percent of cases the HIV status of the PLWHA was not known to the other patients and hence the question of discriminatory treatment against them does not arise. About 25 percent of PLWHA complained that they were isolated and neglected by other patients. Some of the

PLWHA were abused. In some cases, the HIV-negative patients refused to take treatment with the PLWHA. However, in about 21 percent of the cases the PLWHA were not discriminated against by the 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 HIV-positive 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 (See Box 8).

These findings are also corroborated by the existing literature in the field. In a study conducted in Mumbai and Bangalore, many healthcare providers and facilities were found to deny care, treat patients poorly, and stipulate conditions for agreeing to treat HIV patients (Bharat et al, 2001). Doctors often refuse to aid the delivery of a pregnant woman, despite minimal risk of contracting the infection (ILO, 2003).

Recently, however, Indian courts have started exhibiting sensitivity towards PLWHA. In November 2002, the Delhi High Court issued notices to both the Union Government and the Delhi Government seeking their replies on the refusal of several city hospitals to treat an HIV-positive person. Notices were also issued to several hospitals where the person had gone for treatment, only to be turned away (UNDP, 2003).

The discrimination ranged from not agreeing to treat HIV-positive patients to ill-treating them, not touching the patient, informing others about the patient's HIV-positive status, charging additional fees from them, etc

Case Study 8: The struggle of an HIV-positive couple to secure treatment for their child

Parents will do anything to ensure the well-being of their children. For HIV-positive parents, this becomes an even bigger issue when they are denied proper treatment for their children- because of stigma attached to HIV.

Despite being HIV-positive, a couple from Nagpur, Maharashtra, decided to have a baby since for the last 25 years nobody in the family had had a child. Both husband and wife were explained the risk of having a child and the possibility of the child being infected by the mother. They made an informed decision and took all precautions, including not breast-feeding the child.

Their child was born and test have revealed that she is HIV-negative. When their child fell sick with a minor ailment some time back, they took her to a private doctor and rightly informed the doctor of their HIV-positive status. He refused to treat the child. Then, they then took the child to Childline at Nagpur where

some medical attention was given but they started giving the child ARV drugs. This was taken to be a very serious issue by the Z and X and they complained that since the child's HIV status is not yet fully confirmed (given the window period), she should not be given this drug. They were asked to take the child to any other place at their own risk and they did so. They took the child to medical college but there too the child did not get any medical help. Finally, the child was given Ayurvedic treatment at Chandrapur and got well.

This is a case study of someone who is running from pillar to post to get medical treatment for a sick child. The father is working in an NGO involved in AIDS awareness campaign. What will be the situation of others who don't know who exactly to approach.

Although the family is very supportive to the couple, they fear discrimination and have not disclosed their HIV status to anyone in the neighbourhood and community.

8.5.4 Discrimination at the time AIDS related death

Because of the stigma attached to HIV, not only are PLWHA discriminated against during their lifetime, but this discrimination continues even after death. Out of all the households that were considered for the study in the six states, there emerged 502 cases of AIDS related death. Although, the number of deaths that occurred in hospitals is not available, there have been cases where people have faced discrimination in hospitals when a family member died due to AIDS related illnesses. The percentage indicated has been taken out of the total number of AIDS death reported (not only in the hospital) and could be the reason for the small percentage (4%) reporting discrimination. The staff refusing to lift or touch the dead body has been the most common complaint

(75%). The other kinds of discrimination have been—using plastic sheet to wrap the body, reluctant to provide transport for the body and not willing to keep the body in the hospital mortuary for long.

Respondents also reported facing discrimination at the time of cremating the body of a family member who died due to AIDS related complications. While in some cases they were unable to obtain transport to take the body to the cremation ground, in a large number of cases the community would not allow them to perform the last rites. In a small percentage of cases there was no co-operation from the staff of the cremation ground. Social boycott has been seen to be much higher in rural areas compared to urban areas (See Box 9).

Table 8.10

Distribution of PLWHA reporting discrimination at the time of AIDS related death in the family

(in Percentages)

Characteristics	HIV household		
	Rural	Urban	Total
Respondents reported facing discrimination in hospital at time of death of any family member due to AIDS related complications	3.0	4.9	4.0
Type of discrimination*			
Staff refused to lift or touch the dead body	85.7	69.2	75.0
Used plastic sheet to wrap the dead body	28.6	15.4	20.0
Reluctant to provide transport for the body	14.3	30.8	25.0
Not willing to keep the body in the hospital or mortuary for long	14.3	38.5	30.0
Others	14.0	15.4	15.0
Percentage of respondent reported facing discrimination in cremating the body of any family member who died due to AIDS related complications	6.4	6.7	6.6
Kind of problems			
Transport	13.3	22.2	18.2
Performing rituals	40	44.4	42.4
Use of common cremation ground (non-co-operation from staff)	6.7	11.1	9.1
Social boycott	40	5.6	21.2
Others	-	16.7	9.1
Total	236	266	502

*Multiple response

8.6 Knowledge and awareness about HIV and AIDS and attitude towards PLWHA

Stigma, negative responses and attitude towards PLWHA are generally the result of lack of knowledge about HIV and AIDS and in particular about the routes of transmission. Hence in this study, through a survey of non-HIV households, an attempt was made to find out about the general level of knowledge and awareness. Both men and women in the age group of 20 to 60 years were asked a series of questions not only to judge their knowledge about the infection, but also to know their attitude towards PLWHA. In all 6,224 persons, 3,299 men and 2,925 women, were interviewed in total. The

results of the survey are presented in Table 8.11.

The survey shows that 98 percent of men and 96 percent of women have heard about HIV and AIDS. However, not all of them have heard of HIV and in many cases they could not distinguish between HIV status and AIDS. During the FGDs the HIV-positive people showed their displeasure about this. In their opinion the moment somebody tests positive generally people start calling him/her an AIDS patient. This attitude of not distinguishing between HIV and AIDS has serious implications from the point of view of job prospects for the PLWHA as well as attitude of people towards them.

Case Study 9: How unsupportive family members can ostracise their own

Soon after completing matriculation, she was forced to marry at a young age. She was married to 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 treatment, 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 parent's house with her two kids, with the instructions on not to disclose her illness to anyone, as the news of her husband's and her disease would spoil 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 he was left 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 catch the infection. She was also deprived of her legitimate share in the family property.

The media, especially television and radio seem to have played a key role in creating awareness about HIV and AIDS; while more than 60 percent have come to know about the infection through various television channels, more than 30 percent have become aware of it because of programmes or advertisements on the

radio. This is not surprising considering that a very high proportion of sample men and women are in the habit of watching television and listening to radio quite regularly (Table 8.12). Interestingly, newspapers, books and magazines also seem to have played a role in spreading knowledge about the infection. For

Table 8.11

Distribution of respondents according to their knowledge and awareness about HIV and AIDS

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Percentage of people reporting ever heard about HIV and AIDS	97.2	95.3	98.5	96.5	98.0	96.0
Source of information *						
Radio	36.2	37.1	32.6	28.2	34.1	31.9
TV	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	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
Percentage of people who think HIV can be prevented	62.6	52.7	62.9	49.5	62.8	50.8
Percentage of people who know where to go for voluntary testing for HIV	49.0	34.3	54.0	37.1	51.9	35.9
Percentage of people willing to go for testing for HIV	49.0	34.3	54.0	37.1	51.9	35.9
Percentage of people who know someone suffering from HIV and AIDS	33.7	25.9	39.1	26.7	36.9	26.4
Percentage of people who 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

*Multiple response

about 25 percent of the respondents the source of information has turned out to be friends/relatives.

Although everyone has heard about HIV and AIDS, not all of them seem to have knowledge about other details like whether transmission of HIV could be prevented and where to go for voluntary testing. Only about 51 percent of the women and 63 percent of the men knew that HIV could be prevented. About 36 percent of women and 52 percent of men knew where to go for voluntary testing. Women appear to be less knowledgeable about information

related to HIV and AIDS as compared to men.

8.6.1 Knowledge about modes of transmission

Table 8.13 presents percentage distribution of respondents according to their knowledge about the various modes of transmission. A little more than 50 percent of the sample could mention all the right modes of transmission of HIV which includes sexual contact, sharing needle with an infected person, transfusion of infected blood and transmission from mother to child.

Table 8.12
Distribution of respondents by exposure to media

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
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						
Weekly/daily	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 newspapers/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	6.3
Occasionally	23.7	28.0	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

It appears that men are slightly more knowledgeable than women regarding the modes of transmission of the virus. Similarly, people from rural areas seem to be slightly better informed than their urban counterparts regarding all the modes of transmission. The percentage of people not knowing even a single mode of transmission is very small, although higher in case of women respondents.

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 HIV affected persons. The most common

misconceptions seem to be that sharing of razors (more than 75%) and mosquito bites (about 36%) could spread AIDS. A few of them believe that hugging and kissing a PLWHA or sharing food and utensils and touching or shaking hands with PLWHA could be affected as well.

As compared to women, men seem to know more about sexually transmitted infections; while more than 50 percent of respondents knew about STI, only about 36 percent of women have heard of this infection. Again a much higher percentage of men (59%) than women (42%) knew that a person suffering from STI has a greater chance of getting HIV. The knowledge about STI seems to be more among the urban than the rural people.

Table 8.13
Distribution of respondents according to their knowledge
about modes of transmission of HIV

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Reporting right mode of transmission						
All modes	59.0	56.5	56.3	52.7	57.5	54.3
Some modes	39.8	41.1	42.8	46.0	41.6	44.0
Not at all	1.2	2.5	0.9	1.3	1.0	1.8
People who had misconception that HIV can spread through						
Hugging/kissing PLWHA	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/razor	79.3	69.9	81.1	72.9	80.4	71.7
People who have heard of any other disease transmitted through sexual contact						
	46.6	31.6	56.1	39.6	52.2	36.3
People who know that a person suffering from STI has greater chance of getting HIV						
	53.2	38.4	62.5	45.9	58.7	42.8

Table 8.14
Distribution of respondents according to their knowledge about usage of condom

(in Percentages)

Characteristics	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
People knowing right usage of condom						
Avoiding pregnancy/as FP method	79.6	70.7	80.9	73.5	80.4	72.2
Prevention of STI	23.3	19.7	28.8	23.3	26.5	21.5
Prevention of 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

Knowledge and awareness about condoms assumes significance in the context of avoiding 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 right uses of condom namely: avoiding pregnancy, STIs and HIV infection. While

maximum number of people are aware of the use of condoms for avoiding pregnancy, lesser number are aware that it can be used for prevention of HIV and people are least knowledgeable about its use in prevention of STI. The knowledge regarding usage of condom for preventing transmission of HIV is slightly higher among the urban sample as compared to the rural sample. In spite of the various

Misconceptions regarding the spread of the infection have led to high-prevalence of discrimination and negative responses and attitudes of people towards PLWHA

efforts being taken to promote use of condoms, a very small percentage have reported using them. What is shocking is that a study conducted in Kerala among PLWHA found that 41.7 percent of the sample never used condoms. What is more shocking is that atleast some of them are involving in high risk behaviours not due to mere ignorance but with revenge (Arun Kumar et al, 2004).

8.6.2 Attitude of people towards PLWHA

Stigma and discrimination contribute to the socio-economic vulnerability of PLWHA. Existing misconceptions regarding the spread of the infection have led to high-prevalence of discrimination and negative responses and attitudes of people towards PLWHA.

Table 8.15 presents percentage distribution of respondents according to their attitude towards PLWHA. The table clearly shows that people do have negative attitude towards PLWHA

and as compared to men, women are more prejudiced and have negative attitude towards such persons. People are generally more hesitant to avail the health facilities used by PLWHA, to allow their children to mingle with children belonging to HIV households and to send their children to a school where HIV-positive children are studying. As compared to men and women living in rural areas, the urbanites seem to be open and are less prejudiced. These negative responses arise mainly due to their misconceptions about the mode 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.

8.7 Observations

Stigma is a great impediment in HIV detection and at the same time an obstacle to creating effective HIV prevention and care programmes. It makes people hesitant to go in for HIV

Table 8.15
Distribution of respondents according to their attitude towards PLWHA

(in Percentages)

	Rural		Urban		Total	
	Men	Women	Men	Women	Men	Women
Reporting that they would						
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 a PLWHA	52.3	41.6	60.5	45.4	57.1	43.8
Send their children to a school where HIV-positive children study	48.3	38.5	62.3	51.1	56.5	45.8
Purchase fruits, vegetables, etc from a shopkeeper who is HIV-positive	56.7	47.1	69.3	59.5	64.1	54.3
Accept a HIV-positive person 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

tests and those who test positive are reluctant to reveal their status. Priority should be given to educating the people about how HIV is and is not transmitted, since stigma is more likely to thrive in an environment of ignorance and half-truths. Efforts should be made to create greater awareness about HIV and AIDS, especially about the modes of transmission of the infection, and also to change the attitude of people towards PLWHA by using popular television channels and radio stations.

The survey reveals that PLWHA are in many cases getting support from their families; but there are also those who are being discriminated against by their families. It is also seen that discrimination against women is relatively more than against men. The knowledge and awareness levels of women are also lower.

The survey reveals that most people have not revealed their status in the workplace. This reflected in the small percentage of PLWHA who are discriminated against in the workplace. Organisations like the CII and the Chambers of Commerce are making efforts to have a common workplace policy for industry and to frame workplace protocols. These would aim at educating workers and managers about HIV and AIDS so that they do not fear contracting the virus at workplace and will not dismiss or shun workers with the infection—actions that make it much less likely that the infected will seek medical testing and treatment. However, much more needs to be done in this direction. If a PLWHA is unable to discharge his duties because of ill health

and the nature of the work, some other lighter work which he is able to do well should be assigned to him to ensure financial support.

The survey results and the Focus Group Discussions make it evident that there is a lot of discrimination in hospitals—both government and private and by doctors, nurses, ward boys, in fact everyone concerned. For a person diagnosed with AIDS, treatment of any opportunistic illness becomes very important. Steps should be taken to ensure that such people get access to treatment from both government and private health facilities. In fact, their right to treatment should be ensured. If the discrimination continues, the PLWHA may withhold their status, increasing the chances of spreading the infection.

Positive people who speak out in public, challenge societal attitudes. These people are usually passionately motivated either to stop the discrimination against HIV-positive people, or to prevent further spread of HIV and save lives. They show their communities that anybody is vulnerable to HIV infection and that PLWHA can lead positive and productive lives for many years. Hence they should be encouraged and suitable platforms should be provided for them.

Finally as Kofi Annan, the UN Secretary General said on World AIDS Day, 1st December 2002, “Let us resolve to replace stigma with support, fear with hope and silence with solidarity. Let us act on the understanding that this work begins with each and every one of us.”

Priority should be given to educating the people about how HIV is and is not transmitted, since stigma is more likely to thrive in an environment of ignorance and half-truths

Impact and Consequences:

Impact and Consequences: Gender and HIV and AIDS

9.1 Introduction

Globally, by the end of 2005 an estimated 40.3 million (36.7-45.3 million) people were living with HIV and of these 40 million people, as many as 17.5 million i.e., more than 40 percent were women (UNAIDS, 2005). The proportion of women being infected by the epidemic continued to increase and the “feminisation” of the pandemic is most apparent in sub-Saharan Africa where an estimated 13.5 million (12.5 to 15.1 million) women live with HIV and they account for 57 percent of the infection among adults in this region. 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 men. Now HIV has infected tens of millions, many of them women who contracted it from their husbands or partners.

The rates of HIV infection amongst women in India are also steadily rising. Women account for around 20 lakh of the approximately 52 lakh documented cases of PLWHA, constituting nearly 40 percent of all HIV infections (Table 9.1). Of these, only 0.5 percent of the women are sex workers. Of the 1,11,608 cases of AIDS deaths reported in the country till 31 July, 2005, women accounted for nearly 30 percent.

Table 9.1

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

*This chapter is a summary of the forthcoming report titled “Gender Impact of HIV and AIDS in India”.

The riskiest mode of transmission of HIV for many women and girls is through heterosexual sex: almost 85 percent of infections in women result from sex with their husbands or primary partners. A number of studies in India have shown that a large proportion of women in monogamous marriages are increasingly susceptible to HIV (See Suneetha Kandiyala and Barnett, 2004). 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.

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

9.1.1 Vulnerability of women/ girls

There are a number of factors – biological, socio-cultural and economic, which make women and young girls more vulnerable to HIV. 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 the infection. HIV is more easily transmitted from men to women than women to men; man-to-woman transmission during sex is about twice as likely as woman-to-man 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 linkage between gender inequality and vulnerability to HIV 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. Women in

India have a low economic and social status and these gender inequalities get reflected in the sexual relations between husband and wife. First, in the Indian context women do not have control over their own body and they do not have the right to decide when to have sex. As a result, women cannot negotiate safe sex and ask the men to use condom. There is also lack of availability of women controlled HIV prevention methods. Secondly, the cultural norms and attitude of society towards men of condoning multiple partnership or pre-marital or extra-marital sexual affairs of men, 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 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.

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 weaken their position. In addition, the various forms of violence against women further increases the risk of contracting HIV as sex is often forced on them.

9.1.2 Impact of HIV and AIDS on women and girls

Women and girls seem to bear the brunt of the pandemic in many ways and the infection psychologically, socially and economically affects them disproportionately. To begin, it has been

found that women PLWHA are likely to suffer additional burden of stigma, discrimination and marginalisation. Often, a woman is 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. 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 family members.

The illness/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, 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 not only to bear the burden of domestic and economic duties, but also have to take care of the family members who fall ill due to HIV and AIDS. The burden of care and domestic work is shouldered not only by the women adults of the household, but also by girls who are often withdrawn from school to share such responsibilities.

In this chapter, the impact of HIV and AIDS on women and children is being assessed using both quantitative and qualitative research and for the first time an attempt has been made to quantify the gender differences in the stigma and discrimination experienced by the PLWHA. In the following sections, the

gender differences in the impact of HIV and AIDS are assessed in terms of:

- (a) the burden of care, domestic work and economic responsibilities on women as caregivers of AIDS patients;
- (b) gender differences in the 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 children in school, gender differences in the reasons for discontinuation of schooling and the type of school attended in the HIV households;
- (d) gender differences in the stigma and discrimination experienced by the PLWHA in the family and community;
- (e) gender differences in the knowledge, awareness and misconception about HIV and AIDS, and attitude towards PLWHA among the general population and
- (f) the status of HIV-positive widows.

9.2 Role of women as caregivers

World over, mostly women are responsible for domestic work within the household, bringing up children and providing care for the sick and 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, fetching water and fuel and bringing up children and taking care of the elderly and the sick. In households where earning male members are affected by HIV and AIDS, women may be forced to complement paid worker with household activities. Not only may they have to take up paid work, but in addition to the routine household activities, they may have to

The burden of care and domestic work is shouldered not only by the women adults of the household, but also by girls who are often withdrawn from school to share such responsibilities

Table 9.2
Details about caregivers of AIDS patients

	Men	Women	Total
1. Number of caregivers	255	627	882
2. Age group of caregivers (percentages)			
Upto 15 years	16.1	5.1	8.3
15-59	75.3	91.2	86.6
60 and above	8.6	3.7	5.1
3. (A) Percentage of caregivers who are HIV-positive	16.5	20.7	19.5
(B) If positive, stage of infection (percentage distribution)			
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)

take care of their sick relatives as well (UNDP, 2003). 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 work for the 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/AIDS).

It has been estimated that globally, upto 90 percent of the care due to AIDS is provided in the home by women and girls (UNAIDS/ UNIFPA/UNIFEM, 2004). A recent household survey in South Africa showed that two-thirds of caregivers were women with almost a quarter of them over the age of 60

(UNICEF, 2005). In the present study, details about caregivers were collected from the HIV households to understand the role of women as caregivers. As mentioned in Chapter 4, out of the total 2376 PLWHA interviewed, 683 reported that they needed care and 882 household members were providing care to these persons who were at the advance stage of HIV infection. The details about these caregivers are presented in Table 9.2.

Not surprisingly, women accounted for more than 70 percent of the caregivers and 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 HIV-positive; the percentage of PLWHA among the caregivers is marginally higher among women; it is 21 among women as against 17 among men. Fortunately, more than 80 percent of the HIV-positive caregivers are at the early stage of the infection, i.e. Stage I or II.

It can be seen from the table that nearly one-third of the women 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 is a 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 being absent from work 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 children orphaned by AIDS 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 is enough evidence to show that again 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 subsequently take care of the orphaned grandchildren. In this context it is worth mentioning that in an innovative programme in Vijayawada in Andhra Pradesh the grandmothers are being trained to start income-earning activities so that they could take care of their grandchildren. (See box in Chapter six).

9.3 Gender differences in morbidity, health-seeking behaviour and household expenditure

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 have profound implications on 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. The results of the survey indicate that not only are there differences in the health-seeking behaviour and out-of-pocket expenditure on healthcare between men and women PLWHA, but also in the prevalence rate of illnesses. The prevalence rate of both non-hospitalised illnesses and hospitalisation cases are lower for women compared to men. While the prevalence rates of non-hospitalised illnesses have been calculated based on the reporting of illnesses in the last one month preceding the date of interview, the prevalence rates of hospitalisation are based on the number of hospitalisation cases reported during the last one year preceding the date of interview. Since the number of times an HIV-positive person falls sick depends on the stage of infection, the prevalence rates are calculated by stage (Table 9.3)

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

Table 9.3
Gender differences in 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					
Men	943.9	1,582.2	2,390.3	2,500.0	1,722.2
Women	844.8	1,330.3	2,164.0	2,424.2	1,375.5
F/M	0.90	0.85	0.91	0.97	0.80
Hospitalisation during last one year					
Men	312.8	617.5	1,204.1	1,707.1	799.5
Women	178.9	359.6	980.0	1,469.7	477.6
F/M	0.57	0.58	0.81	0.86	0.60
Number of persons					
Men	374	570	392	140	1,476
Women	464	445	250	66	1,225
Total	838	1,015	642	206	2,701

While the prevalence rates of non-hospitalised illnesses are only slightly lower for women than men at each stage, the reported number of hospitalisation cases shows greater variation

The prevalence rates of both non-hospitalised and hospitalised illnesses go up with the increase in the stage of infection for both men and women, although at each stage, the rates are lower for the women as compared to men. While the prevalence rates of non-hospitalised illnesses are only slightly lower for women than men at each stage, the reported number of hospitalisation cases shows greater variation. However, particularly in hospitalisation cases it can be seen that the gap between the reported cases for men and women decreases with the increase in the stage of infection. (0.57 in stage I to 0.86 in stage IV). This could be due to a number of reasons: (1) women may not be taking minor ailments very seriously, (2) as the routine of the household is likely to be disrupted more by the sickness of the women, they might be going to the doctor only when it becomes imperative, (3) in households where both men and women are sick, more importance could be given to see that the man – the bread

–winner gets well first, (4) it is possible that in case of a widow, whether staying by herself or with the in-laws, there may be nobody who is prepared to take her to the doctor and finally (5) financial constraints.

The large difference in the hospitalisation rates noted, especially in the first two stages of the illness, could be the combined effect of (i) greater costs of hospitalisation (ii) fear of disruption of the household routine (iii) lack of caretakers. As the stage of infection advances, due to the severity of the illness, women may have no choice but to get hospitalised.

In addition to the lower perception of illness, resulting in lower reporting of illnesses by women, as compared to men, in the case of women, a higher percentage of illnesses were left untreated. As already seen in Chapter 7, 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 gender gap in the treatment seeking behaviour. 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. 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. This point was also raised in the Focus Group Discussions held in Mumbai. A few of the women participants mentioned that they generally do not get much family support for seeking treatment and when they have to go for treatment no one is willing to accompany them. In addition, in another two percent cases women could not seek treatment due to lack of cooperation from the family.

As it has already been pointed out in Chapter seven, for both non-hospitalised and hospitalised illnesses, as compared to men, a higher percentage of women have sought treatment from government hospitals. But irrespective of the source of treatment, as compared to men, the out-of-pocket expenditure incurred per illness is less for women. (Refer to Tables 7.11 & 7.16).

In all it can be stated that women infected by HIV are not getting equal treatment as the men affected by it. It was, however, seen that of the six states where the survey was conducted, 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 level of education of the female PLWHA is better than that in the other states. Percentage of women PLWHA who are salary-earners is also slightly higher in these two states. 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.

9.4 Impact of HIV and AIDS on the education of girls

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 the 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 are considerable variations in gender gap in enrolment among children with two living parents and those who have lost both parents. 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 study, 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

Women who are better educated and have better income are also likely to have better access to health facilities

A very high percentage of women had gone for HIV test after they came to know about the HIV status of their husbands

and current enrolment as well as dropout percentages of children from HIV and non-HIV households. The survey results do indicate that HIV and AIDS has an adverse effect on the education of the girls. For instance, the ever enrolled and currently enrolled percentages for boys and girls belonging to HIV and non-HIV households show that it is more difficult for girls not only to get enrolled, but also to continue education as compared to boys particularly in the higher classes. While this is true of HIV and non-HIV households, the state of girls in HIV households is worse than that of similarly placed girls in non-HIV households. (Refer to Table 6.1 of Chapter 6).

Since the expenses in government schools are lower, it is not surprising that compared to non-HIV households, a higher percentage of children from the HIV households are studying in these schools. The HIV households seem to be cutting down the expenditure on the education of children in order to compensate for the heavy burden of expenditure on healthcare. But, once again, it is seen that it is the girls who have become the victims. Not only is the percentage of girls from HIV households studying in government schools higher than that of the boys from HIV households, it is also more than that of girls from non-HIV households, irrespective of the age group (refer to Table 6.6 of Chapter 6). This again suggests that given the limited resources, the HIV households are likely to spend more on the education of boys than on girls.

The impact of HIV and AIDS on the education of girls may appear miniscule while comparing the gender gap between children from HIV and non-HIV households. What is to be remembered

is that in the present study, the children from HIV households have at least one parent who is alive; in spite of this the ever and current enrolment of girls is lower. The impact may be much more severe when these children lose both the parents and become orphans. Though the education of both boys and girls would be affected, girls may be worse off, given the social conditions that exist in India. This is indeed a vicious cycle; it is necessary to educate girls and empower them so that they do not become vulnerable to HIV. Because of the HIV status of the parents, the girls are finding it difficult to get access to good education.

9.5 Gender differences in stigma and discrimination

Even though every PLWHA, whether male or female, is stigmatised and is the object of discrimination, the fate of a female PLWHA is seen to be worse than that of a male PLWHA. This is in spite of the fact that women are more vulnerable to HIV than men because of biological differences as well as the social and economic conditions of women in our society. 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 present sample, which includes PLWHA from two North Eastern states also shows that the main mode of transmission is through heterosexual contact, though the percentage is slightly lower. Again, percentage of women who have got it through heterosexual contact is higher than that of men. The data does give indication that most of the women have got infected from their partners. A very high percentage of women had gone for HIV test after they came to know about the HIV status of their husbands; the

percentage of HIV-positive widows in the sample is also much higher than the widowers.

In the Focus Group Discussions (FGD) 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. But one thing that came out clearly was that the daughters-in-law were treated much worse than the sons, and there was no place in the family for them 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 Mumbai, 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, since there was no other male child in the family.
- (2) Whenever men needed to go to hospital, wives accompanied them. However, when women had to go for treatment or collecting ARV drugs, 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 women participants came to know of their HIV status only after the death of their husbands. While sons who were HIV-positive were given care and support by the family, there was

no such consideration for their wives. In fact, many a time the daughters-in-law were abused for being the cause of their son's infection.

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 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 stopped from returning and also deprived of her legitimate share in the family property. (See Chapter 8)

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, 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 to 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 knowledge of status. HIV-positive mothers also reported separation from children or being forced to give up their babies (Bharat et al 2001, ILO 2003).

Whenever men needed to go to hospital, wives accompanied them. However, when women had to go for treatment or collecting ARV drugs, no one accompanied them

9.6 Gender differences in knowledge and awareness about HIV and AIDS and attitude towards PLWHA

The stigma and the resulting discrimination against the PLWHA are the direct consequence of the lack of knowledge and awareness among people about HIV and AIDS and in particular about the mode of transmission of the infection. The data on knowledge about HIV and AIDS collected in a number of countries shows that globally most of the women do not have sufficient knowledge about how HIV and AIDS is transmitted and also have little or no information on protection methods. (UNAIDS/UNFPA/UNIFEM, 2004) and this makes women more vulnerable to the infection. Through the survey of non-HIV households, 3,299 currently married men and 2,925 women in the age group 20-60 years were interviewed in the six high-prevalence states to find out their knowledge, awareness and attitude and the results are presented in Tables 8.13 to 8.15 of Chapter 8. These results clearly indicate that there is a gender gap in not only knowledge about the infection, but also in the attitude towards PLWHA.

Fifty-two percent of the men knew where to go for voluntary testing, only 36 percent of the women had this information

The results indicate that:

- (a) As compared to men, the percentage of women who have heard about HIV and AIDS is marginally lower. When it comes to details about the infection, women seem far less knowledgeable than men. While 63 percent of the men knew that HIV could be prevented, only about 51 percent of the women knew this. Similarly, while 52 percent of the men knew where to go for voluntary testing, only 36 percent of the women had this information.
- (b) Knowledge about the right modes of transmission is very important, for not only does it help protect themselves

from the infection, but also reduces stigma and discrimination and helps to overcome the negative attitudes about PLWHA. Here again, it was seen that while 58 percent men knew all the right modes of transmission, the percentage of women who knew the same was less at 54 percent. The myths and misconceptions about the modes of transmission, which accentuate the stigma and discrimination against PLWHA were also generally more amongst women.

- (c) Not all of them knew the link between STI and HIV. Only 42 percent women knew that a person suffering from STI has a greater chance of getting HIV, while 59 percent men knew about this.
- (d) Unprotected sex with multiple partners and non-regular partners is an important mode of HIV transmission and hence knowledge about uses of condom assumes significance in controlling the spread of HIV. In the present survey, a higher percentage of men than women reported knowing the three benefits of condom-use namely—avoiding pregnancy, prevention of STI and AIDS.
- (e) Apart from these, it was also seen that there were gender differences even regarding the sources by which people acquired knowledge about HIV and AIDS. One significant fact that emerged was that the knowledge and awareness generally increased with the level of education of the respondents. While the percentage of men and women exposed to television was almost the same, those who were exposed to print media was lesser among women. This is because the percentage of illiterates was higher among women in the sample and also the level of education of women was lower as compared to men.

(f) It has already been noticed that HIV-positive women are discriminated against more as compared to HIV-positive women and that too by other women. This has also been borne out by the fact that the attitude of women towards PLWHA is generally more negative than that of men.

9.7 The status of HIV-positive widows

In India, widows have a very low status in the society and in spite of efforts by social reformers, widow discrimination continues. There is the practice of Sati, which still continues in some villages. Widows are supposed to give up all the pleasures of life, wear white clothes, and even their presence is considered inauspicious on certain occasions. The position of HIV widows is worse. They not only have to face the grief of the death of their husband and the economic repercussions, but also 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 HIV-positive children.

HIV affects people in their prime, and since wives in India are generally much younger than their husbands, the HIV widows are mostly very young and also generally have young children. Also since the diseases related to HIV infection tend to progress more rapidly with age, older HIV-positive husbands are more likely to die before their younger wives. While HIV-positive women are discriminated against more than HIV-positive men, the plight of HIV-positive widows is indeed much worse. They face discrimination on three counts – for being a woman, for

being HIV-positive and finally for being a widow.

The profile of the HIV-positive widows in the sample as given in Table 9.4 indicates that these women are very young with nearly 57 percent between 20 and 30 years. A very high percentage of widows are illiterate, while only six percent are graduates/diploma holders. Although nearly 75 percent of them are involved in income-earning activities, they are probably forced to do so because of circumstances. Nearly 30 percent are wage labourers indicating their low economic status.

In terms of economic conditions too, the HIV widow households seem much worse off than the remaining HIV households. Table 9.5 gives the comparative picture of the income of widow households with that of the other HIV households. It can be seen that nearly half the widow households belong to the lowest income category and because of this, the average income of the widow households is much less than that of the remaining households in both the urban as well as the rural sample. This could be viewed as the direct impact of the death of a bread-winner in the widow households.

Apart from the income, the HIV widow households have lesser assets like agricultural land and livestock as compared to the other HIV households. A comparison of the basic amenities that are available in the household and the consumer goods they possess indicate that the standard of living of HIV widow households is worse than that of the other households which are already quite low.

Table 9.6 compares the average per capita per month expenditure of the two

Widows face discrimination on three counts for being a woman, for being HIV-positive and finally for being a widow

Table 9.4
Profile of HIV-positive widows

(in Percentages)

	Rural	Urban	Total
Age (Years)			
< 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	18.9	14.9	16.8
Upto middle	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
Agri. 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
Income from pension, rent, interest, dividend etc.	0.5	2.6	1.6
Domestic servant	1.9	10.2	6.4
Others (housewives)	25.2	25.1	25.2
N	206	233	439

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 probably to be expected since the income of widow households is also lesser than that of the remaining households. However, one interesting observation worth noticing is that the expenditure of widow households on all items including food, medical etc. is lower than that of the remaining households, except for expenditure on the education of children. This shows that the HIV widows are very keen to educate

their children so that they could stand on their feet and take care of themselves.

The fact that the HIV widow households are spending less even on food, whether cereal, pulses or other food, raises the question of nutritional status of these household members. 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 among them. A comparison of the HIV widow households with the other HIV households also reveals that their savings are lower,

Table 9.5
Distribution of sample widow and
other HIV households by household income categories

(in Percentages)

Annual HH income (Rs.)	HIV Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
1. Upto 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

percentage of households which have either borrowed or liquidated assets after a family member became HIV-positive is much higher, as also borrowings in the last one year. Further, a higher percentage of these widow households are below the poverty line compared to others. Thus economically and socially the HIV widow households are worse off than the other HIV households.

9.8 Observations

The survey results clearly indicate that though both men and women PLWHA are socially and economically hit, comparatively the women PLWHA seem worse off in many respects. It has been found that it is mostly the women of the household who provide bulk of the care to AIDS patients like caring

Economically and socially, the HIV widow households are worse off than the other HIV households

Table 9.6
Average per capita per month expenditure on some major items

(in Rupees)

	HIV 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

for the sick, bringing up children and orphans, in addition to their routine household chores. These demands take a toll on women emotionally, physically and financially. These caregivers need psychological and financial support so that they do not get burnt out.

The survey results show that as compared to men, women have far less knowledge and awareness about HIV and AIDS and misconceptions about the transmission of the infection. As a result they have a negative attitude towards PLWHA. There is a need to impart correct knowledge about HIV and AIDS among women, not only to change their negative attitude, but also to protect them from contracting the infection.

As compared to other HIV-positive households, the plight of HIV-positive widows seems deplorable. They seem to be socially and economically much worse off than the other HIV households. Denial of share in the property and lack of any other avenue of income could force these widows into risky behaviour and push them in to making sub-optimal choices like entering sex trade, as seen in one of the case studies conducted in Manipur. Improving women's legal position relating to inheritance and property ownership as well as maximising their access to credit and their income-generating ability are needed to empower women.

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Conclusion and Policy Implications

In this study, data used is from a primary survey of 2068 HIV households and 6224 non-HIV households spread over the rural and urban areas of six high-prevalence states to investigate the household level impact of HIV and AIDS. The results suggest that even though the aggregate impact of the epidemic may not appear to be large now, the impact on households affected by the epidemic is very severe. The impact is felt on income, employment, consumption expenditure (especially, education and medicine) and savings. The poor households and particularly female members are more vulnerable than the male members of the households. The study also goes into details of the impact on education of children and problems faced by PLWHA in getting medical treatment. Social stigma emerged as a serious issue. It prevents the PLWHA from disclosing their status not only in the community but also at times to their spouse and family. The root cause of stigma and discrimination is the low level of awareness about the correct information on routes of transmission of HIV. The specific conclusions and policy implications are detailed below.

The prevalence of HIV is higher among the working people in the sample. This is a matter of concern from the point of view of the economic impact of the epidemic on the household as well as

at a more aggregated level. For the HIV households it has resulted in higher prevalence of child labour as compared to non-HIV households. Also there is higher Work Force Participation Rate among the elderly in the HIV households, which raises the question of education for the children and security for the old. Given these indicators, the long-run impact of the epidemic can be disastrous if the incidence of HIV continues to rise.

The aggregate economic impact of the infection does not appear to be much, given a reduction in income of the HIV households by around 9 percent of their current income in the sample. Given the current prevalence rate, extrapolation of this figure at the level of the state or the national economy may not show a large impact, though this needs to be seen in the context that the sample is skewed towards lower income groups. However, the survey clearly demonstrates that the impact at the household level is severe. And this is something that cannot be ignored.

The major difference in consumption expenditure of non-HIV and HIV households is that the medical expenses of the HIV households are much higher than those of the non-HIV households by almost around four times of the per capita per month. The combined

The combined impact of lower income and increased expenditure, especially on medical care, has an impact on the asset and savings position of the households

impact of lower income and increased expenditure, especially on medical care, has an impact on the asset and savings position of the households. The HIV households liquidate their fixed assets in order to cope with the burden of health care. The asset most likely to be liquidated is a house in urban areas or a piece of land in the rural areas. This explains why HIV households spend a higher proportion of their total consumption expenditure on rent. The liquidation of assets and increase in borrowings implies a loss of wealth for the households and hence lower capacity to deal with exogenous shocks in the future. For the economy, in case the HIV spreads, it implies reduced availability of savings, which can result in reduced investment and economic growth. This is particularly so since households are the major source of savings in case of India. The study finds that almost 43 percent of the sample households had either borrowed or liquidated assets to cope with the financial burden after a member was detected to be HIV-positive. The percentage of such households was very high for the lowest income group going down with the rise in the level of income of the households.

The percentage of households that have negative savings is a mere 4.3 percent in the case of non-HIV households as compared to 18.1 percent of HIV households. The negative savers among HIV households dis-save nearly 52 percent of the amount saved by positive savers. In comparison, among the non-HIV households, the amount of dis-saving by negative savers is only around 15 percent of the savings done by the positive savers. Overall, the results show that not only is the average and per capita savings of HIV households lower than that of the non-HIV households for the lower income groups, it also results

in a much larger negative impact on aggregate savings. This suggests that the long-term consequences of HIV and AIDS on total and household savings can be disastrous even though the impact may not be visible yet in the Indian case given the fact that the proportion of households affected by HIV and AIDS is still quite low.

Apart from savings and liquidation of assets, coping with the epidemic influences the level of indebtedness among HIV households. The percentage of households that borrowed in the last one year is seen to rise continuously with the decline in the level of income of the household. The percentage of HIV households that borrowed is nearly double that of the non-HIV households. The lowest income group in the case of HIV households has the second highest share in the total borrowings by all households, while this income group has the lowest share in total borrowings in the case of non-HIV households.

The impact is particularly severe in the case of poor households. A very stark contrast is seen in terms of rate of savings between poor HIV and poor non-HIV households. The former group has a negative rate of savings while this is positive for the latter. In terms of consumption poverty, it is seen that head count ratio is lower in the case of HIV households in urban areas. In rural areas, it is almost the same as in the case of non-HIV households, even though higher income poverty for HIV households was observed. Clearly, the reason for much lower savings rate among income poor HIV households must lie in greater emphasis placed by HIV households on consumption. The poor among HIV households are under much serious constraint of trying to meet their consumption expenditure and their

struggle to cope with the AIDS epidemic. The impact is also felt by the members of the households who are not themselves HIV-positive. It points towards the threat that HIV could increase the incidence as well as severity of poverty.

Regarding the education of children, it is seen that the HIV households, in both rural and urban areas, spend a lower proportion of their total expenditure on education though the difference is larger in urban areas. This upholds the general idea in the literature that HIV and AIDS might affect the education of children. Both the average household and per capita expenditure of the HIV households on education is less than that of the non-HIV households. Both HIV and non-HIV households reported financial constraint as an important reason for discontinuation of schooling. This is especially so with regard to education beyond middle school. However, in the case of children in HIV households, taking up a paid job/taking care of younger siblings/the sick /looking after household chores also emerged as important reasons for dropping out of school. This shows that for these children the opportunity cost has also worked as a barrier to school participation.

Given the strong family ties in India, a number of PLWHA respondents, especially the widows, were confident that the grandparents or the uncles would take care of their children. Others hope that the government or an NGO would come to their rescue. In reality, often it is the grandparents who take care of the AIDS orphan. There are also residential schools in some of the high-prevalence states where children of HIV-positive parents are studying. But these are few and far between. Some support system needs to be developed and simultaneously the families of PLWHA

need to be prepared to look after the children who lose both the parents.

As has already been noted, health expenditure of households affected by HIV and AIDS is a major concern. Many of the sample PLWHA had gone in for a HIV test after suffering from prolonged illnesses like undiagnosed fever, tuberculosis and diarrhea. The prevalence rates of both non-hospitalised and hospitalised illnesses are seen to be much higher for the HIV households as compared to non-HIV households. The study reveals a heavy burden of disease on the HIV households. As may be expected, the burden of disease increases as the stage of infection advances.

PLWHA seem to depend mostly on the health facilities provided by the government and the NGOs as far as in-patient treatment is concerned. However, they are also dependent on private doctors especially for the treatment of non-hospitalised illness episodes. The cost of treatment in private health facilities is very high but the PLWHA seem to be spending a lot of money even if the treatment is sought from a government health facility. It is the Care and Support Homes run by NGOs that appear to be least costly. In order to meet this burden of expenditure, the HIV affected families' resort to borrowings and liquidation of assets. The borrowings and liquidation of assets increase as the stage of infection advances.

Gender differences have been observed in the treatment of health-related problems. 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. The percentage reporting hospitalisation is much higher for men as compared to women. The average household expenditure per

PLWHA seem to depend mostly on the health facilities provided by the government and the NGOs as far as in-patient treatment is concerned

In addition to the scaling up of national poverty reduction strategies, special social protection programmes are required to support the people, households and communities that are hardest hit by the epidemic

hospitalisation is Rs. 2,994 for men; this average is much lower at Rs. 1,953 for women. Clearly, health-related problems of women receive less attention than in the case of men.

Stigma is a big impediment to creating effective HIV prevention and care programmes. It makes people hesitant to go in for HIV tests and those who are positive do not wish to reveal their status, at times even to the immediate family.

The survey reveals that PLWHA are in many cases getting support from their families; but there are also those who are being discriminated against by their own families. It is also seen that discrimination against women is relatively more than against men. Women also came out to have lower level of knowledge and awareness about HIV and AIDS. This not only makes them less sensitive towards PLWHA but also makes them more vulnerable to the epidemic, particularly in the household setting.

The survey indicates that most people have not revealed their status in the workplace. This is reflected in the small percentage of PLWHA who are discriminated against in the workplace. Much needs to be done in this direction.

The survey results and the Focus Group Discussions make it evident that there is a lot of discrimination in hospitals – both government and private. For a person living with HIV and AIDS, treatment of any opportunistic illness becomes very important.

To sum up, in addition to the scaling up of national poverty reduction strategies, special social protection programmes are required to support the people, households and communities that are hardest hit by the epidemic. The scale

of impact is likely to increase in the future as the number of households affected would increase. Greater number of currently working PLWHA would withdraw from labour force due to illness. This is accompanied by reduced income and savings, liquidation of assets and increased indebtedness of HIV households. Reduction of human capital not only due to death and morbidity of PLWHA but also due to reduced investment in education of children will only increase the impact of the epidemic.

The study clearly brings out the deplorable condition of HIV-positive widows. In the absence of the bread-earner, the widow households are much worse off than the other HIV households, in terms of household income, expenditure, borrowings and liquidation of assets. Denial of share in the property and lack of any other avenue of income could push these widows into risky behaviour.

10.1 Policy recommendations

The findings of this study call for urgent policy action in order to mitigate the negative impact generated by HIV and AIDS. This response needs to be multi-pronged as the issues are diverse and complicated. Some of the urgent policy implications are:

- One of the channels reducing the impact on labour supply is policy intervention directed at keeping the PLWHA in good health for a longer period. This might have an impact on the economy as well as mitigate the severity at the household level. Ensuring access to anti-retroviral treatment, is a step in the right direction.
- The status of wage labourers who

do not have any social security and therefore, are hard hit by any episode of illness is of particular concern. This gets aggravated in the case of HIV positive wage labourers.

The PLWHA households have to cope mostly with the medical expenses related with the epidemic on their own rather than receiving support from the government. These households need much greater support from the government in terms of access and affordability of medical care. Special attention has to be directed at the wage labour households who have to reallocate consumption expenditure to medical expenses out of the existing lower level of consumption expenditure, mainly by substituting away from food expenditure.

The average amount borrowed by the HIV household is almost double that of the same household group in non-HIV households, bringing out the vulnerability of HIV households. There is therefore a need for better access and terms for credit on one hand and a special focus at reducing the burden of the medical expenses related to the treatment of PLWHA on the other.

Even though parents are altruistic about investing in the education of their children, the financial burden imposed on them due to HIV and AIDS prevents them from doing so. A policy intervention targeted at continuation of schooling especially so in the case of girls is clearly needed.

Given the low level of literacy, especially among women, the major source of information regarding HIV and AIDS came out to be television and radio. These mediums need to be used more intensively to spread awareness.

- PLWHA who speak out in public challenge societal attitudes. These people are usually passionately motivated either to stop the discrimination against PLWHA, or to prevent further spread of HIV and save lives. They show their communities that anybody is vulnerable to HIV infection and that people living with HIV can lead positive and productive lives for many years. Hence, they should be encouraged and suitable platforms should be provided for them.
- Priority should be given to educating people about how HIV is and is not transmitted, since stigma is more likely to thrive in an environment of ignorance and half-truths. Equally, efforts need to be made to create greater awareness about HIV and AIDS, especially about the modes of transmission of the infection, so as to help change the attitude of people towards PLWHA.
- Efforts directed at extending the working life of PLWHA, including change in the nature of duties are necessary. The focus has to be on "Living with HIV".
- Improving women's legal position relating to inheritance and property ownership as well as maximising their access to credit and their income-generating ability are needed to empower women.
- Given the heavy burden that the epidemic is putting on women as caretakers and income earners, social security arrangements are needed to respond to their needs. There is a need to work on options for sustainable livelihoods including provision of vocational skills, start up funds for micro-enterprise, partnerships with the private sector, linkages with the market, etc.

Stigma is a great impediment to creating effective HIV prevention and care programmes

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