

Socio-Economic impact of HIV/AIDS on people living with HIV/AIDS and their families

A study conducted by

Delhi Network of Positive People

Manipur Network of People Living With HIV/AIDS

Network of Maharashtra by People Living With HIV/AIDS and

Positive Women's Network of South India

With support from



International Labour Office
New Delhi

**'Prevention of HIV/AIDS in the World of Work:
A Tripartite Response'**

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Foreword

I am pleased to present this study report on '*Socio-economic impact of HIV/AIDS on people living with HIV/AIDS and their families*'. This study is significant as it was carried out by networks of People Living with HIV/AIDS (PLWHA) in four Indian states. I would like to compliment the PLWHA networks, particularly their members, for doing an excellent work. These networks are doing a great service to the cause of PLWHA by highlighting critical issues and undertaking advocacy at different levels.

The International Labour Organization (ILO) is a strong supporter of GIPA (Greater Involvement of People Living with AIDS) and is committed to ensure effective application of its principles. PLWHA are represented in the Project Management Team, which takes all policy decisions related to the ILO's HIV/AIDS work in India. Secondly, in ILO's training and advocacy work, there is a consistent involvement of PLWHA. Interactive sessions with PLWHA have been found to be most effective by ILO's constituents and other key partners very often. The ILO's HIV/AIDS programme follows a rights-based approach. The guidelines are given in the ILO code of practice on HIV/AIDS and the world of work. These principles are directly linked to the technical work supporting the development of policies and programmes for HIV/AIDS interventions in the world of work.

I am deeply concerned at the instances of stigma and discrimination highlighted in this study. The world of work can play a key role in ensuring that the rights of PLWHA related to employment, non-discrimination, treatment and social security are respected. While access to affordable treatment is indeed a key issue, perhaps an equally important, if not greater, need is to provide access to regular income to PLWHA, as the report clearly indicates the adverse impact of HIV/AIDS on the economic condition of PLWHA and their families. Another issue causing concern is the reduced expenditure on children's education in PLWHA families, and the need for children to take up jobs to complement existing family incomes. This is an indication that HIV may be exacerbating child labour in India, as observed in several worst-affected countries.

I thank the networks for their relentless effort in undertaking this study. The ILO is very pleased with this collaboration. I sincerely hope that its findings will influence policy initiatives and will be used by various development partners for implementing meaningful care and support programmes for PLWHAs in India.

Herman van der Laan

Director,

ILO Subregional Office for South Asia &

ILO Representative in India

Acknowledgement

This study was undertaken by the networks of People Living With HIV/AIDS (PLWHA) to understand the socio-economic impact of HIV/AIDS on infected persons and their families, particularly on women and children. Reaching out to PLWHA and getting them to talk about what they had gone through or how they were coping with their HIV status was not easy. It required investigators who would be extremely sensitive and empathize with their subjects. Therefore, our sincere thanks are due to the four PLWHA networks, which collaborated with ILO and undertook the survey in their respective states.

All the members of the networks played a very important role. We acknowledge their contributions, as without their dedicated and sincere cooperation this work would not have been completed. Thanks in particular are due to Ms. Kousalya, Positive Women Network of South India (PWN+), Mr. Deepak Singh, Manipur Network of Positive People (MNP+), Mr. Naveen Kumar, Delhi Network of Positive People (DNP+) and Mr. Manoj Pardesi, Network of Maharashtra by People living with HIV/AIDS (NMP+), who coordinated the survey in their respective states.

We would like to thank all the respondents who participated in the study and took pains to answer the questionnaire, a relatively long one. I can imagine that while answering some of the questions, particularly on stigma and discrimination, they would have had to relive some of their bitter experiences. We would like to offer our apologies if the process, in any way, added to their agony. At our end, we tried to reduce this by involving the PLWHA networks, in place of any other agency. This ensured that the investigators were PLWHA themselves. No one else, possibly, was more qualified or more sensitive to handle the job.

The study was completed with technical support from the ILO project team. A very special thanks is due to Mr. Ravi Subbiah, Programme Officer (Research and Documentation) for providing technical support to the networks in development of research design and instruments, methodology, training of investigators, support during the fieldwork and review of reports. Ravi coordinated the entire process with remarkable ease, and was there to help whenever needed. Other members of the ILO project team, Ms. P. Joshila, Ms. Divya Verma and Ms. Seena Chatterjee

also deserve to be acknowledged for their contributions in technical as well as logistical matters.

We would also like to thank Dr. Upma Sharma, who merged the data sets of four states, did the final analysis and prepared the combined report. Dr. Sanjay Sahai deserves a special mention for designing the cover page.

Finally, we would like to thank and acknowledge Ms. Chitra Narayanan for her painstaking efforts in editing and putting together this report.

S.M. Afsar

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List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti Retroviral Therapy
CNP+	Churachandpur Network of Positive People
DNP+	Delhi Network of Positive People
GIPA	Greater Involvement of People Living with HIV/AIDS
HIV	Human Immune Deficiency Virus
ILO	International Labour Organization
INP+	Indian Network for People Living with HIV/AIDS
NACO	National AIDS Control Organisation
NGOs	Non-Governmental Organizations
NMP+	Network of Maharashtra by People Living with HIV/AIDS
PLWHA	People Living with HIV/AIDS
PWN+	Positive Women's Network of South India
WGNLI	V.V. Giri National Labour Institute
WLHA	Women Living with HIV/AIDS
SRO	Subregional Office for South Asia

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1. Executive summary

The study '*Socio-economic impact of HIV/AIDS on people living with HIV/AIDS (PLWHA) and their families*' was undertaken with the following objectives:

- (a) To document the overall experiences of PLWHA and their families ever since the discovery of their HIV+ status. (Stigma faced, impact on employment status, family income and expenditure, availability of care and support services, etc.)
- (b) To understand the impact of HIV/AIDS on women and children.

The study was conducted in four states — Delhi, Maharashtra, Manipur and Tamil Nadu through the networks of people living with HIV/AIDS. Thus, Delhi Network of Positive People (DNP+), Manipur Network of People Living With HIV/AIDS (MNP+), Network of Maharashtra by People Living With HIV/AIDS (NMP+) and Positive Women's Network of South India (PWN) were involved.

In all, 292 respondents, of whom 42 per cent were women, were covered in the study. Data was collected from infected and affected people through interviews, focus group discussions and in-depth interviews.

The involvement of PLWHA networks in this research work had certain distinct advantages. For one, it became easier to reach out to PLWHA for collecting information. Secondly, since the researchers were PLWHA themselves they were very sensitive towards the respondents and did their best to respect their sentiments and confidentiality.

However, there were certain limitations as well. For one, PLWHA are not professional researchers. Many of them were involved in an exercise like this for the first time. To overcome this, the International Labour Organization (ILO) worked very closely with them and provided technical support at every stage. ILO was also looking at this process as capacity building of PLWHA, enabling them to identify and highlight their own key issues and concerns. Secondly, it was difficult to get the perspectives of PLWHA who are not part of these networks. This number will definitely be large considering that the PLWHA network movement is still fairly young in India.

The study brings out a number of striking findings. It has revealed that HIV has, in general, made a deeper impact on women who have faced more discrimination, more hardships and had to assume more responsibilities to run the households once their husbands died of AIDS.

About 92 per cent of the respondents were in the age-group 19-40 years, which is the most productive age-group. The mean age of respondents was 32.05 years (Men: 33.5 years and women 30.1 years).

The mean age of women at the time of HIV testing was 24.4 years as compared to 28.03 years in the case of men. This shows that women are getting infected at a very young age. Most of the women (nearly 90%) got the infection from their husbands. So, marriage is a route of transmission of HIV for women.

The data revealed that HIV is infecting people with varied educational backgrounds. However, people with higher educational qualifications are coping better. Women, in general, had received lesser education, making them more vulnerable to infections and economic insecurity.

About 70 per cent respondents received pre-and-post HIV test counselling. The data shows that counselling was done mainly at the government hospitals and not in private institutions providing HIV-testing facilities. The importance of counselling is brought home by the fact that about 78 per cent of those who had been counselled took precautions to protect their partner/child from getting infected. However, in most cases, people came to know of their HIV+ status only after a period of prolonged illness. Unfortunately, by this time the infection had already spread to their partner/spouse.

Around 47.54 per cent women respondents were widows. Given the mean age of women respondents (30.1 years), this shows that women are increasingly becoming widowed at a very young age as a result of AIDS. There were many instances of women being treated badly in their husband's home, doubts being raised on their chastity and being blamed for their husband's illness. Their sufferings only multiplied after the death of their husband when often in-laws discarded them. About 89 per cent respondents said they needed someone to take care of them when they were ill and in most cases the care-givers were women. This places an additional burden on women who have to handle regular household chores as well.

Stigma and discrimination associated with HIV continues to be a major challenge. As many as 70 per cent of the respondents reported that they faced discrimination. Reported discrimination was more in the case of women (74%) than men (68%). Maximum discrimination was reported from within the family (33.33%), closely followed by health care settings (32.5%). Nearly 18.3 per cent people faced discrimination from their neighbours and nine per cent from community/educational institutes/ relatives, etc.

Around six per cent respondents reported discrimination at the workplace. Instances of discrimination might have been higher but for the fact that many PLWHA had not

disclosed their status to the employers as they feared losing their job. Denial of promotion, forced to take voluntary retirement are some of the reported instances of discrimination at the workplace. Discrimination from co-workers was also highlighted as the main reason for changing jobs. This shows that confidentiality norms are not being followed or are difficult to follow at the workplace.

About 27 per cent of the respondents had other HIV+ members in the family. Of these 81 per cent were their spouses. Caregivers who looked after PLWHA were mostly spouses (60%), followed by parents (32%), children (6%) and siblings (2%).

The economic condition of the respondents was not very good. About 29 per cent respondents were unemployed. Ill health was one of the major reasons for unemployment. Nearly 39 per cent were employed in public or private sector (mainly NGOs). Nearly 20 per cent of the respondents lost their income due to absence from work.

Average monthly income of PLWHA families was reported to be Rs.1,117, whereas the average monthly expenditure was Rs. 3,185. On food alone, the increase in the average monthly expenditure of families post-HIV infection was Rs. 350, while the rise in expenditure on medicines was Rs. 468 (almost double). Consequently, there was decrease in expenditure on entertainment by Rs. 522 per month and on education of children by Rs. 266. As their income was not sufficient to meet their expenditure, people had to sell off their assets and borrow from friends and relatives. As a result, debts in such families increased to the tune of Rs. 4,818 per family on an average.

Children of PLWHA also faced discrimination due to the HIV+ status of their parents. They were not allowed to play with other children, verbally abused or teased. Decrease in monthly expenditure on education clearly indicates that children are being withdrawn from schools. About 35 per cent children were denied basic amenities and about 17 per cent had to take up some petty jobs to fulfill the increasing monetary demands of the family. This indicates HIV may be exacerbating child labour in India as in other worst-affected countries.

Not surprisingly the key concerns expressed by PLWHA are: regular income in the households; care of their spouses and children, particularly after their death; and access to treatment.

2. Introduction

2.1 Background

Health is considered a fundamental human right and a worldwide social goal. A healthy person is an asset to any society. However, the illness caused by HIV and its possible fatal consequences is a major health challenge. In the absence of cure or vaccine, the enormous number of debilitating illnesses and deaths that will be caused by the rapid spread of HIV in South-east and South Asia, particularly in India, is a major developmental problem with far-reaching impact beyond the health sector. AIDS is becoming a major cause of adult mortality that challenges conventional views of public health progress.

With an estimated 3.97 million HIV+ people (2001 figures), India has become the nation with the second-largest number of people living with HIV/AIDS after South Africa. Estimates reveal that roughly one out of 10 HIV+ persons in the world is an Indian. Given India's huge population, even low-prevalence rates here indicate a large number of people living with the virus. The first HIV+ case in India was reported in Chennai in 1986. The major concentration of AIDS cases then gradually moved to three states — Maharashtra, Tamil Nadu and later to Manipur. The situation, at present, is worse, with HIV cases spreading across all the states in India. The epidemic is no longer confined to the high-risk groups of sex workers, migrant workers, truck drivers, injecting drug users etc., but has blanketed the general population.

2.2 Statement of the problem

In general population, the infection very often results in unemployment, rejection by spouse or partner, family or community, disruption in inter-personal relationships due to guilt and shame, taboo, and social stigmatization.

Societal, economic and cultural impact is generally disastrous for HIV+ people and their families (or group). The professional and social rejection of the infected people frequently results in destruction of personal and community ties and deep moral, cultural and economic distress. For these reasons, infected people often tend not to disclose their status to their spouse or regular sexual partner.

In some cases, people are not worried about HIV infection due to other, more pressing concerns associated with their 'under-privileged' socio-economic situation.

The 400-million working population in India, defined as anyone seeking employment, falls in the 15-49 age-group. Around 89 per cent of the reported HIV cases affects this age group, highlighting the risk it poses to the economically active segment of society. About 92 per cent of the workforce is in the informal sector, which is characterized by low productivity/income levels and poor social protection, and hence, is more vulnerable to HIV.

2.3 ILO response in India

The ILO has increasingly recognized and responded to the threat to the world of work posed by HIV/AIDS. In consultation with its Indian tripartite constituents and National AIDS Control Organisation (NACO), ILO India has developed a three-phased programme, aimed at establishing a sustainable national action plan on HIV/AIDS prevention, care and support in the world of work.

The project is supported by U.S. Department of Labor and implemented by V.V. Giri National Labour Institute.

Very little data is available on the effects of HIV illness and deaths on the economic situations of individuals and families in India. It is, however, imperative that any assessment attempt should not only include attempts to quantify the direct impact of HIV/AIDS mortality and morbidity costs, but also the socio-economic impact on individuals, families and communities.

2.4 Objectives of the study

The study has two main objectives:

1. To document the overall experiences of PLWHA and their families since the discovery of their HIV status. (Stigma faced, impact on employment status, family income and expenditure, availability of care and support services, etc.)
2. To understand the impact of HIV/AIDS on women and children.

The specific issues that were to be studied were:

1. The time and manner of discovery of HIV status of PLWHA and the efforts made to protect the spouse/ child from getting infected;
2. The impact on women of the affected households, in terms of additional responsibilities taken to support the family, attitude of family elders towards the woman, etc and the special impact on girl child;

3. The impact on children in terms of denial of education and other opportunities, forced entry into child labour, etc.;
4. The overall impact of HIV/AIDS on families of PLWHA, including problems faced due to stigma and discrimination;
5. The differentials of impact in terms of families where the main breadwinner has the support of his/her employer versus those who had to lose their job because of their HIV status;
6. Cost incurred on treatment of opportunistic infections¹.

2.5 Limitations of the study

One of the hurdles in collecting information was to get responses from people affected by HIV/AIDS as it was a sensitive topic. Data could be collected only once they were reassured that their identities would remain confidential.

It was very difficult to contact the infected persons directly. Stigma attached with HIV status is so high that people often feel reluctant to talk about it or share their experiences. It was made possible only by contacting the networks of positive people. Hence, purposive sampling method was adopted.

It was important to have an equal number of men and women in the study to clearly understand the impact of HIV, particularly on women. However, the study included fewer women respondents (170 men and 122 women), as fewer number of women came forward and disclosed their identity and HIV status.

¹ Infections that occur as a result of weak immune system. The most common opportunistic infections among those affected by HIV are tuberculosis, pneumonia and fungal infections.

3. Methodology

3.1 Selection of the area

The study was conducted in four states, namely Delhi, Maharashtra, Manipur and Tamil Nadu through the state-level networks of HIV+ people. Districts covered were Imphal and Churachandpur in Manipur; Mumbai, Pune and Satara in Maharashtra and Chennai, Namakkal and Erode in Tamil Nadu.

State-level networks, i.e. Delhi Network for Positive People (DNP+), Manipur Network of People Living With HIV/AIDS (MNP+), Network of Maharashtra by people living with HIV/AIDS (NMP+) and Positive Women's Network of South India (PWN+) were deliberately selected for the study since it was felt that it would be difficult for outside agencies to contact and study problems of HIV+ people. Secondly, being a very sensitive issue, it was assumed that the networks would handle the issues of positive people with more sensitivity.

3.2 Selection of the sample

The sampling framework was purposive. The study covered 150 respondents in New Delhi, Imphal and Churachandpur. One interview schedule had to be discarded as it got damaged. Ninety six respondents were from three districts of Maharashtra and 47 were from three districts of Tamil Nadu. The 292 respondents studied were PLWHA and information was also drawn from families of people infected by HIV/AIDS.

The rationale for selecting these particular sites for the study was because of their identification as high-prevalence states. In Delhi, Maharashtra and Tamil Nadu, the major mode of transmission was through heterosexual contact while in Manipur it was through injecting drug use.

To understand the impact of HIV/AIDS, particularly on women and children, an effort was made to include sufficient number of respondents from either sex in the study. So, data was collected from all the available males and females.

Two categories of respondents were contacted. The first category of respondents was those who were infected by HIV/AIDS.

In the second category, a close relative, preferably the spouse who would presumably know all the details of the infected person was interviewed. Since the number of

respondents in this category was very small, no separate report has been prepared from this data. However it is worth mentioning that these findings support the findings of the data of the first category.

3.3 Developing tools for data collection

Three research tools were developed for data collection:

- Interview schedule
- Focus group discussions
- In-depth interviews

The interview schedule was developed by the ILO and refined in consultation with the PLWHA networks. The purpose of the survey was to collect information on issues that need to be addressed through interventions in the project. The instrument was field-tested before implementation. Two sets of interview schedules were developed, one for infected persons and another for affected persons.

The quantitative information was substantiated with the qualitative information. Guidelines for focus group discussions and in-depth interviews were developed. A three-day training programme was conducted for the investigators who were comprehensively trained on how to implement the research tools. The training of investigators was done with technical support from the ILO. The investigators were trained in New Delhi and Pune, with the coordination of the networks, so that a standard method for the study across all the study sites could be evolved.

3.4 Data collection

The research teams comprised people from the local network who could speak the local language and had an understanding of the local culture. Care was taken to ensure a good mix of both male and female investigators so that respondents could be interviewed by members of their own sex. The fieldwork was coordinated by the ILO.

The fieldwork was conducted between March and April 2002. DNP+ collected the data from Delhi while MNP+ collected data from Imphal and Churachandpur. PWN+ and NMP+ collected data from Tamil Nadu and Maharashtra respectively.

The advantages of selecting networks of positive people for data collection were:

- All the members of these networks are HIV+.
- Most of the HIV+ remain socially invisible in order to protect themselves and their families from possible social ostracism. It would be much easier for a positive

network to access and interview its own members as well as other HIV+ in the community than for an outside agency.

- Being an HIV+ person himself/herself, and thus sensitive to the feelings of the respondent, the interviewer would be able to draw the required information without much hesitation.

3.5 Analysis and report writing

The analysis of the data was done using SPSS¹ computer package. The data was cleaned, coded and analyzed. Cross tabulations were done to probe further into the impact of HIV infection on families. Key findings were shared with the investigating team to confirm trends.

Finally, data of all the four states was compiled and a comprehensive report prepared.

¹ Statistical computer software used for data analysis.

4. Findings

4.1 Profile of the infected respondents

The profile of the respondents has been presented under different sub-sections.

4.1.1 Area

Data was collected from four different states — Delhi, Manipur, Tamil Nadu and Maharashtra. Thus the data represents the four geographical areas, viz. North, South, East and West.

Table 4.1: Area profile of the respondents

Area	No.	Percentage
Delhi	43	14.73
Maharashtra	96	32.88
Manipur	106	36.30
Tamil Nadu	47	16.09
Total	292	100

The data of 292 people was analyzed. Of these 58 per cent were males and 42 per cent were females.

4.1.2 Age

The age range of the respondents was 19-62 years. But all the women respondents were below 50 years of age. The mean age of the respondents was 32.05 years.

More than half the respondents were in the 19-32 age group and about 92 per cent of them were around 19-40 years, which is sexually active and coincides with the economically productive segment of the population.

The mean age of women was 30.1 years and the mean age of men was 33.5 years. The data showed that women were comparatively younger to men. The data in all the four states reflected this same trend.

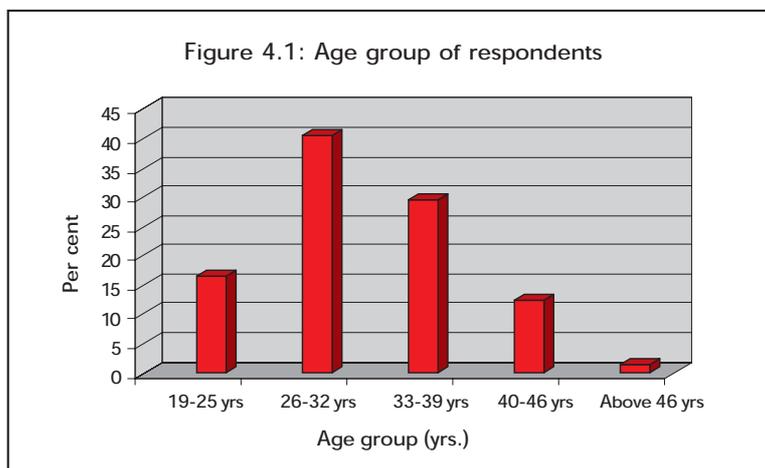


Table 4.2: Area-wise age-distribution of the respondents

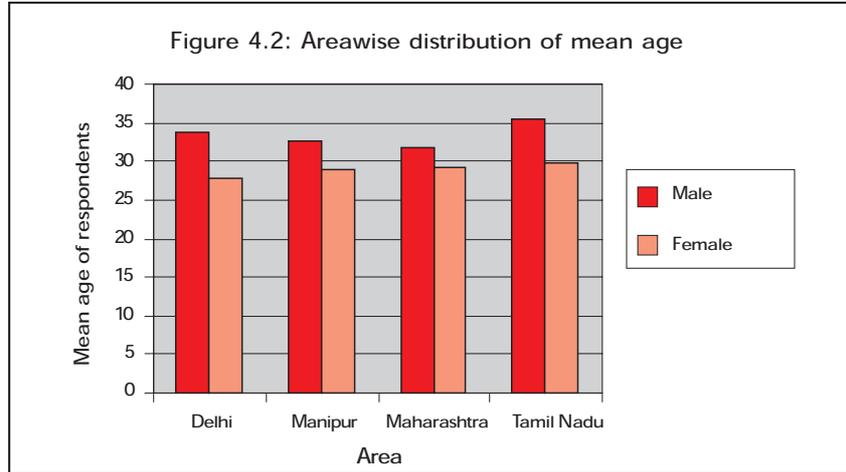
Area		Age-range (years)	Mean age (years)
Delhi	Males	19-45	33.76
	Females	21-38	27.73
Maharashtra	Males	21-45	31.67
	Females	20-45	29.34
Manipur	Males	23-62	32.51
	Females	19-45	28.82
Tamil Nadu	Males	21-48	35.56
	Females	22-50	29.90

The figures in Table 4.2 reveal that women respondents from Delhi were the youngest while Maharashtra had the youngest male respondents. The age range of male respondents was 19-62 years while women respondents were in the 19-50 age range.

4.1.3 Educational status

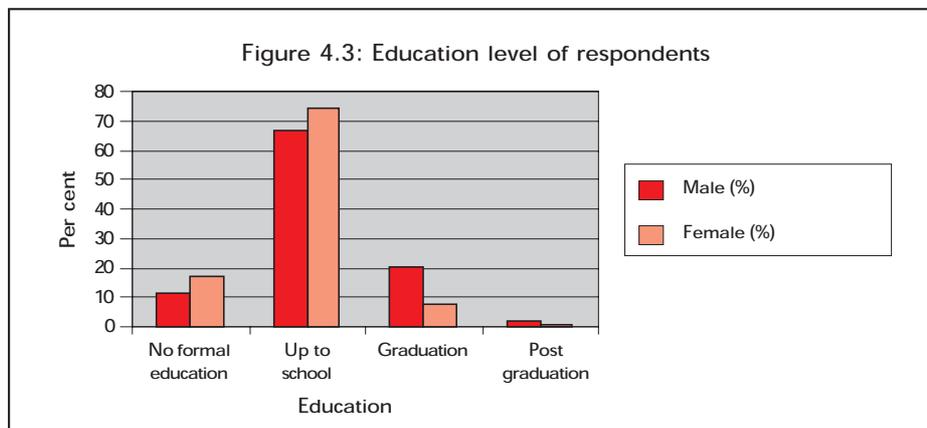
A majority of the respondents (69.86%) had received education up to school level. About 14 per cent respondents had no formal education. Only four respondents were post-graduates, out of which one was a female. The data thus revealed that education had no effect on HIV infection.

The data further showed that the education level of men was better than women. There were about 17.21 per cent illiterate women as compared to 11.18 per cent illiterate



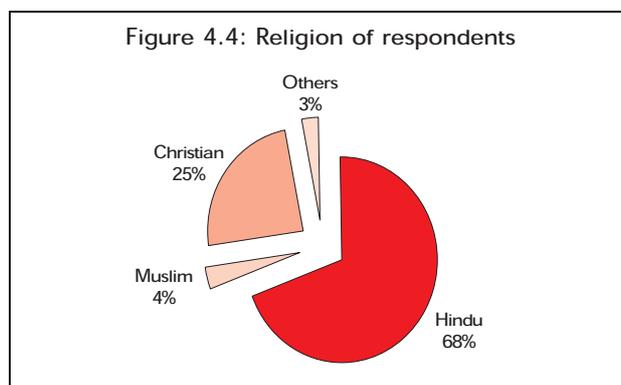
men. At the same time, about 22 per cent men were graduates or above but only about eight per cent women were graduates or above.

The data thus highlighted that more women were illiterate or lesser educated, putting them at higher risk of economic insecurity and discrimination.



4.1.4 Religion

HIV does not know the boundaries of religion and it has spread to all the segments of society. The data revealed that a majority of the respondents were Hindus (68.83%) followed by Christians (24.66%). About four per cent were Muslims and about three per cent belonged to other faiths.



The sex-wise break-up of religious faith (Table 4.3) also showed the same pattern. There were maximum number of Hindu men and women respondents followed by Christian men and women.

Table 4.3: Sex-wise distribution of the respondents

Religion	Males (%)	Females (%)
Hindu	70.59	66.34
Muslim	3.52	4.09
Christian	22.94	27.05
Others	2.95	2.52
Total	100	100

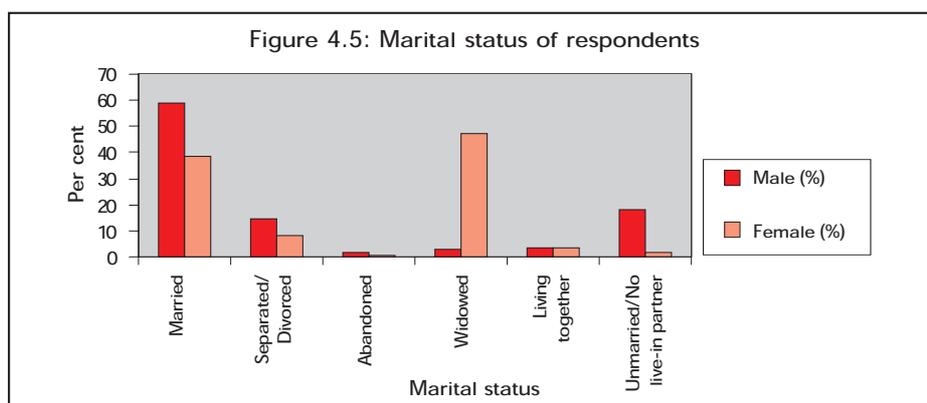
4.1.5 Marital status

Marriage in India is the universal institution, sanctioned by society, to establish durable bonds between a man and woman and to permit sexual intercourse for the implied purpose of parenthood and creating a family. In the study, marital status was subdivided into six categories — married, separated/divorced, abandoned, widowed, living together and unmarried/ no live-in partner (Figure 4.5).

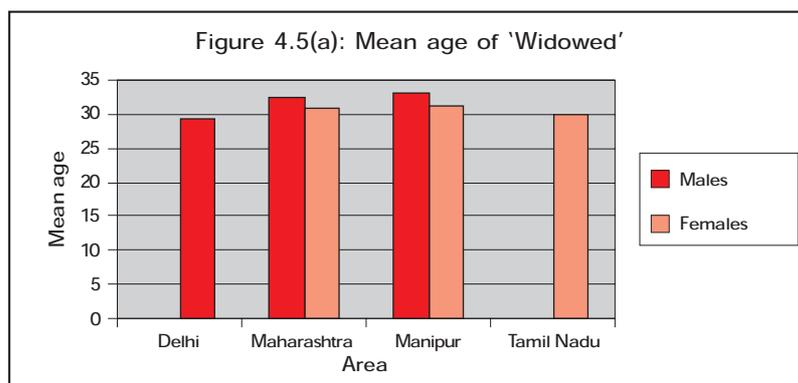
More than half the respondents (50.42%) were married. About 22 per cent respondents were 'widowed' while 12 per cent were separated/divorced. About 11 per cent respondents were unmarried. Four respondents (three males and one female) were abandoned by their spouse.

Almost an equal number of men (3.53%) and women (3.28%) were living together. About 18 per cent men were unmarried, whereas only about two per cent women

were unmarried. More men (14.70%) were divorced as compared to women (8.20%). The high percentage of women in 'married' and 'widowed' categories indicates that the transmission of HIV among women takes place predominantly within the institution of marriage.



In India, widowhood is generally considered inauspicious and as a result, a woman who has lost her spouse has to bear a lot of stigma. Nearly five per cent of the women interviewed were widowed as compared to three per cent men who had lost their spouse. The age range of widowed women was 20-50 years, the average age was as low as 30.5 years as compared to 32.6 years in the case of men who had lost their spouse (widowers were in the 26-40 years age-group) (Figure 4.5(a)). This implies that more men are dying and more women are becoming widowed at a younger age as compared to men. This also highlights that in such a situation, more women have to bear an additional burden of earning a living to support their family. A majority of men (58.82%) and about 39 per cent women were married.



Area-wise analysis of the category 'widowed' showed that there were no widowers in Delhi and Tamil Nadu. In Maharashtra, the mean age of male respondents (32.33) was higher than that of females (30.75). Similar responses were observed in Manipur where the mean age of male respondents was 33 years and that of female respondents was 31.23 years.

4.1.6 State of residence

As many as 34 per cent of the respondents hailed from Manipur, out of which about 18 per cent belonged to Churachandpur and 16 per cent to Imphal. About 32 per cent respondents hailed from Maharashtra and 18 per cent from Tamil Nadu. About seven per cent respondents belonged to Delhi. The rest of the respondents had migrated from other states.

Of the 27 per cent who had migrated, a majority had moved to Maharashtra (49.65%) or Tamil Nadu (31.51%) for reasons as varied as employment, marriage, education, medical or rehabilitation.

4.1.7 Area of residence

Area of residence had three sub-categories: urban, semi-urban and rural. A majority of the respondents belonged to urban areas (64.04%) followed by rural (23.97%) and semi-urban areas (11.99%). About a quarter of respondents were residing in rural areas where there were more chances of facing discrimination due to lower HIV/AIDS awareness. This also indicates the spread into general population.

All the four post graduate respondents stayed in the urban areas. Of the graduate respondents, about 79 per cent belonged to urban areas. Thus, the data depicts that higher educated people prefer to stay in urban areas.

Of the respondents living in rural areas, about 82 per cent were educated up to school level while nine per cent each were illiterate and graduates. The problems faced by infected persons gets aggravated in rural areas as educational levels are comparatively lower and work opportunities are fewer.

Of the respondents staying in semi-urban areas, a majority (85.71%) were educated up to the school level.

4.1.8 Family status

Family is the basic unit of social organization. This is where the socialization process begins, where the behaviour and roles are taught and gender norms defined. A majority (57.04%) of the respondents were living with their parents or in joint families. About 27 per cent were staying with their spouse/ sex partner and only about 16 per cent of the respondents were living alone (Table 4.4).

Table 4.4: Location of current residential area and family status

Family status		Percentage
Living with parent/joint family	Rural	27.71
	Semi-Urban	12.05
	Urban	60.24
Living separately with spouse/partner	Rural	17.72
	Semi-Urban	13.92
	Urban	68.36
Living alone	Rural	21.74
	Semi-Urban	8.69
	Urban	69.57

Of the respondents living in rural areas, a majority (65.71%) were in joint family set-ups. Only about 14 per cent respondents were living alone. Among those living with spouse/partner, about 68 per cent belonged to urban areas. And, of the respondents living alone, about 70 per cent were in urban areas.

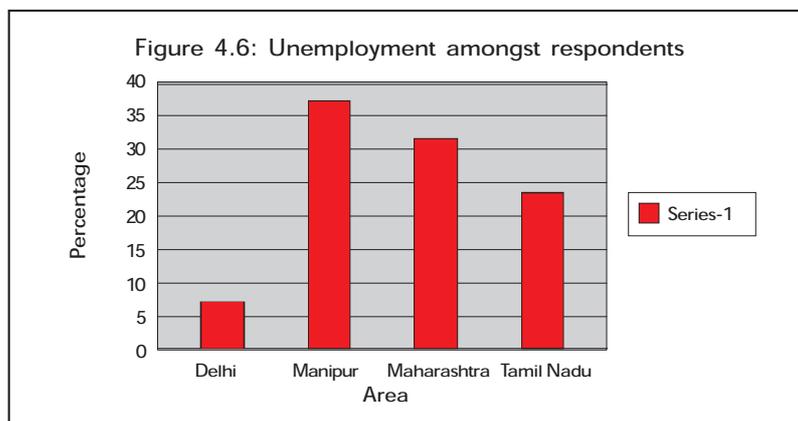
What emerged from the data was that the problem cannot be seen in isolation. In any illness, a person feels more secure when he or she is with family. The support of family is very vital at that stage. It was observed that most of the respondents were living with their families. But, at the same time, in a joint family or in a large family, there are fewer chances of concealing one's HIV status and consequently more chances of discrimination. So, sensitizing families becomes an important challenge for HIV prevention and care programmes.

4.1.9 Occupational status

Overall, about 39 per cent respondents were employed in the private or public sector. The rest of the respondents were either unemployed or self-employed. Of the people living in rural areas, about 37 per cent were employed and about 29 per cent were unemployed. The rest were self-employed.

Of the people living in urban areas, about 42 per cent were employed in public or private sector and about 28 per cent were self-employed. About 29 per cent respondents were unemployed. Various case studies also emphasized ill-health as one of the major reasons for unemployment.

As shown in Figure 4.6 unemployment was highest in Manipur where 38 per cent respondents were without jobs. In Maharashtra 31 per cent respondents were unemployed. About 23 per cent respondents in Tamil Nadu did not have any job. Unemployment was least among the respondents of Delhi, where only seven per cent were without work.



Of the four postgraduate respondents, three were employed and one was unemployed. Of the graduate respondents, more than half (52.38%) were employed. Of the respondents who had received education only up to school level, about 34 per cent were unemployed.

A job not only gives a person economic independence but also a social status and satisfaction. The data highlights that the economic condition of the respondents was not very sound. Moreover, illiterate or less educated people had fewer chances of employment.

4.2 Living with HIV - Experiences, problems and concerns

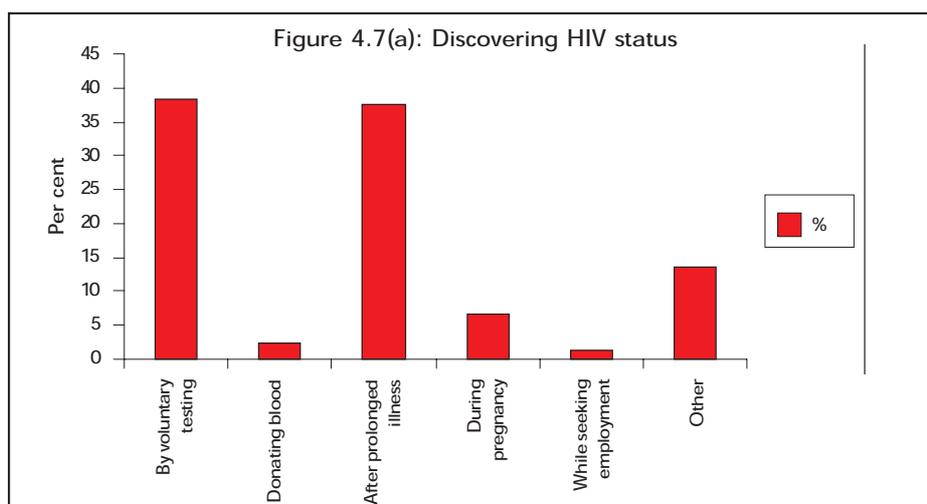
4.2.1 Discovering HIV Status

The data showed that the majority of respondents got tested in the late 90s. About 12 per cent women and 13 per cent men got tested before 1995 and the rest of the respondents got tested during or after 1995. More women got tested since 2000 (40%) as compared to men (37.07%).

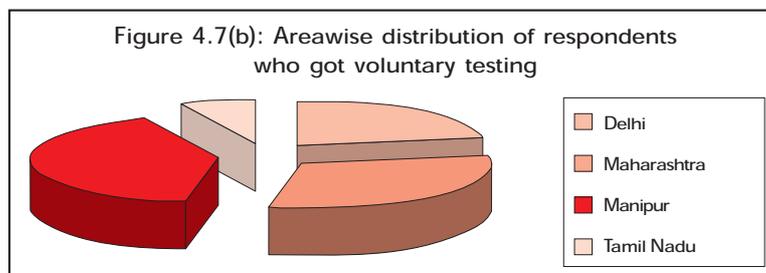
The data reveals that women in the age group 11-47 years got tested. The mean age of women at the time of testing was found to be 24.4 years. Men in the age group 12-45 years got tested. The mean age of men at the time of testing was 28.03 years, which shows that women are getting infected at a younger age as compared to men.

About 38 per cent respondents discovered their HIV status by voluntary testing (see Figure 4.7(a)). Of those who came to know about their HIV status by voluntary testing,

about 36 per cent were from Manipur followed by Maharashtra (30.55%). Of those who came to know about their HIV status by voluntary testing, only about six per cent were from Tamil Nadu (see Figure 4.7(b)).



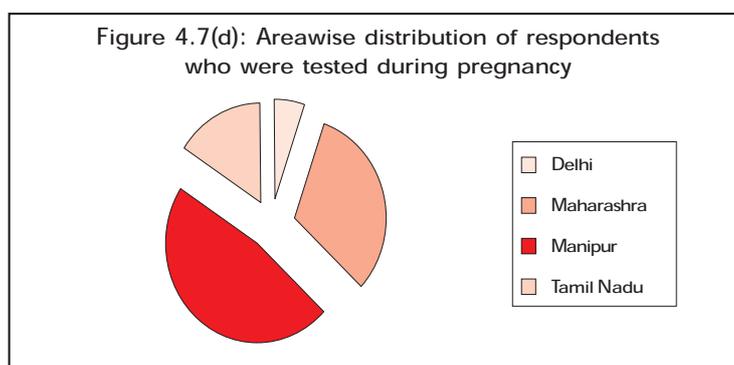
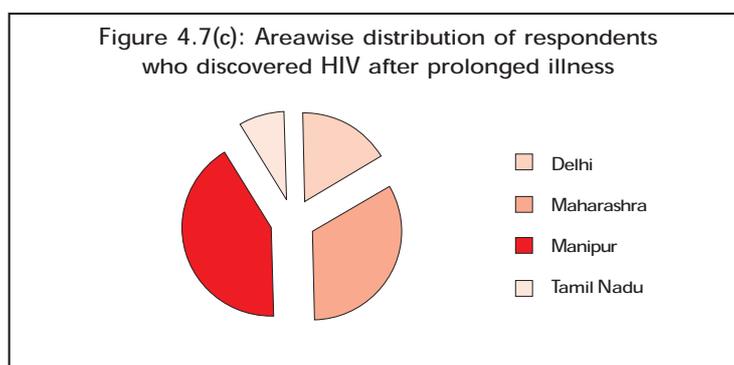
Almost an equal number of respondents (37.59%) got themselves tested for HIV after prolonged illness. Of those who discovered their HIV status after prolonged illness, about 41 per cent were from Manipur (Figure 4.7(c)).



About seven per cent respondents had undergone testing during pregnancy. Of those who were tested positive during pregnancy, about 47 per cent were from Manipur (Figure 4.7(d)).

Only about two per cent respondents came to know about their HIV status while donating blood. About 14 per cent respondents had decided to go in for tests for other reasons such as advised by spouse, etc.

In both, rural as well as urban settings (35.71% and 37.97% respectively), a majority of the respondents had gone in for voluntary testing. However, in semi-urban settings,



more than half (54.29%) the respondents got themselves tested only after prolonged illness. About 34 per cent respondents in semi-urban settings had undergone voluntary testing.

All the four respondents who were tested while seeking employment abroad were from urban areas.

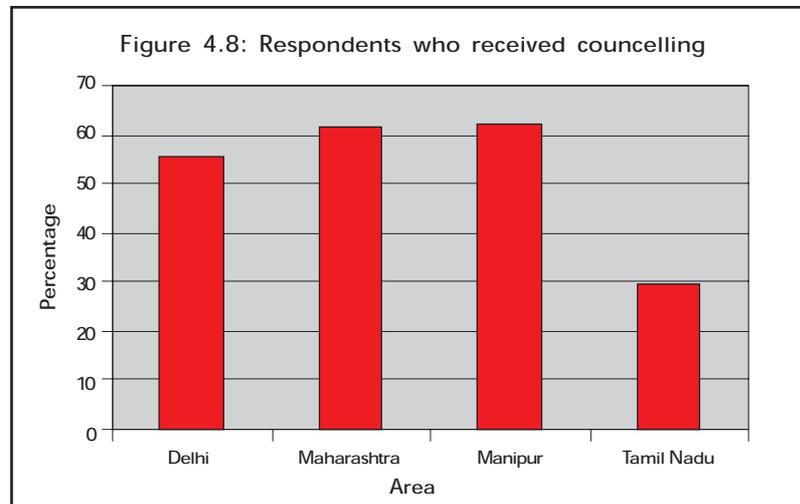
Of the graduate respondents, about 52 per cent had gone in for voluntary testing. Of the respondents who were educated up to school level, about 36 per cent went in for testing only after prolonged illness, while 32 per cent had undergone voluntary testing. Of the respondents who had no formal education, about 48 per cent had undergone testing only after a period of prolonged illness.

The data shows that the majority of people had voluntarily opted for HIV tests, which indicates a higher level of awareness about HIV.

Almost an equal number of respondents took their tests in private and government hospitals. Of the respondents who took their tests in private hospitals, about 45 per

cent were employed. Of those who had undergone testing at government hospitals, about 34 per cent were unemployed, which shows that money plays a significant role in deciding the selection of testing facilities.

About 70 per cent of the respondents received pre-test and post-test counselling. The data shows that counselling was mainly done in government hospitals, not in private hospitals. Of the respondents who received counselling, about 68 per cent were tested at government hospitals.



The data further showed that about 62 per cent of people in Manipur received counselling. In Maharashtra, about 61 per cent respondents received counselling. About 55 per cent respondents in Delhi and about 30 per cent respondents in Tamil Nadu received counselling (Figure 4.8).

The cost of testing varied a lot in government and private hospitals. In government hospitals, it varied from zero expenditure to Rs. 3,700 (average being Rs. 40.47). In private hospitals, it varied from nil to Rs. 3,500. NGOs picked up the bill for many respondents, which is why in many cases the test costs were nil. However, the average cost of testing in private hospitals worked out to around Rs. 380.

4.3 Disclosure of status

About 93 per cent respondents disclosed their HIV status to someone or the other. The confidants were the spouse, sibling, parent/s, friends, co-workers, neighbours or any close relative. Of those who disclosed their status, a majority revealed it to their

spouse (76.86%) followed by parents (10.2%) and friends (5.09%), which highlights the strong bondage between couples and the need for support that HIV+ persons seek from their spouse.

Among those who did not disclose their results, the main reason was the fear of stigma and discrimination. They said that they didn't reveal their status when they visited private clinics for common cold or cough because of the fear that they would either be refused treatment or extra money would be demanded from them. They also mentioned the fear of losing their jobs as well as fear of ill-feeling and ill-treatment from the community.

A positive trend was that a majority of the infected persons behaved responsibly and wanted to protect their partner or children. Of the eligible respondents, about 76 per cent said that they took precautions to protect their partner/spouse from getting infected.

"Since the day, I was detected positive, I have been using condoms and I try my level best to abstain from sex."

A man from Maharashtra

However, the general consensus was that the protection of spouse/partner was applicable only in cases where the person got to know his/her status either before marriage itself, or before having unsafe sex. But in most cases, the person got to know his/her HIV status only after a prolonged illness, by which time the partner might have been already infected.

The significance of pre-test and post-test counselling became evident from the fact that of all respondents who took precautions, about 78 per cent had undergone counselling. The precautions included consistent use of condoms (51.79%), abstaining from sex (34.53%) and refraining from sharing needles (10.79%). One respondent said that he became more careful with his open wounds.

When asked about the protection of their children, only about 17 per cent said they did not take any precaution. About 38 per cent responded that they took precautions and about 44 per cent replied that they had decided not to have a child. Of those who took precautionary measures, about 35 per cent respondents decided not to breastfeed their child and about 18 per cent used drugs such as AZT/Nevirapine during pregnancy.

4.3.1 Discrimination of infected and affected people

The stigma attached to HIV/AIDS often leads to discrimination against infected people and their families. Discrimination hampers the prevention and care efforts of the illness

as it sustains silence and denial about HIV/AIDS. It further reinforces the marginalization of PLWHA and those who are vulnerable to infection.

Discrimination occurs when people or institutes take negative actions that result in the unfair or unjust treatment of a person affected by HIV.

Stigma also arises through internalization by PLWHA of their negative perceptions of themselves. It can have *devastating* psychological consequences, which may lead to depression, lack of self-worth and despair.

Generally, it was observed that there was rampant discrimination among different sections of the society. As high as about 70 per cent of the respondents said that they faced discrimination. Family is one of the major institutions of society, which provides a sense of security to an individual. Ironically enough, discrimination mainly occurred at the family level (33.33%) and in hospitals (32.5%). At the next level was discrimination by neighbours (18.3%), in community (9.17%), educational institutes, relatives and workplace.

"After my family knew about my HIV status, they immediately kept my glass, plates, clothes, etc., separate and I was given a separate bedroom."

-A man from Delhi

Women faced more discrimination as compared to men. About 74 per cent women mentioned that they faced discrimination as against 68 per cent men. In general, a woman does all the household chores and manages the family. However, paradoxically enough, it was the family, which discriminated against her the most. About 23 per cent women were discriminated by the family (as compared to 19.82% men). A similar trend was observed in the context of neighbours (12.82% women as against 10.81% men), educational institutes (3.85% women as against 0.90% men) and community (6.41% women as against 5.40% men) per se. However, at hospitals, men faced more discrimination (23.42% men as opposed to 16.67% women). Possible reasons for such variation may be that women tend to visit hospitals less.

Education is often viewed as a panacea for most social and economic problems. It appeared true in the case of discrimination too. None of the post-graduates faced any discrimination. Fewer graduate respondents (58.8%) faced discrimination as compared to those who were illiterate (71.42%) or were educated only up to school level (74.01%).

Mrs. A, abandoned by her first husband, married again and brought the child from her first marriage to her second husband's place. Both work as caretakers in an NGO. When tested, the couple and child were HIV+. The child died soon thereafter due to Hepatitis. Mrs. A's in-laws are fond of her and praise her for reforming her husband, who was a drug addict. But she dare not tell them about her HIV status, so much so that when she suffered from fever while visiting them, she refused to go to the doctor. The couple wants to have another child but there is no financial support. At present, they have no major problems and are receiving care and support from NGOs. But, they are worried about the future. They think that they would have been able to save their child if they had had enough money.

(Excerpts from a case study in Delhi)

The respondents also narrated various instances/acts through which they felt discriminated. These included:

- Neglect by family
- Denial of treatment by doctors/nurses
- Referred to other hospital
- Blackmailing by employer and threats to disclose the HIV status
- Physical abuse
- Verbal abuse
- Children were rejected and were not allowed to play with other children
- Deprived of love and care
- Accused of spreading virus
- Moving away when the infected person passed by
- Not allowed in social gatherings
- Asked to leave the place

The respondents also added that in order to protect their children from stigma, they hid the truth and said that they were suffering from either jaundice or cancer or tuberculosis.

4.3.2 Health care system

PLWHA often face discrimination in health care settings. This discrimination may vary from isolation, breach of confidentiality to simply being denied access to treatment.

Some respondents revealed instances where their HIV results had been published in the local newspapers along with their names.

"The hospital staff has given us a yellow card so that people can easily identify us as HIV+."

- A woman from Tamil Nadu

Focus group discussions highlighted that hospital staff often presume that if one partner is positive, the other is too. So, not only the infected person but affected persons are also discriminated against and sometimes even denied treatment.

"The doctor asked my spouse to administer injection and saline fluids on his own."

- A woman from Tamil Nadu

A hospital is an institution, which is supposed to provide treatment and care. It is the place that one associates with providing care and support to the sick. However, when discrimination takes place here, one's faith in the system is totally shattered. This feeling is reflected in the stories of the HIV-infected people.

"The remarks made by the hospital staff made me feel very ashamed."

- A woman from Tamil Nadu

4.3.3 Future concerns

The major future concerns of HIV-infected persons are: who will take care of them when they are ill and who will look after their children. Finding a regular source of money is another concern, as they would like economic security for the future. They also have worries about their medication and the costs involved. Would the effect of the drug relapse if they discontinued it due to lack of resources, is another worry. They also fear the prospect of losing their jobs when they are not healthy enough to work.

The concerns of HIV-infected people not only revolve around their physical and economic conditions but also around their social relationships. They are worried about their education, marriage, procreation, children, their upbringing and education.

In addition, they are also afraid of discrimination at various levels and their acceptance in the family. Many of them are undecided whether to disclose their HIV status or not.

And if they do wish to disclose it, they are concerned about who they should reveal it to, how and the consequences.

Mr. Y's brother was a drug user. When he became ill, he was admitted to a hospital and discharged without any improvement and without any follow-up from hospital authorities. Doctors said they would not be able to treat him but did not mention the reason for his illness. He died within a year. Mr. Y had to accept his sister-in-law as his wife and look after the three children of his brother. After two years, when the youngest child died of AIDS, it was only then that he came to know the real reason behind his brother's death. Mr. Y felt that due to the doctor's negligence, he had also become a victim of HIV. Meanwhile, his wife delivered a baby girl who was HIV+ . His wife died after some time. At present, Mr. Y, his surviving children and old parents are facing financial problems. There are four HIV+ persons and only one earning man and so managing needs has become difficult. They received no support from the community people who felt the illness was a sign of wrath of God. It has really become a challenge for him to carry out his duty as the only son in the family.

(Excerpts from a case study in Churachandpur)

Apart from their concerns for themselves and their families, they are also anxious about the increasing spread of HIV and wish to educate society. They want to do something so that the lot of the PLWHA improves. They suggested that PLWHA should be empowered so that they don't face discrimination and can live life on their own terms.

4.4 Impact on families

Family satisfies the basic psychological needs of an individual. In addition, family is expected to provide a support structure to the infected individuals, which becomes even more central in the absence of state-sponsored welfare programmes.

About 27 per cent of the respondents had other HIV+ members in their family. Of them, 81 per cent respondents said their spouses were also infected. Siblings of about 10 per cent were infected. The general initial reaction of the family after learning about the HIV status of the respondent was shock (40.57%) followed by denial (12.74%). At the same time, it was quite heartwarming to observe that about 88 per cent of the families accepted them, though they took long to reconcile to the fact. The

acceptance time varied from just one month to two years. This highlights the strong network and close-knit relationships that still exist in Indian families, which needs to be strengthened further.

4.4.1 Impact on women

Women are particularly important in any approach to HIV/AIDS prevention. Women's disadvantaged biological, economic, social and reproductive position in most societies is a major factor influencing the spread of HIV. In general, women face greater risk of rejection, ostracism and neglect when they are infected. Women's sufferings only increase when their in-laws discard them after the death of their husband.

The respondents felt that after the disclosure of HIV, women are treated badly in the husband's home. Often, aspersions are cast on the woman's chastity and she is blamed for her husband's illness.

Focus group discussions further revealed that women were accused of causing the husband's infection, irrespective of whether she got infected first or her husband, and were sent back to the parental home.

"We (my husband and I) were separated without our consent. The worst part in my life is that I can't live with my children."

- A woman from Churachandpur

However, women are not only discriminated against by their in-laws, but also experience it in their parental family. Even the other women in the household are not sympathetic to HIV-infected women, perhaps, because of the fear of society. The women reported that though they were not subjected to physical abuse, verbal abuse was very high.

In most cases women were the care-takers, looking after the infected persons. About 89 per cent respondents said they needed someone to take care of them when they were ill. The main care-takers were spouses (59.83%) and parents (31.96%). As about 58 per cent respondents were males, the major group of care-takers was women. It was observed that women had to take on the additional responsibility of looking after the ill apart from earning money and doing household chores. In a few cases, children (5.73%) and siblings (2.48%) also took care of the ill.

Of them, about 44 per cent respondents reported a loss of income while taking care of the infected person. The loss of income ranged from Rs. 100 to as much as Rs. 18,000. The average loss of income was found to be about Rs. 2,700.

Of the family members, who had to take care of the infected member, 41 per cent had to take up a job to meet the family expenses. About 37 per cent had to take on an additional job to meet the increasing expenditure. About 15 per cent had to leave their jobs in order to look after the ill person.

Monthly income of the women varied from Rs. 300-7,500. The average monthly income of women respondents was around Rs. 1,850 per month, which shows that it is very difficult for an isolated woman to live independently, without any economic support. Ironically, there were instances of their money and property being snatched away after the death of the husband.

"After my husband's death, all I got was blame... and... harsh words."

- A woman from Maharashtra

The general perception was that women needed to be economically independent to feed themselves and their children, to buy medicines and so on. They had a great deal of worries about the future of their children.

4.4.2 Impact on children

Children are the future of this country. Yet the future of children whose parents are affected by HIV/AIDS appears bleak. Most children of infected parents faced discrimination. With infected parents, economic insecurity, discrimination and lack of facilities, their survival, health, development, education and safety are all in jeopardy. It was sad to note that about 35 per cent children were denied even basic amenities. About 17 per cent children had to take up petty jobs to fulfill the increasing monetary demands of the family.

Focus group discussions highlighted that in many cases children were compelled to support their families and were engaged in income-generation activities, where there was danger of developing bad habits such as alcohol or drug addiction. However, no substantial evidence was obtained on forced entry in child labour. Not just that – about five per cent children were deprived of basic education and were withdrawn from the school.

About 18 per cent respondents said their children were treated differently in the community due to PLWHA in the family. Of them, about 76 per cent children were neglected and isolated, they were not allowed to play with other children (10.8%) and were verbally abused and teased (8.1%).

Due to constant illnesses in the family, with either or both parents falling sick, some of the children were affected psychologically and their school performance

dropped. In many cases, children were shifted to cheaper schools due to economic constraints.

There were mixed responses regarding the impact on girl child as compared to their male counterpart. Half the respondents opined that boys and girls were equal in the context of impact of HIV. They supported this statement by saying that the danger from society in terms of child abuse was equal to both.

"I have nobody in the world. After my time, I am sure that my daughter will definitely be abused."

- A woman from Tamil Nadu

Others felt that the impact of having an HIV+ person in the family is more on the girl child. Since boys are traditionally favoured in Indian culture, when resources are limited, it is the girl child who is given less. In terms of treatment too, the girl child is often 'left to her fate'. When someone in the family falls ill, again it's the girl who usually has to take care and as a result her studies suffer. At the time of marriage too, girls are more discriminated against as compared to boys.

4.4.3 Support of the spouse

Husbands seemed to be supportive of their wives. In general, men expressed their concern for their wives. Unmarried males expressed their intention not to get married and infect another person. And, married men wanted to take all possible precautions to protect their wives. However, despite these sentiments what came through in the focus group discussions was that protection of spouse was applicable only in cases where the person had got to know his status either before marriage or before having unsafe sex with spouse after marriage. But in most of the cases, it was already much too late.

In cases, where the HIV status of wife was also positive, men were worried about the future of their children.

Women were even more supportive to their husbands. In general, it was observed that despite being infected by their husbands, most of the women had reconciled to the situation after initial negative reactions.

"Having experienced the harsh reality of being a wife of positive husband, we have come to a mutual understanding."

- A woman from Maharashtra

However, the attitude of the family initially was not healthy towards the infected/affected spouse. About 26 per cent of the respondents felt neglected and were isolated by the family. They were verbally abused (4%), asked to leave home (2%), and were physically abused (1%). In one case, property was taken away from the spouse of the infected person.

4.5 Experiences with employers

To earn a living and to be gainfully employed is a basic human right. However, HIV/AIDS-related issues seem to have an impact on hiring and firing policies, work allocation, pay and benefits, attitude of employer and other employees, promotion and employment security.

4.5.1 Attitude of the employer

Of the employed respondents, employers of 53 per cent people knew about their HIV status. It was quite heartening to note that about 74 per cent respondents received support from their employers. Of those who received support from employers, a majority were from Delhi (32.56%) followed by Maharashtra (18.75%). Moreover, it is worth mentioning that most of the employers who supported their HIV+ respondents were from NGOs/institutes working in the field of HIV and were sensitive to the issue.

In cases, where the employers were not supportive, the respondents had to face demotion or they had to search for a new job where they were supposed not to reveal their status to save their jobs. They had to use up their past savings, sell their assets, borrow from others and stop taking medicines.

The support was mainly in the form of medical expenditure (67%). It was one of the most important contributions from the employers because medicines cost a lot. This was followed by paid leave (7.69%). Some of the respondents mentioned that they received moral support from the employers, which was *invaluable* to them.

In case of non-support from the employers or in self-business, the infected persons had to meet their medical expenses on their own. About 34 per cent used their past savings to meet the increased expenditure. About 29 per cent had to borrow from the others. In some cases, it was so difficult to manage the increased expenses that they had to sell (4.6%) or mortgage their assets (2.78%). One respondent had to take a loan from his employer to meet his needs.

It was observed that NGOs are playing a significant role in this field. As many as about 17 per cent said that they received support from NGOs.

4.5.2 Discrimination at workplace

Stigma and discrimination was faced by PLWHA at every place and the workplace was no exception. About six per cent reported discrimination at the workplace. Out of them, no benefits were given to about 33 per cent respondents. Moreover, their promotion was denied (25%) and they were forced to take voluntary retirement (25%). For the others who faced no discrimination, the factors varied from their workplace being conducive, their employers being supportive, their co-workers were not aware of their status, to the fact that they were working in a network or in an NGO.

One respondent was forced to take voluntary retirement. One of the respondents was sacked after the disclosure of HIV status, though his/her employer was a medical doctor. It signifies that even highly-educated people are ignorant about the modes of HIV transmission. Interventions must be planned to change the existing behaviour of people.

4.5.3 Attitude of co-workers

The behaviour of co-workers is an important issue as one spends a major part of one's day with co-workers. Sadly, there were many instances of the respondents feeling neglected or isolated by the co-workers. Such indifferent behaviour forced respondents to change their jobs frequently (11.79%). These respondents changed, on an average, two jobs in six months. One of the major reasons for change/loss of jobs was ill-health of the respondent (61.54%). Some were also asked to quit their jobs (15.38%). About eight per cent respondents changed their jobs due to discrimination by their co-workers. One respondent was sacked.

4.5.4 Economic loss to infected persons

Some of the respondents were forced to take frequent leave from work due to different infections and illness. However, the period of absence from work varied from not taking a single day's leave to as high as six months' leave during the past six months. On an average, the respondent was absent from work for about 6.12 days in the last six months.

About 20 per cent of the respondents reported a loss in income due to their absence from work. The amount varied from Rs. 30 to Rs. 1,00,000 in the last six months. On an average, the loss in income was as high as Rs. 7,500 per person. The amount of fringe benefits lost varied from Rs. 300 to Rs. 10,000.

In case of unemployed respondents, daily expenses were met mainly through family (71.25%) and the support of NGOs (11.25%). One of the respondents received support from the community.

4.6 Economic impact

Monthly income of the respondents varied from Rs. 300-Rs.20,000. The average income of those respondents who were earning was Rs. 3,200 per month. The average monthly income of the respondents showed regional variations. It was highest in Delhi (Rs. 3,177.78) followed by Maharashtra (Rs. 3,017.19) and Manipur (1,545.67) indicating that respondents found more economic opportunities in Delhi as compared to other states. Sources of income were jobs, business or petty shops.

The monthly income of families of respondents varied from Rs. 500-Rs. 50,000 per month. However, the average monthly income of each family was as low as Rs. 1,117.31. About 20 per cent respondents reported that their family members were taking on additional work to compensate for the loss of income and time due to their illness. While some of the family members were doing jobs (73.33%), the rest had set up their own small-scale business. However, it was meeting only part of their increased expenses.

"I have sent my daughter to an urban home to do household manual work to support her and me."

- A woman from Maharashtra

The monthly household expenses on food varied from Rs. 300-6,000. On an average, food bills came to Rs.1,725.62. The monthly household expenses on clothing varied from Rs. 5 to Rs. 5,000, which meant an average expenditure of Rs. 263.99. The monthly expenditure on education varied from Rs. 45-Rs.4,500. On an average, about Rs. 257.28 was spent on education. Money spent per month on rent/accommodation varied from Rs. 25-3,300. On an average, this worked out to Rs. 266.12. The monthly household expenses on medicines varied from Rs.30-Rs.8,500, implying an average of Rs. 575.72 per person. The monthly household expenses on conveyance and entertainment varied from Rs.30-Rs.3000, which meant that it cost Rs. 285.63, on an average. Other expenditure varied from Rs.50-Rs.10,000, yielding an average of Rs. 427.41.

The total monthly expenditure varied from Rs. 235-Rs.30,503. On an average, this cost Rs. 3,185.81.

According to the infected persons, they would have earned better (about Rs.6,900 more) if they had been free of illness during the last six months. The amount that might have been earned varied from Rs.600-62,000, which could have made a remarkable difference in their economic conditions.

4.6.1 Before and after HIV detection

There were major differences in the expenditure before and after the advent of HIV in the family. Expenditure increased on basic needs such as food and medicines and people had no option but to cut their costs on entertainment and education.

Table 4.5: Average monthly expenditure before and after advent of HIV

Items	Average monthly expenditure before (Rs.)	Average monthly expenditure after (Rs.)	Average increase/decrease (Rs.)
Food	1862.40.	2212.50	+350.10
Medicine	444.09	912.09	+468.00
Education	333.33	166.67	-266.66
Entertainment	802.60	280.00	-522.60
Debts	-	-	4818.19

Expenditure on education decreased only in three per cent cases. It decreased from an average of Rs. 333.33 to Rs. 166.67. Expenditure on entertainment decreased in the case of 23 per cent respondents. It decreased from an average of Rs. 802.60 to Rs. 280 only. Of the graduate respondents, about 38 per cent reduced their expenditure on entertainment. Of the respondents who had only been to school, about 21 per cent cut their entertainment expenditure. Of the illiterate respondents, 20 per cent reduced their expenditure on entertainment. The data indicates that educated respondents were more concerned about their savings or expenditure on medicines and food and gave entertainment a secondary priority.

In 33 per cent cases, the expenditure on food increased. It increased from an average of Rs. 1,862.40 to Rs. 2,212.50. Expenditure on food showed an increasing trend with education of the respondents. About 47 per cent graduate respondents increased their expenses on food as compared to those who had only been to school (34.48%) or were illiterate (32.50%). It clearly indicated that educated respondents were more concerned about their nutrition and dietary requirements.

Expenditure on medicines increased in 38 per cent cases. It doubled from an average of Rs. 444.09 to Rs. 912.09. Expenditure on medicines also showed the same trend.

About 58 per cent graduate respondents increased their expenditure on medicines as compared to those who had only been to school (40.39%) or were illiterate (37.5%). It showed that educated respondents were more aware about the significance of medicines and were also able to afford them. The data showed that expenditure on medicines, in general, was higher than even the expenditure on food and to continue their medicines, the respondents had to make adjustments in their dietary requirements.

Debts of about 26 per cent respondents have increased. It increased on an average by Rs. 4,818.19. The increase in expenditure and decrease in income due to HIV-related causes has, thus, led to an overall increase in the debts of the respondents.

Mr. X, a 32-year old businessman in Delhi was earning Rs. 1,20,000 per annum. After a prolonged illness, he got himself tested and was diagnosed as HIV+ . He got married, without disclosing his HIV status to his partner. His wife was also tested positive. But their son proved to be HIV negative. As the couple gradually started showing symptoms, Mr. X could not continue his business. They were thrown out by their family and faced a financial crisis. This compelled Mr. X's wife to work. She started a boutique and earns about Rs. 5,000 per month. But their expenditure on food, medicines and rent amounts to Rs. 5,000. The couple is worried about the education of their child. Whenever Mr. X falls sick, Mrs. X has to take time out from her work, which leads to increase in expenditure and decrease in income.

(Excerpts from a case study of Delhi)

4.6.2 Medical expenditure

The cost of treatment of opportunistic infections varied from Rs. 50-35,000 in the last six months. The average cost was as high as Rs. 4,682.62 per person.

HIV-infected people have to go for regular check-ups of viral loads and CD4/CD 8¹ counts. But, in a country like India, such tests cost a lot. Only 45 respondents had

¹ T-Cell Analysis (CD4/CD8) - T-cells are a type of lymphocyte (white blood cell). They are an important part of the immune system. When HIV infects humans, the cells it infects most often are CD4+ cells. The virus becomes part of the cells, and when they multiply to fight an infection, they also make more copies of HIV.

undergone such tests. The costs incurred ranged from Rs. 20-Rs 46,000 during the last six months. The average cost on such tests was Rs.4,521.22 for one person during the last six months.

As regards anti-retroviral therapy (ART), it was observed that only 18 people were taking it. The cost of ART varied from Rs.800-Rs.8,000. The average cost of ART per person worked out to Rs. 3,156.78, which was almost three times the monthly income of families (Rs. 1,117.31) and clearly shows that affordability of ART is very very low.

Other general medical tests cost an average of Rs. 923.62, varying from Rs.50-Rs. 9,000.

4.6.3 Meeting the costs

A majority of the respondents felt that though treatment was expensive in private hospitals, it was much better than the government hospitals.

Many of them had experimented with Siddha therapy to cure HIV and had spent as much as Rs. 5,000 - Rs. 15,000 on this form of treatment, which ultimately proved to be of no benefit to them.

In addition to medicines, the other costs involved are general consultation fees, X-rays, other tests and travel expenditure. People managed these costs by selling their assets or taking loans. Many of them also received support, in the form of medicines, hospitalization, referrals and counselling, from NGOs and networks.

5. Conclusions and recommendations

The study clearly indicates that more and more HIV+ people are coming forward and many are also beginning to raise their voices through the networks on core issues concerning infected and affected people. The positive networks have thus helped in facilitating a supportive environment.

An encouraging trend was that more and more positive people are trying to mobilize infected people to fight for their rights and increase social acceptance. They are attempting to reduce the stigma associated with the illness and the consequent discrimination.

The findings show that a majority of the infected people fall in the highly productive and reproductive age-group. Thus, interventions should be developed for specific target groups. Intensive efforts should be made to reach out to the youth and lesser-privileged groups.

About 38 per cent respondents opted for voluntary testing. Among the eligible respondents, about 76 per cent said that they took precautions to protect their spouse, which shows that the respondents had a high level of awareness. This, however, needs to be intensified further.

Given the high costs of the epidemic, the need for preventive policies is generally accepted. Policymakers need to recognize that cost effective IEC (information, education and communication) must be well designed and target-group oriented. In addition to preventive efforts, government and non-governmental agencies should also emphasize the importance of proper diet, exercise, medication and healthy lifestyle to the infected persons. Medicines should be made available at highly subsidized rates, if not free of cost.

Family provides a vital social support to any individual. About 27 per cent respondents had other HIV+ member in their family. However, many respondents reported facing discrimination in the family. At the same time, after the initial rejection, about 88 per cent respondents were accepted by their families. Thus the role of family becomes very crucial in planning various interventions for HIV prevention, care and support.

The attitude of hospital staff towards infected persons was, in general, not healthy. In many cases, there was no one to take care of the sick in hospitals. Looking at

both private and government hospitals, services provided in government hospitals were better though there was more discrimination in government hospitals. Of the respondents who received counselling, about 68 per cent were tested at government hospitals. Government hospitals were also a lot more affordable. Therefore, existing structure in healthcare settings needs to be strengthened. In addition, referral centres and facilities should be made available. Orphanages and adoption centres need to be opened to take care of the affected children.

Having a job is very important for infected people. It gives them economic security, a sense of satisfaction and also keeps them occupied. It also helps them remain healthy for a longer time as they can then afford proper medicines and diet. About 29 per cent respondents were unemployed. Of the employed respondents, a majority of them received support from their employers in different forms. This was an encouraging trend but needs to be augmented more. Corporate sectors should be encouraged to absorb infected people. All corporate organizations have some social objectives in their agenda. They should be motivated to plan and implement employee welfare schemes and modify existing schemes. Government may introduce some incentives for such initiatives. Some HIV+ persons also suggested introducing income-generation schemes so that they could make themselves economically strong.

Policies should be made stringent so that HIV-infected persons are not thrown out of their jobs. There is a need to modify the workplace policies so that other family members can get the job during the illness/after the death of HIV+ persons. Policy options should also include ensuring access to education and basic health services; protecting inheritance rights of widows and orphans.

The study revealed how HIV has an adverse impact on women. About 47 per cent women were widowed. The responsibility of taking care of infected persons usually falls on women. The major group of care-takers was women. This highlights that not only do women have to take care of the ill, but they have to take on an additional responsibility of earning money while still doing the normal household chores.

The study has shown that close interpersonal interaction of NGOs with people has proved extremely useful. This can help in implementing behavioural interventions necessary for HIV/AIDS care and support and to shun discrimination. The study also highlighted the lack of counselling services at testing centres/hospitals. However, NGOs/networks often interact with the infected persons, which help them cope with their problems. This should be further strengthened.

There is an urgent need to encourage infected people and their families to come forward and voice their problems, so that they can be helped to lead a normal and healthy

life, without any imprints of stigma and discrimination. They need to be empowered to demand their rights. Discrimination at any level is a violation of human rights. Fundamental human rights are for everyone, irrespective of the HIV status. Hence, PLWHA should have the same rights as uninfected people to education, social security, health, employment, etc. They should not be deprived of their basic rights.

6. Case studies*

6.1 Maharashtra

Case 1: Kavita is a 22-year-old married woman from Pune, employed with an NGO. She has been living with HIV for the past one year. She got to know her HIV status in the seventh month of her pregnancy, during routine tests. However, no pre or post-test counseling was given to her. Her child is HIV negative.

Only close family members know about Kavita's HIV status. She is economically dependent on her husband whose salary is meagre. Her general health right now is fine and she is not under any medication.

Future concerns are:

1. Wants to be economically independent and earn a decent salary, so that she can easily afford anti-retroviral treatment.
2. Worried about the future of her child.

Case 2: Ms.Urmila is an educated woman from an upper-class Maharashtrian family. She had done her masters in social work with the intention of working as a counsellor. Urmila was married to a mechanical engineer who worked as a manager in a reputed firm. Life was going on comfortably at her in-laws' house, where she was pampered and well-looked after. But suddenly everything changed dramatically when she was diagnosed HIV+ during her fifth month of pregnancy. Soon after her husband too was tested positive for HIV. This was a period of acute depression for her.

Both husband and wife supported each other during the crisis, but due to lack of proper guidance by the doctors and lack of counselling, she delivered an HIV-infected child. Soon after, she also lost her husband. Since she was given a lot of misleading information about how to combat HIV she ended up spending a lot of money during her pregnancy.

After her husband's death, her in-laws did not support her. On the contrary, even as she was suffering from depression, they made her sign various documents and

* Names have been changed to protect the identities of the persons concerned.

took away her and her son's property rights. Her in-laws also struck off her and her child's name from the ration card.

Finally, she had to leave the house and go back to her parents who supported her. Today her son is being looked after by her parents in Mumbai.

Meanwhile, even as she was undergoing treatment for opportunistic infections in Pune, Urmila came in contact with an activist working with a network of positive people in Maharashtra. Today she too has joined the organization as an active member.

Urmila has joined a project which provides community care and support in the field of HIV/AIDS. She is a community health worker and is posted at one of the worst slum areas of the project.

Now, Urmila is trying to identify PLWHA in the slums so as to empower them and their families to fight for their rights. She wants to reduce the stigma and discrimination associated with the illness and increase social acceptance. The platform that she has got from the project has been a good opportunity for benefiting herself as well as the positive people who are working with her.

Future concerns

1. Worried about the future of her son.
2. Wants her property back.
3. Concerned as to whether her son would get anti-retroviral drugs.

Case 3: Rohan is a 27-year old graduate from Mumbai. He is currently working with two NGOs in Pune and is the sole bread-earner of the family.

Rohan came to know that he was HIV+ about five months ago. He was employed with an NGO that used to impart awareness about HIV/AIDS to people. One day, he realized that he should also go for an HIV test and got himself tested at a private clinic. To his shock he tested positive.

Only close friends and colleagues know about his HIV status. He has not disclosed his status to his family (mother and sister) as he feels they would be shattered. He is unmarried and the family is forcing him to get married, but so far he has managed to evade it.

Right now he does not have any HIV/AIDS-related symptoms, but sometimes feel tired after work.

Future concerns

1. How will the family react when they get to know his HIV status? What will happen to his mother and sister?
2. What will happen to his nieces and nephews who depend upon him for their educational expenses?

Case 4: Sunita is 30-year old divorcee from Mumbai. She has a background in nursing and is currently employed with a positive network in Maharashtra.

She has been living with HIV for the last four years. She came to know about her HIV status during the delivery of her second child, who was still born.

Her husband (HIV negative) was the first one to know about her HIV status, which he immediately shared with his family and friends. Only after 15 days was she told about her status. The hospital she was working with threw her away from the job.

Sunita takes Ciplin daily and has not had any opportunistic infections for the past six months. She never took the CD4 and CD8 tests as she cannot afford them.

Future concerns:

1. Lost her job, wants the same job again.
2. Feels that HIV/AIDS-related medicines should be given free to HIV/AIDS patients.
3. All HIV/AIDS persons should be made aware about healthy diet and about their health conditions.

Case 5: Shanti is a 30-year old married woman living in Pune. A B.Com graduate, she is currently employed with an NGO and is economically independent.

She has been living with HIV for the last eight years. Her first husband died of AIDS, which is why she underwent a test. However, no pre- or post-test counselling was given. After the death of her first husband, her in-laws forced her out of the house.

Her HIV status is widely known. Her family, friends and neighbours are all aware that she is HIV+. However, she has not disclosed the status to her house-owner for fear that he might throw her out of her rented house.

Her economic and health conditions are okay right now.

Future concerns:

1. She feels that later, when she might need it, she would not be able to afford anti-retroviral drugs.

2. People are dying of HIV/AIDS without any treatment since they cannot afford treatment.
3. Uncertain about future.

Case 6: Amit is a 34-year old former hotel employee based in Mumbai. He got to know about his HIV status when he was admitted to the ESIC hospital with a severe backache. The doctor conducted tests without consent from him and Amit was diagnosed as having HIV. Later his discharge card (routine health card) was submitted to the hotel where he was working. He was declared unfit for heavy and strenuous work and was promptly sacked from the hotel. After that he was unemployed for quite sometime.

Amit is now working with an NGO. His health is fine. He is working hard to earn a decent livelihood. He is supporting a younger brother who is fully dependent on him.

Case 7: Madhavi is 23-year-old widow from Pune. She lives with her parents and is studying. Side by side she also works for an NGO in Pune.

Madhavi has been living with HIV for the past four years. She was asked to undergo an HIV test when her husband was found to be positive. Her HIV status is known to friends, family and the college where she is studying. However, she has received support and encouragement from her family and friends.

Right now her health is alright. She has never tested for CD4 and CD8 and has not taken any medicines so far.

Future concerns:

1. Accessibility to anti-retroviral drugs.
2. Reduction in discrimination and stigma towards PLWHA.

6.2 Tamil Nadu

Case 1: Snehlata is a 28-year old widow based in Chennai. She has studied up to 11th standard and is currently employed with an NGO as an HIV/AIDS activist.

She has been living with HIV for the last seven years. She took the HIV test after her husband tested positive. And, her husband became aware of his status only after suffering from prolonged illness. Once his status was known, she was also advised to take the HIV test.

Snehlata's HIV status is widely known. Yet, she has received support and encouragement from her family and friends. Being part of a network of People Living with HIV/AIDS (PLWHA) has filled her with a sense of reassurance and developed positive attitudes towards life.

Snehlata works as a co-ordinator for a PLWHA network. She is on anti-retroviral drugs, supported by a care-agency for some of her treatment. But her economic status restricts her from going in for more treatment.

Future concerns are:

1. Access to drugs at an affordable cost.
2. Facilitate a supportive environment for PLWHA.
3. To obtain property that she is entitled to, from her family.

Case 2: Radha is a 27-year-old unemployed from Namakkal. She is supported by her husband and the two live with her parents. She has a 7-year old boy who is HIV negative.

She has been living with HIV for the past 5½ years. Her husband discovered that he was HIV+ when he went for voluntary testing. He refused to accept his status, however, and visited a quack in Kerala for treatment. At this point, Radha too went for an HIV test and was tested positive. Her husband, however, refused to accept his status and went for tests nearly three times before finally coming to terms with his HIV status.

Radha is quite visible as an HIV+ person. Her family, a few of her relatives, a few neighbours, some NGOs working in the district hospital staff of the local government hospital, the network of positive people, etc., are all aware of her HIV status. However, she has not revealed her status in public. But she says she wouldn't mind revealing her status to media anytime, if necessary.

Currently her economic condition is not good. Her father provides her with some money whenever needed. She generally keeps good health and does not suffer from any opportunistic infections.

Her future concerns are:

1. She is extremely worried about her economic dependency. Today, her father supports her. What will happen tomorrow?
2. She needs to find a job to sustain herself.

Case 3: Reshma, 31, is married with two daughters – the elder one is nine, while the younger is five – and lives in a nuclear family. A graduate, she is employed and lives in Chennai. Reshma earns about Rs.4,000 a month and the total family income is Rs.10,000. She has been working as an Advocacy Manager for the positive network for the last three years.

She was diagnosed as HIV+ about four years ago. At first, her husband discovered his status, when he was falling sick frequently and was advised by his family doctors to take the test. Three months later, Reshma too took a test and found that she was HIV+.

Her HIV status was first revealed to her parents. A few relatives also have got to know her status from her parents. One of her friends and co-workers also know her status.

She is visible as an HIV+ person to some extent but has not faced any discrimination so far.

She feels her current economic status is fine. But she is concerned that half her salary is spent on medicines and on children's education. She feels healthy, her CD4 count is 200 and the doctor has advised her to start ART.

Future concerns:

1. She is worried about her daughters' future. Today, she and her husband can take care of them but what will happen to them once they are unable to earn.
2. She hopes to gain wide social acceptance.
3. Access to anti-retroviral drugs is one of the concerns she expressed.

Case 4: Ratna is a 30-year old woman, separated and living alone in Chennai. Her husband looks after their six-year old daughter. Ratna holds a Bachelor of Science degree, a Masters in Public Administration and currently works as counsellor in the Positive Women Network. She earns about Rs.4,000 a month and had been working with the positive network for the past three years.

Ratna has been living with HIV since the last four years. She came to know of her status while donating blood for an emergency case at the hospital where she worked as a lab technician. She did her own HIV test. Soon her husband revealed her status to the community, her relatives in her home town and the government organization where she worked. As a result, she lost her job and experienced severe negative reactions from her family. Now, since she is part of the network, she is open about her HIV status and has gone public in voicing issues affecting PLWHA. This has facilitated a supportive environment and helped in self-empowerment.

Since she stays alone, her current income satisfies her basic needs. Additional expenditure on medicine, tests, etc., pose a burden and affect her physical and mental health.

Future concerns:

1. Access to ART is the main concern.
2. She longs to join her husband and daughter.

Case 5: Prabha is a 21-year old unmarried woman from Erode district of Tamil Nadu, who works with the positive network for women. She earns a monthly salary of Rs. 3,000.

She has been living with HIV for the past two years. She was tested positive while undergoing a surgery for tonsillitis. She was then referred to another district hospital for confirmatory tests. The remarks made by the hospital staff about her HIV status made her feel very ashamed. So, without the knowledge of her parents, she went for voluntary HIV testing and was found to be positive.

She is open about her HIV status among the network members. She has not revealed her status to her parents since she feels it will cause them pain. This has caused some problems for her as they want her to get married. Her co-workers and the network have been very supportive and have instilled in her a positive outlook.

She works in a district-based network as a co-ordinator. The income earned does meet her basic requirements but is not sufficient to obtain other treatment facilities.

Future concerns:

1. To reveal her HIV status to family members.
2. Get married.

Case 6: Shanti is a 27-year-old widow from Chennai. She is employed in the network of positive women and earns Rs. 4,000 a month. Shanti lives with her parents.

She has been living with HIV for the past six years. After a prolonged period of sickness, her husband was tested for HIV and was found to be positive. At this point, he took her for an HIV test as well and it was found that she was also HIV+.

Shanti's HIV+ status is public to a certain extent. Her family, a few of her relatives, one of her friends and co-workers know about her HIV status. She does not mind revealing her status as and when needed.

Since she lives with her parents and also earns a salary, her economic status, as of now, is fine. But she can't depend on her family forever and, therefore, requires a

permanent job in the future. She keeps good health now without any opportunistic infections. However, she suffers from kidney stones, which is painful.

Future concerns:

She is worried about her economic status. She needs to ensure a good stable job with reasonable salary so that she doesn't have to suffer without money in the future.

6.3 Delhi & Manipur

Case 1 - Delhi: Mrs N got married for the second time in 1998 after her first husband abandoned her and their son. She and her second husband, a reformed drug addict, took up a room in Neb Sarai, where they lived with the child. The couple worked at a Care Centre as care workers, looking after the sick and taking care of their needs.

Soon, the couple got to know that they were HIV+ . After they got to know their status, they decided to get their child also tested and discovered he too was positive. Though they disclosed their HIV status to friends and co-workers in Delhi, they didn't reveal this fact to their family. In fact, soon after her marriage, when Mrs. N visited her husband's family in Kolkata, her brother-in-law and sister-in-law were full of praise for her for transforming him from a drug addict to a sober person.

In early 2002, their child developed a liver infection. For two months he suffered from Hepatitis and expired on June 22, 2002. After the death of the child, the couple went to Kolkata again to visit their relatives. While there, Mrs. N frequently got fever, yet refused to consult her in-laws' family physician as she didn't want them to know about their HIV status.

As a care worker, herself Mrs. N's husband earns a salary of Rs. 3,000 per month, while she herself earns Rs. 4,000 from her job as a care worker in Care Home. The total earnings of the couple amount to Rs. 7,000 a month. Of this, they spend Rs. 3,500 on food and Rs. 500.00 on nutrition and diet. About Rs 1,500 is spent on accommodation and rent, while the expenditure on general medicines for a month is approximately Rs. 600.

Mrs. N is keen to have another child, especially since her in-laws keep pressing her, but for this she needs financial support. "At present, we have no major problems, we are receiving care and support from NGOs. But I'm worried about my future; I'm really worrying about where to get money for anti-retroviral therapy (ART) for me and my wife," says Mrs. N's husband, adding: "If I had

enough money to buy ART for my deceased son, things might have been different!”

Key concerns:

1. Arranging finances for ART.
2. Would they be able to have a normal child?

Case 2 - Delhi: Mr. K was born and brought up in Delhi. The 42-year old works as a supervisor in a public sector enterprise, and is staying with his wife, two daughters and son.

In 2000, he had a sudden attack of diarrhoea and lost a lot of weight. After consulting his family doctor, he took an HIV test and was shocked to find he was positive. At first when he learnt about his HIV status, he was depressed and believed he would be able to live for only a year or two. He did not disclose his HIV status to anybody except his wife, whose initial reaction was anger. But, in due course, she became reconciled and was supportive.

Mr. K was constantly plagued by the fear that his virus would develop into a full blown case of AIDS. Because of this fear, he was extra careful and took his CD4 and CD8 test every six months. Altogether, he has spent Rs. 10,000 on his CD tests so far. At first Mr. K did not know about the testing facilities for HIV/AIDS. As a result of this, when the doctors in AIIMS sent him to a private laboratory for his CDs test, he spent about Rs. 1,500 per test. He was shocked to learn that the test was available at AIIMS itself.

Though he knows he can get some kind of benefits from his company, he has not disclosed his HIV status to his employer or co-workers due to the fear of stigma and discrimination. As a result, he misses all the benefits.

Mr. K's monthly income works out to Rs. 8,000 (after all the deductions). He stays with his wife and children in his own house, so he has no expense on rent and accommodation. However, he spends about Rs. 3,000 per month on his children's education and approximately Rs. 600 on general medicines. Other expenses include food, clothes, conveyance, entertainment, etc.

After getting in touch with the Positive Peoples Network he came to learn more about HIV and AIDS. He is living in the hope that, one day, medical science will provide an answer to the common question of a cure for AIDS.

Case 3 – Delhi: Mr. Z is 31 years old. He came from Myanmar to India in 1991, while his three brothers stayed back with his parents in Myanmar. He had studied up to 10th class in a Myanmar school but could not continue his education due to early drug abuse. For the last 15 years he has been an injecting drug user.

It was only in 2001, when he suffered from tuberculosis, that he came to know about his HIV status. He believes that he must have acquired the virus by sharing injecting equipment. ELISA and Western Blot test were used for the diagnosis.

“When I discovered my HIV status as positive, it was like a heavy blow. Since I didn’t have much knowledge about HIV/AIDS, my first reaction was that I was going to die very soon. Later, I came to know that there were medicines to control the virus,” he says. Mr Z also stresses that positive living/thinking is very important for a person who is HIV+.

At present, he has disclosed his HIV status to only a few of his close friends. He does not want to let his family know about his HIV status. As he is undergoing rehabilitation in a Care Centre, he has no income sources. His medical bills for the past nine months when he suffered from tuberculosis were borne by the Care Centre.

“The main concern for my future is how I am going to get the money for ART. I need a job to finance my needs,” he says.

Case 4 - Delhi: “I first started taking drugs when I was only 16 years old. This was in Churachandpur. At that time I had heard about HIV/AIDS through posters and banners. Though I was aware of HIV and AIDS, because of my ignorance and stupidity, I never tried to get more information about it.

“Before completing my college, I approached a rehabilitation centre for drug abuse. During my rehabilitation programme, a friend of mine who is from Jerusalem offered me a chance to go to our native land Israel. At that time everyone in the community came to know about my addiction and I couldn’t hide it from anybody.”

“I joined the Synagogue Prayer Services for three months after my stint at the rehabilitation centre. I had completed all the necessary rituals and got all the required materials ready for the trip. But some of the community leaders were suspicious that I might have the HIV infection. So, they introduced a policy of mandatory HIV testing for people who had indulged in high-risk behaviour. In order to make sure that I was fit enough to get a visa for the Holy Land, I went for the test at one of the Testing and Counselling Centres in the town. The result was declared on the same day and unexpectedly I was told that I had tested positive for HIV.”

"From that day onwards, everyone would stare at me in the Synagogue and discuss my drug addiction. The level of discrimination towards me became intolerable. No one wanted to sit next to me on the same bench, no one dared to drink water in the glass that was used by me."

"With the support of an NGO in Churachandpur, I was sent to Delhi to attend Hands-on-Care training course in Michael's Care Home. There I came to know about network of positive people and by joining their weekly meetings and other activities I came to know that I was not the only one infected by this particular virus. At the same time I also came to realize that being tested positive for HIV was not the end. There were still lots of things I could do with my life. From that moment, I came to accept myself as who I was, and kicked off all my negative attitudes and thinking about life."

"I was the only son with four sisters in a family. My father was a jobless alcoholic. My mother was the breadwinner of the family. She could hardly manage to earn enough to meet our household expenditure. As I was the only and eldest son in the family, all the members turned towards me with trust and hope."

"But, two years ago, when they learnt about my drug addiction, they lost all hope in me. I never saw a smiling face inside the house, none of the family wanted to talk or trust me. I lost all the enjoyment and happiness I once had with the drugs. Everyone seemed to avoid me and I felt totally alone."

"Now, after finally kicking the drug habit, I have been able to earn the trust and love of my family. But, this doesn't give me any satisfaction, especially as I have learnt about my HIV status. As I don't want to lose my family's love and trust for the second time. I have taken a firm decision not to disclose my HIV status to them. Though I personally have accepted my positive status, I have a strong feeling that my parents will not be able to accept it."

Case 5 - Delhi: Thirty-two year old Mr. X lived in a joint family, with his parents and two brothers. He was a businessman, earning approximately Rs 120,000 per annum, which was a good source of income for the whole family.

In 1994, he suffered from a prolonged illness as a result of which he lost a lot of weight. Upon consulting a doctor, he was told to undergo a blood test for HIV and was diagnosed as positive. In 1996, he got married and did not disclose his HIV status to his wife. Due to lack of proper information and knowledge, the couple indulged in unprotected sex. Shortly thereafter, his wife also tested positive for HIV. This was when she learnt about Mr. X's status.

As they started showing symptoms, the couple became worried. They were also unable to take a clear decision on whether to have a child or not. But after consulting a homeopathic doctor, they were filled with hope and decided to have a child by following the prescribed therapy. As a result of this, Mrs. X got pregnant and delivered a healthy boy who was tested negative for HIV. Today, the boy has already celebrated his third birthday and is in good health.

Meanwhile, as the couple started showing symptoms and frequently falling sick, Mr. X was forced to leave his business in 1999 and became worthless for the family. When the family learnt about the couple's HIV status, they began discriminating against them. Mr. X and his wife were subjected to a lot of ill-treatment. Mrs. X's expensive jewelry was taken away by her in-laws. Even the child was not spared and was not allowed to share the household amenities. The other children in the family were warned to keep a safe distance from him. Finally, the couple was told to leave home. This created a financial crisis for them, compelling Mrs. X to start an enterprise in order to support the family.

After working hard for sometime, Mrs. X managed to earn about Rs 5,000 a month from the boutique she had set up. Yet it wasn't enough to meet ends. They incurred a minimum expenditure of Rs. 3,000 for food, Rs. 1,000 for medicines and Rs. 1,000 for power and rent every month. This left nothing for their son's education, a cause that caused them deep concern.

After all the trials and tribulations they have faced, there's a ray of light. Their neighbour is caring and helpful, and provides them with moral support. The people in the neighbourhood too empathize with Mr. X and his family.

Now, Mr. X has begun falling sick frequently. As there is nobody else in the family to take care of him but his wife, she has to take time off from her work often – in other words, a decrease in her income. She fears, how long will she be able to bear her responsibility as a caregiver and a breadwinner? Who will look after the boy after their death?

Case 6 - Delhi: Thirty-five year old Shyamal lives with his wife and two-year old son. Currently, he works as a counsellor in an NGO working in the field of HIV/AIDS.

Shyamal lost his mother when he was barely eight years old. After her death, he lived with his younger sister and father, who ran a provisional store in Kolkata. He completed his graduation from Calcutta University in 1979.

After the death of his mother, his father started having affairs with different women in the locality. This caused friction between Shyamal and his father, so much so that

in 1980, his father threw him out of the house. Shyamal then went to Bombay where he set up a successful textile business. About 3-4 years later, he went to Gujarat, where he met Sapna, whom he married in 1997. After marriage, the couple moved to Delhi.

In 2000 Shyamal fell seriously ill and was admitted to the Safdarjung Hospital. Here it was diagnosed that he was HIV+. Around the same time, his pregnant wife was admitted in the same hospital where she delivered a boy. Shyamal believes that he contracted the virus through sexual contact. During his stay in the hospital, he met a counsellor who told him about care home and its support structure. After his discharge from Safdarjung hospital, he was admitted to care home with pulmonary tuberculosis. He remained here for 10 months after which he was discharged. He started anti-retroviral treatment from July 2001 under the prescription of Dr. Lal Thangsing. From that time he started working as a counsellor in an NGO.

Meanwhile, Sapna, his wife, had got admitted to care home, where she found she too was HIV+. After that she began working for an NGO as a 'care-taker' in a programme for infected children. But in 2001, she began showing symptoms of AIDS and had to stop working. As a result, the couple's finances were badly affected. Shyamal could not continue taking medicines because of the shortage of income. Now, he urgently needs some kind of external support for the medication.

Case 7 - Delhi: Q is currently staying with his wife and two sons. His elder son is three while the younger one is just two months old. Before he was identified as HIV+, he was staying with his parents and two younger brothers. He was working on a contract basis in a marketing firm.

Q came to know about his HIV status in October 2000 after he had a prolonged attack of tuberculosis and was advised by a doctor to undergo a test. The doctor disclosed his HIV test result in front of his brother and father, which shocked them. Later, his wife and two children also underwent HIV tests but tested negative. Earlier, he never took any kind of precautions, but upon learning his status he was advised to restrict sexual contact and had limited sex with his wife.

When Q was diagnosed as HIV+, his first child was already born. All the family members, except his in-laws were aware about his HIV status. He reports that he began experiencing discrimination and stigmatization from his family members as soon as they got to know his status. They started to keep his glass, plates, clothes, etc. separate, and he was given a separate bedroom. Apart from his wife and children, no one else in the family would talk to him. Though his wife and children tested negative for HIV, they were discriminated against as well. His wife was verbally abused and

given so much household work to do that she did not get any time to pay attention to the children.

As soon as Q recovered from his illness, the couple was asked to leave home. As they did not receive any monetary help from his parents after moving out, Q's wife had to take on the role of caregiver. Although she did not take up any additional responsibilities of job, she began doing all the chores that was normally handled by him when he was well, such as purchasing of household rations and requirements, etc.

As Q had no employer support, he tried to manage with his savings. Occasionally he stopped taking his medicines when there was a shortage of money. During the last six months he has not worked for three months and has had to forego emoluments worth Rs. 18,000. Although his was not a permanent job with benefits, there was considerable side income on job contract assignment work, where he could have earned as much as Rs. 18,000. During the last six months he has changed his job twice due to frequent illnesses.

Q spends Rs. 1,500 per month on food and Rs. 1,000 on rent. As the children haven't started their schooling, there is as yet no additional burden of educational expenses. He spends Rs. 3,000 on medicines every month, and nothing on entertainment, conveyance etc. According to his estimate, he would have managed to earn at least Rs. 36,000 if he had been free of sickness during the past six months. So far, on opportunistic infections he has spent about Rs. 10,000, mainly from his own pocket.

Case 8 - Churachandpur, Manipur: Mr. Y is the second son of a retired church worker in Churachandpur. He has three sisters and a brother. His brother, a drug-user, was married in 1989 and had three sons with his wife.

In 1996, Mr. Y's brother started falling sick frequently. He kept getting hospitalised but was discharged by the authorities even when he showed no improvement. There were no proper follow-ups by the hospital either. The doctors who attended to his brother told the family members that they would not be able to treat him and said that they had already done all they could. Strangely enough, they never mentioned the reason for his deteriorating health. This negligence by the medical team prevented the family from seeking further treatment.

In 1997, Mr. Y's brother died. At this point his parents asked him to marry the wife of his deceased brother and to take on the responsibility of bringing up her three children. With his parents constantly exhorting him to show some humanity

towards the children, he finally yielded and agreed to accept his sister-in-law as his wife.

But just two years after his brother's death in 1999, the youngest son of his deceased brother started showing symptoms of AIDS and died. That is when Mr. Y's parents realised that their son must have died due to AIDS. They blamed the doctors for not informing them about his HIV status. As Mr Y says bitterly: "If the doctors had done their duty of informing the patient's partner or spouse, I, as a third person, might not have been infected. This is really negligence of duty."

Meanwhile, Mr. Y's wife delivered a lovely daughter. But the couple was consumed with anxiety about the HIV status of their new born-child. In November 2001, they conducted a test and were shattered to hear that she was HIV+ . They sought treatment for the baby but were unsuccessful. On 15 January 2002, Mr. Y's wife died leaving him to look after the children.

Now, Mr. Y and the surviving children are living with his old mother and father. Mr. Y earns daily wages ranging from Rs 30-50 through manual labour and is the main breadwinner of the family. His father gets a pension of Rs 500 a month. Their household expenses on food alone is approximately Rs. 2,300 per month. For medical and other expenses, which work out to Rs 300 per month, they have to constantly borrow money.

Mr. Y is already experiencing the difficulties of managing a family, which has four HIV+ members, with his meager daily wage earnings. Not only does he have to earn enough to feed the family, but he is also the sole caregiver when any household member falls sick. And, this is a frequent occurrence, forcing him to keep away from work. Thus, there is no chance of increasing his income. On the contrary, the family income decreases.

Although the local community is aware of the condition of Mr. Y and his family, they do not help him out. Instead, they have begun avoiding and isolating them, especially in public places or in ceremonies. According to them, the terrible things happening to Mr. Y's family was the sign of the wrath of God, perhaps because one of their forefathers must have committed an evil act in the past.

On the other hand, there are some people who have accepted HIV/AIDS as a part of life and have come forward to help Mr. Y's family. But due to mass poverty and lack of resources in and around the town, they are unable to help him more. Especially, as his family is not the only one facing this kind of crisis in Churachandpur as well as the region.

As time went on, Mr. Y found other positive people in different corners of Churachandpur, who have faced the same problem that he has currently faced. His meetings with the other positive people in the area have helped him become more positive towards life and brought home to him the advantages of being a member of a positive network.

Now, it's a challenge for him to carry out his duty as the only son of a family. But it's hard to imagine what his family's situation will be when Mr. Y reaches the symptomatic stage.

7. State report: Assessing the Socio-economic impact of HIV/AIDS in Delhi and Manipur*

7.1 Introduction

7.1.1 Background

Given the debilitating impact of HIV-related illness on the economic conditions of affected people, it was imperative to conduct a study to assess the problem. And who best to undertake the study than the affected people themselves.

Thus the ILO contracted the Delhi Network of Positive People (DNP+) to undertake a study to assess the socio-economic impact of HIV/AIDS on families of people living with HIV/AIDS (PLWHA). DNP+ collaborated with the Manipur and Churachandpur networks of HIV+ people for the study in those areas.

The advantages of working with DNP+ are the following:

- It's a network of positive people. All the members of the network are HIV+ .
- Most of the HIV+ remain socially invisible in order to protect themselves and their families from possible social ostracism. It would be easier for members of a positive network to contact and interview other members as well as other HIV+ in the community. The access to the affected families also becomes easier.
- Since the interviewer is from within the network and a positive person, he or she would be more sensitive to the issue, making it easier for him or her to elicit the required information.
- The study is unique in the sense that it involves the networks itself to examine its own issues. This, in a sense, would provide the insider's perspective on the issue.

7.1.2 Profile of DNP+

A group of HIV+ people formed and registered a trust in November 2000 and named it The Delhi Network of Positive People (DNP+). DNP+ aims at improving the quality of life of PLWHA through its network. It provides authentic

* Study undertaken by DNP+ in collaboration with MNP+ & CNP+ with support from ILO.

information to anyone who has any doubts about HIV/AIDS and counsels positive people and their families. Currently, the Delhi Network of Positive People has 43 HIV+ members. DNP+ provides emotional and psychological support to its members through its bi-weekly meetings, where all members meet and discuss events of the past week, plan for the coming week as well as look into individual problems and find solutions. This is the core activity of DNP+. Apart from this, DNP+ also helps positive people in other regions of the country to set up their own support group. For example, DNP+ encouraged the PLWHA in Churachandpur, Manipur to form their own network, the Churachandpur Network of Positive People (CNP+).

This study initiated by the ILO has provided an opportunity to the positive networks to enhance their organizational skills in attempting to understand the issues in a collective manner. The study also provided hands-on experience in conducting research studies and reporting the findings, which will help in capacity building in order to undertake similar activities as and when required.

7.1.3 Objectives of the study

The study has two main objectives:

1. To document the overall experiences of PLWHA and their families ever since the discovery of HIV status. (Stigma faced, impact on employment status, family income and expenditure, availability of care and support services, etc.)
2. To understand the impact of HIV/AIDS on women and children.

The specific issues to be studied were:

1. The time and manner of discovery of HIV status of PLWHA and the efforts made to protect the spouse/children from getting infected.
2. The impact on women of the affected households, in terms of additional responsibilities taken to support the family, attitude of family elders towards the woman and the special impact on girl child.
3. The impact on children in terms of denial of education and other opportunities, forced entry into child labour, etc.
4. The overall impact of HIV/AIDS on families of PLWHA, including problems faced due to stigma and discrimination.
5. The differential impact on families where the main breadwinner has the support of his/her employer versus those who had to lose their jobs because of their HIV status.
6. Cost incurred on treatment of opportunistic infections.

7.2 Methodology

The methodology of the study was quantitative as well as qualitative. The instrument/questionnaire was developed in consultation with the PLWHA networks and field-tested before implementation. For the qualitative information, guidelines for focus group discussions and in-depth interviews were developed. A three-day comprehensive training programme was conducted for the investigators in New Delhi, which was coordinated by the networks with technical support from the ILO. Essentially, the investigators were trained to implement the research tools so that a standard method for the study across all the sites could be evolved.

The fieldwork was conducted between March and April 2002. While DNP+ collected data from Delhi, the Manipur Network of Positive People did so from Imphal and Churachandpur.

The research teams comprised people from the local network who could speak the local language and had an understanding of the local culture. Care was taken to ensure that there was a fair mix of both male and female investigators as it was felt that respondents would be more comfortable dealing with their own sex. The fieldwork was coordinated by the ILO, which also provided the technical direction to the study.

7.2.1 Sample selection

The sampling framework was purposive. The study covered 50 respondents from each of the study sites — New Delhi, Imphal and Churachandpur. The respondents were drawn from families of people infected by HIV/AIDS and the PLWHA themselves.

The sites were chosen with careful deliberation, as these were places categorized as high-prevalence areas. In Delhi, the major mode of transmission was through heterosexual contact while in Manipur the major mode of infection/transmission was through injecting drug use.

An effort was made to include sufficient number of women and children as respondents in the study so as to understand the impact on these categories.

7.2.3 Analysis and report writing

After all the data was collected, the analysis was done by Sahara (an NGO working in the field of drugs and AIDS for the last 23 years). SPSS and Epi Info (an epidemiological statistical database developed by the Center for Disease Control, USA and the World Health Organization) was used as the platform for the data analysis.

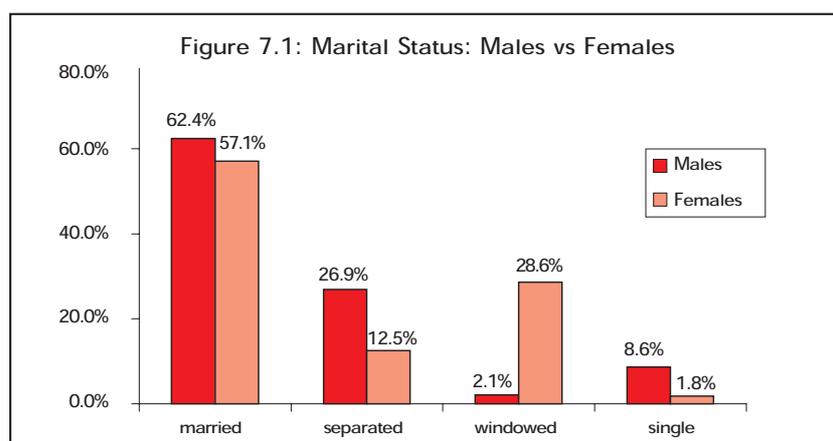
The data was cleaned, coded and analysed. Cross tabulations were done to further probe into the impact of HIV infection on families. Key findings were shared with the investigating team to confirm trends.

7.3 Key findings of the study

In all, 150 people living with HIV/AIDS were interviewed. However, one of the response sheets was damaged and had to be discarded. Thus, the effective sample size was 149 households from New Delhi, Imphal and Churachandpur, involving PLWHA and families affected by the virus, where either a member was HIV+ or had died due to related causes. Out of these 149 respondents, in 11 cases members of the household were also interviewed along with the positive persons. We have referred to them in the study as affected interviews. Apart from these cases, four members of the field investigation team were also interviewed to get a clearer picture of the ground reality.

7.3.1 Socio-economic background

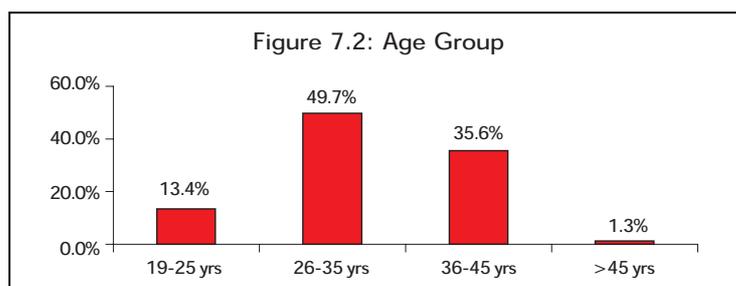
Of the 149 respondents, 28.9 per cent live in Delhi, 30.3 per cent in Imphal and 40.8 per cent in Churachandpur. Around 62.4 per cent of these respondents were still living in the same place since birth while 37.6 per cent of the respondents had migrated from their place of birth. For 53.5 per cent of those who had migrated, it was a question of livelihood that forced them to make the shift, i.e. 48.1 per cent came either because their work brought them or to look for work and 5.4 per cent migrated because of business reasons. Around 20.8 per cent of the respondents lived in rural settings, 18.1 per cent in semi urban areas and 61.1 per cent in urban areas.



Out of the 149 respondents, 62.4 per cent were male and 37.6 per cent were female. Of the 93 males, 62.4 per cent were married, 26.9 per cent were separated and 2.1 per cent widowed. Of the 56 females, 57.1 per cent were married, 12.5 per cent were separated and 28.6 per cent widowed (Figure 7.1).

Most of the respondents (87.9%), had at least the basic formal education with only 12.1 per cent stating that they had never been to school. Around 55.7 per cent had attended secondary school and 18.1 per cent were graduates.

As shown in Figure 7.2, the age group of the PLWHA was around 19–62 years with the mean age of the sample group being 32.9 years. Around 85.3 per cent of the respondents were between the ages of 25 and 45 with only about one per cent older than 45 and 13.4 per cent younger than 25 years.

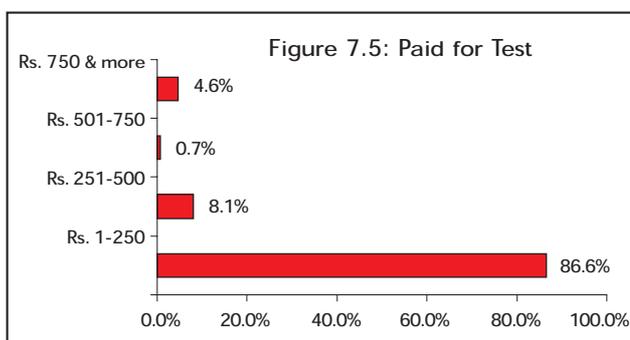
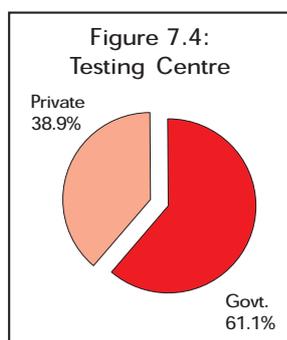
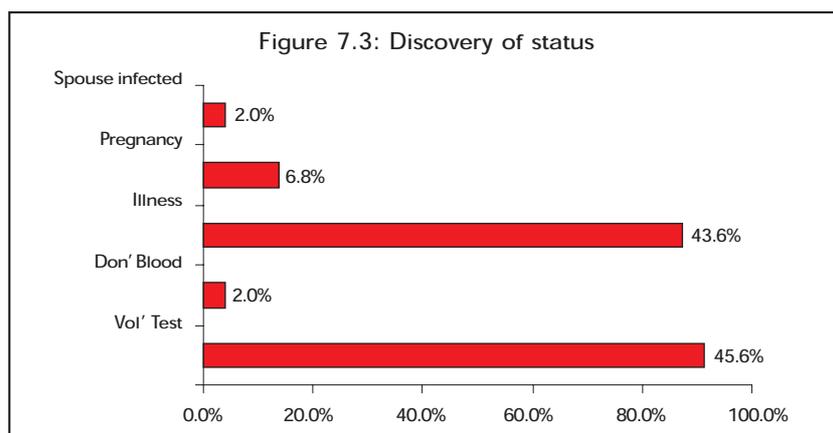


Around 49 per cent of the PLWHA lived in a joint family with their parents and spouses, 37.6 per cent lived separately with their spouses, while only 13.4 per cent chose to live all alone. About 28.9 per cent of the respondents were unemployed, four per cent had jobs in the public sector, 25.5 per cent worked for private firms and 41.6 per cent indicated that they had their own businesses. Various case studies indicate ill health as the primary cause of unemployment.

7.4 Information on HIV/AIDS status

The study instrument was designed to learn about PLWHA and the section on HIV started by asking how the concerned PLWHA had discovered his/her status. About 45.6 per cent had, perhaps, a doubt in their minds as they had voluntarily got themselves tested. However, it was not apparent what prompted these respondents to go in for voluntary testing as they did not disclose the reason they went in for the tests. Around 43.6 per cent had suffered from a prolonged illness and being symptomatic had been advised to get their HIV test done. About seven per cent had gone for the HIV test during pregnancy and discovered that they were HIV+, and

two per cent had discovered they were HIV+ while donating blood. Another two per cent said that they found out they were HIV+ because their spouses had tested positive (Figure 7.3).



Around 61.1 per cent were tested at government testing centres while the rest, 38.9 per cent, of the respondents were tested at private testing centres (Figure 7.4). Only 60.4 per cent had received pre-and-post test counselling and 82.6 per cent said the HIV test was free while 17.4 per cent had to pay for their test (Figure 7.5).

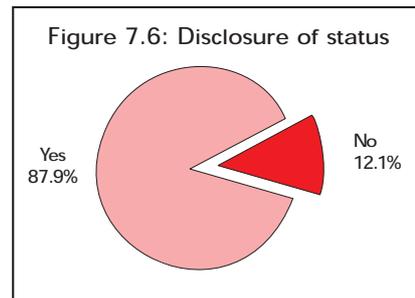
"I was at the rehab centre for detoxification. A team from ICMR came to our centre and took blood samples. After one year we were told of our status."

Assuming that government testing centres are free and private testing centres charge a fee, we probed deeper to find out why, though 38.9 per cent had tested at a private testing centre, only 17.4 per cent had paid for their tests. The explanation given was

that some of these respondents had tested at private centres with the reference of local NGOs who had paid the testing charges for them. The cost of HIV testing on an average is around Rs. 250.

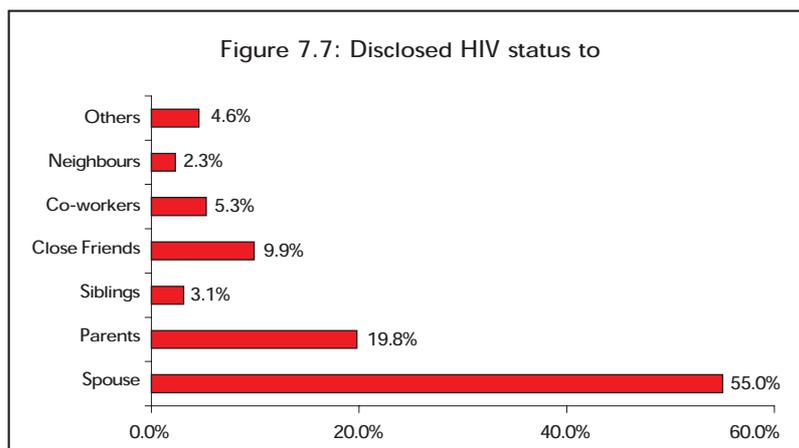
7.4.1 Disclosure of status

The next few questions looked at the dynamics of the relationship between the PLWHA and the society he/she lived in after testing HIV+. The 149 PLWHA were asked about the reaction of their families, friends and the community as a whole to their HIV test results and the effect of the disclosure of their HIV status on their life.



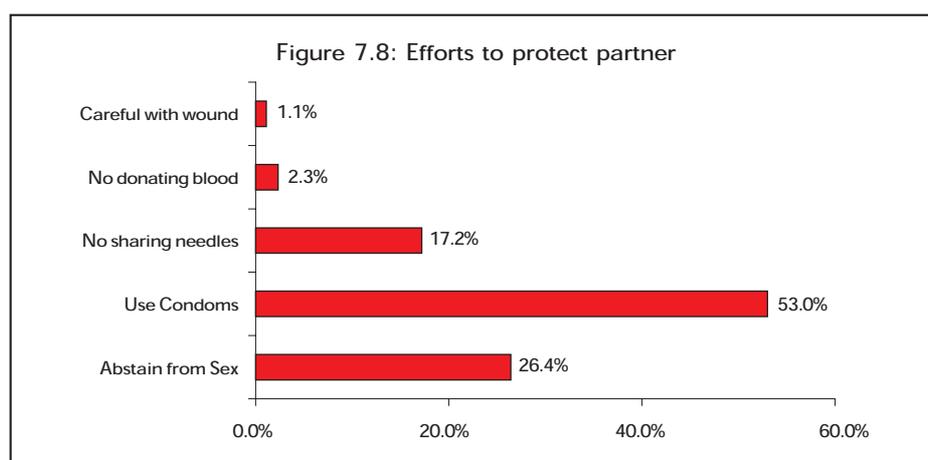
"The community and the neighbours where I live totally ignore and stay away from me. I feel I am isolated."

Of the 149 respondents, 87.9 per cent said they disclosed their status to others while 12.1 per cent (Figure 7.6) said that they did not reveal it. When questioned about their reasons for not disclosing their status, the respondents said they were apprehensive of the stigma, discrimination and rejection attached to being HIV+. Statistically, 50 per cent mentioned stigma and discrimination and 50 per cent cited rejection. Some of the commonly quoted reasons for not disclosing their status were "ill feeling in the community" and "fear of losing their job".



About 77.9 per cent of the respondents had confided only to their immediate family (spouse, parents or siblings) about their HIV status whereas 17.5 per cent had disclosed their HIV status to their neighbours, co-workers or close friends. Of the remaining six respondents, three had disclosed their status to an NGO, one to a network, one to his/her doctor and one had even spoken to the media (TV) about it (Figure 7.7).

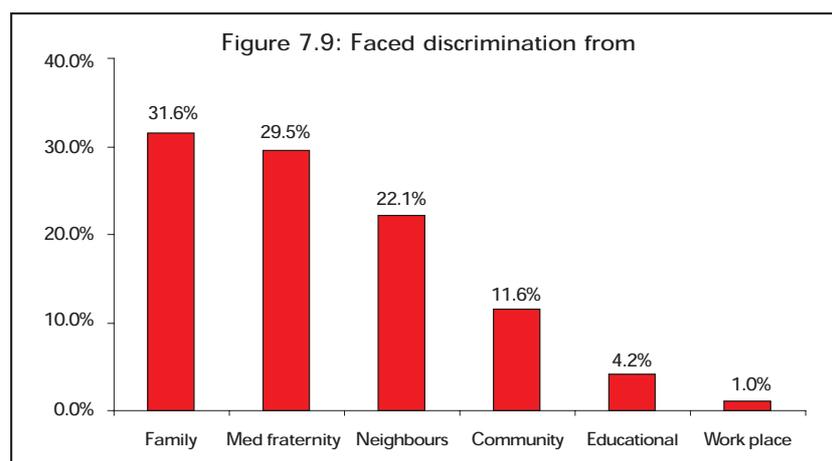
The respondents were asked if they had taken any efforts to protect their partners from HIV after testing positive. As seen in Figure 7.8 of the 115 respondents who answered this question, 24.3 per cent said they did not take any special precautions but 75.7 per cent had taken precautionary steps to protect their spouse/partner. Around 53.0 per cent started using condoms regularly while 26.4 per cent decided to totally abstain from sex, 17.2 per cent stopped sharing injecting equipment and about two per cent said they had stopped donating blood. One respondent said he would be "careful with his open wounds".



The respondents were asked about the steps they had taken to ensure their children didn't get infected. Of the 118 respondents who answered this, 81.36 per cent expressed anxiety about their children getting HIV. About 67.7 per cent decided against having a child and 15.6 per cent said they would not breastfeed. A point to note is that only 9.4 per cent mentioned taking nevirapine to prevent HIV infection in their offspring. This could perhaps indicate that new medical advances to reduce the risk of HIV transmission from mother to child are not yet affordable/accessible to the common person. Fifty-nine respondents responded in the affirmative when asked about other HIV+ members in the family, 79.7 per cent said their spouses were also HIV+.

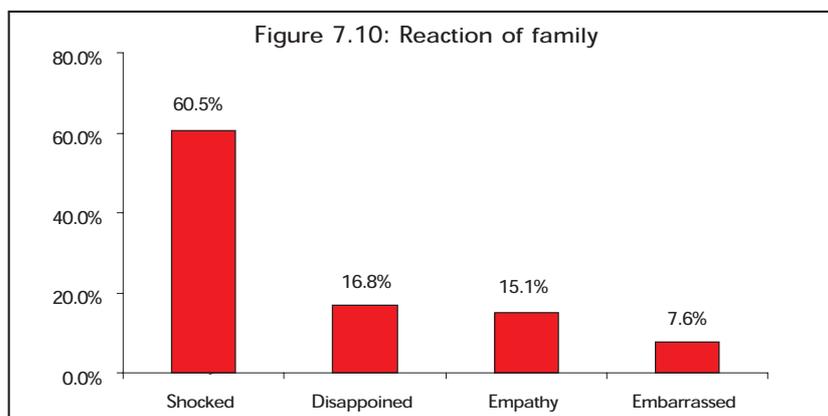
7.4.2 Stigma and discrimination

A majority (63.8%) of the respondents said they had faced discrimination due to their HIV+ status in some form or the other. A startling 82.1 per cent said they faced discrimination from their family (30.5%), medical fraternity (29.5%) or their neighbours (22.1%) (Figure 7.9). This figure is shocking because over the past five or more years, different agencies (government, international and NGOs) have been conducting numerous campaigns to sensitize the public on HIV. Discrimination from the larger community can be expected to an extent but not from the immediate family or the medical fraternity. This is especially true for sites like Imphal and Churachandpur where almost every family has one member who is HIV+ . The attitude of the medical fraternity in terms of the discrimination experienced by PLWHA is inexplicable.



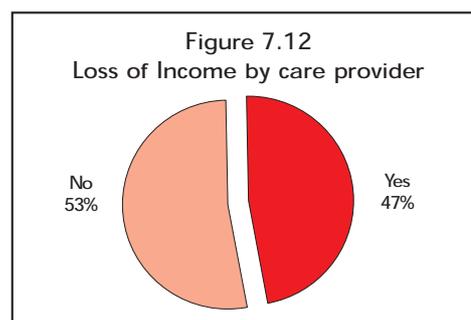
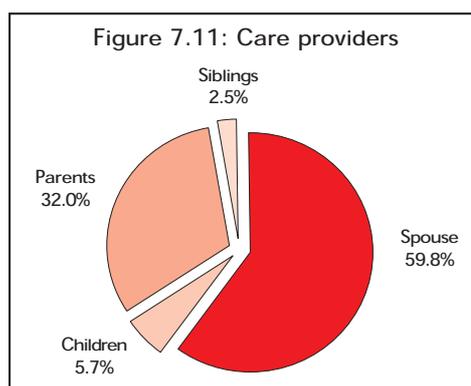
"When my husband was admitted at the hospital the nurse refused to take his blood pressure because of his HIV status."

When the initial acceptance level of the family to their HIV+ status was probed (Figure 7.10) 60.5 per cent of the respondents said their families expressed shock, 16.8 per cent said their families were disappointed and 7.6 per cent said their families were embarrassed. On a positive note, 15.1 per cent of the respondents said their families empathised with them. On the point of eventual acceptance by the family, 57.7 per cent of the respondents said their families accepted them despite their status while 42.3 per cent said their families did not accept them.



7.4.3 Impact on women and children

With the host of opportunistic infections that afflict HIV+ people, the next few questions looked at the issue of care and the care provider. About 81.9 per cent of the respondents said they needed someone to take care of them when they were sick. 59.8 per cent of these respondents named their spouse and 32 per cent named their parents as the care provider (Figure 7.11). For 39 respondents, the care provider was a non-earning member but for the others the care provider was an earning member and 46.4 per cent of these care providers had lost some income due to loss of work time (Figure 7.12). On an average, the income lost was around Rs. 1,600 per month.



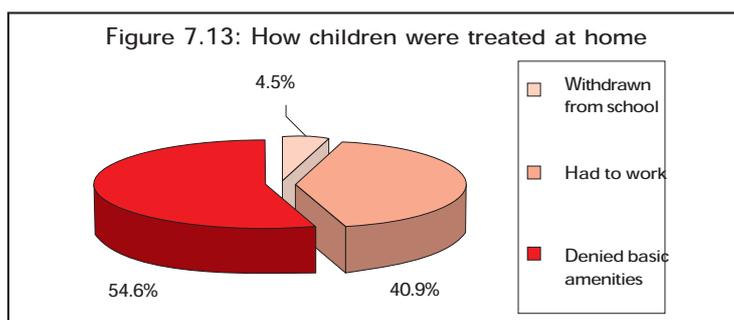
Around 60.4 per cent of the PLWHA said their spouse/children were unable to take on additional responsibilities to support the family. Of the 39.6 per cent whose family members took on extra responsibilities, it was in the form of a non-working spouse/child taking up a job (35.6%) or the spouse/child taking on an additional job (42.4%) to meet the increased expenditure.

Regarding the issue of the spouse of an infected person facing discrimination from the family, 58.4 per cent said there was no such issue. For the 32.9 per cent of the spouses who did face discrimination, it was in the form of the family neglecting, isolating or avoiding them.

"When I was sick, my in-laws forced me to work like a normal person. My health deteriorated and I became a burden on the family in terms of money to support for my medicines as well as my absence in the household affairs."

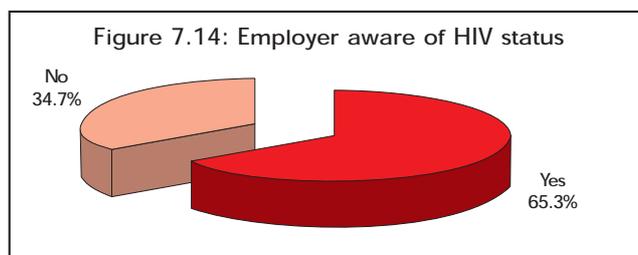
Asked if the children of an HIV+ person were treated badly by others in the community, 35 per cent said "no", but 27.4 per cent said their children did face ill-treatment from the community. About 37.6 per cent said they had preferred not to reveal their HIV status to others in the community because they feared their children might have to face discrimination. On the issue of discrimination faced, 76.5 per cent said their children were neglected, isolated and avoided and 11.8 per cent said their children were not allowed to play with other children in the community. In one case, a child was even expelled from the school because the parent was HIV+.

When further probed if the children of the infected parents were treated differently at home, 54.6 per cent said their children were not provided with basic amenities at home, nearly 41 per cent of children were asked to work and about five per cent of the children were withdrawn from the school. (Figure 7.13). This clearly indicates that HIV is possibly exacerbating the child labour.

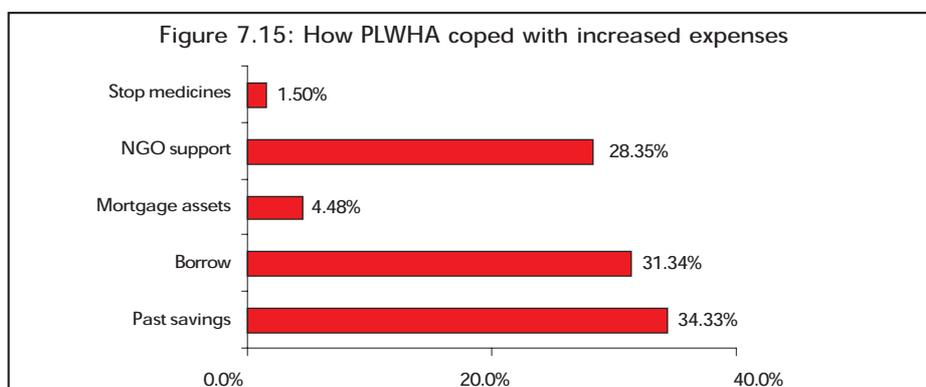


7.4.4 HIV/AIDS and employment

The next section looked at the relationship between the PLWHA and the employer. Of the respondents who had formal jobs, 34.7 per cent did not reveal their HIV+ status to their employer but 65.3 per cent said their employer knew of their HIV+



status (Figure 7.14). Of these 15.6 per cent said they did not get any support from their employer but 84.4 per cent said they did receive some support from their employer. Medical benefits was the form of support that 85.2 per cent received from their employers; for 11.1 per cent it was in the form of paid leave; and one respondent said he/she received moral support from his/her employer. When it was further probed how PLWHA, who did not have support of the employer, coped with the increased expenditure brought on by HIV infection. About 34 per cent said they had to draw from their past savings, 31.3 per cent said they borrowed from others to cope with the increased expenditure and 28.4 per cent said they received support from NGOs. Around four per cent said they had to mortgage assets and one respondent even said he stopped taking medicines as he could not manage the expenses involved (Figure 7.15).



Only 10.4 per cent said they had faced discrimination at the workplace. The discrimination faced by this group was promotion denied (37.5%), forced to take voluntary retirement (37.5%) and benefits not given (25 per cent). At the workplace with regard to the attitude of their colleagues, the respondents said they were not verbally abused or teased but the discrimination was more subtle in that the infected person was neglected, isolated or avoided.

"I find most of the children of infected families are left in urban homes to earn money by doing household manual work. So that they can run their families."

When those respondents who are employed were asked if they had to change jobs in the last six months because of their HIV infection, 78.3 per cent said they did not have to change jobs. Of the 21.7 per cent who did change jobs, on an average the number of jobs changed in the last six months was 1-2 jobs. Around 86.7 per cent gave ill health as the main reason for having to change their jobs, but 13.3 per cent said it was because of discrimination by co-workers. On the question of loss of income due to leave/absence, 39 per cent said they had lost income of around Rs. 2,400 in six months due to leave/absence.

When the respondents who are unemployed were specifically asked how they supported the additional expenses, 70.5 per cent said through family support and 15.9 per cent through either the support of NGOs or the local PLWHA network. The rest mentioned pension or doing odd jobs to augment their income to cope with the additional expense.

7.4.5 Indirect cost

For the 106 respondents who had some means of earning a livelihood, the average monthly income was Rs. 2,900 with the lowest income being Rs. 300 and the highest Rs. 9,000. The average monthly family income of the 149 respondents surveyed was Rs. 4,744 with the minimum monthly income of the family being Rs. 1,000 and the maximum Rs. 17,000.

When questioned if the spouse/children did extra work to compensate for the loss of income due to the PLWHA's illness, 24.2 per cent answered in the affirmative. 6.7 per cent had to start working, 36.6 per cent were already working and took on additional work, 26.7 per cent started small businesses and 30 per cent had to do odd jobs. This extra work taken on by the spouse/children helped 82.8 per cent cover only part of the increased expenditure and only for 17.2 per cent did this extra work help cover all the expenses.

On questioning the respondents on the state of the family's finances vis-à-vis food, medicines, education of children and entertainment/travel, it is evident that HIV infection has had a substantial impact on the family's expenses. The findings suggest that after detection of HIV status (a) average expenditure on food has increased by nearly 20 per cent (b) Average expenditure on entertainment/travel has decreased by half (c) Average expenditure on medicines has more than

doubled (d) Average expenditure on education of children has decreased by about 75 per cent (Table 7.1(a)).

Table 7.1(a): Household expenditure - prior to HIV status

	Rupees
Average monthly expenses on food	1,949.00
Average monthly expenses on clothing	440.00
Average monthly expenses on education	643.00
Average monthly expenses on rent	1,177.00
Average monthly expenses on medicine	902.00
Average monthly expenses on conveyance, entertainment, etc.	521.00
Average total monthly expenditure	4,986.00

Table 7.1(b): Household expenditure - after detection of HIV status

	From	To
	Rupees	
Increase in expenditure on food	1,949.00	2,304.00
Decrease in expenditure on conveyance and entertainment	521.00	280.00
Increase in expenditure on medicines	902.00	1,956.00
Decrease in expenditure on education	643.00	166.00
Increase in debts	-	4,893.00

On questioning the respondents on the state of the family's finances vis-à-vis food, medicines, education of children and entertainment/travel, it is evident that HIV infection has had a substantial impact on the family's expenses. The findings suggest that after detection of HIV status (a) average expenditure on food has increased by nearly 20 per cent (b) Average expenditure on entertainment/travel has decreased by half (c) Average expenditure on medicines has more than doubled (d) Average expenditure on education of children has decreased by about 75 per cent (Table 7.1(b)).

7.4.6 Key concerns for the future

When asked about the most important concerns for the future, the respondents mentioned in order of priority: (1) access to affordable anti-retrovirals and medicines for opportunistic infections (2) well-being of their children in the future (3) to be able

to find or keep a job despite their HIV status (4) a steady source of income as HIV infection brings on increased expenses.

7.5 Conclusions and recommendations

As is evident from the findings, there are more women who have lost their spouses than men. This indicates that the burden of looking after the household will increase for the women. If the man, who is the traditional breadwinner, is no more, the woman will not only have to take care of the children and the elderly members of the family but will also have to work and earn money in order to support the family. This extra burden falls on the woman who herself might be HIV+ . On a larger economic scale this indicates that the workforce (youth between the ages of 25-45) faces the distinct possibility of being wiped out, thereby affecting the economy of the nation. This scenario has already been witnessed in Africa and Brazil.

The group most affected by the HIV epidemic is the youth between the ages of 25 and 35, an age which is the prime and most productive years of life. This indicates a need to launch an intensive effort to reach out to the youth. As the younger population seems to be the worst affected by HIV, perhaps there is a need to include HIV/AIDS education and awareness during the school-going years itself.

Since nearly half the respondents interviewed went in for voluntary testing, this indicates that the awareness of HIV transmission is quite high. But the rest of the respondents got themselves tested symptomatically, which indicates that awareness campaigns need to be intensified further. Early detection of HIV status means that the person infected will be able to adopt a positive lifestyle early enough, which eventually will help to prolong his life and guard against opportunistic infections. The data shows that half the respondents took efforts to protect their spouses from getting infected after they discovered their HIV+ status. This suggests that timely and early detection of HIV status can help prevent the transmission of the infection, especially where the spouses are concerned. To discover one's HIV+ status can be quite an alarming experience for anyone. Apart from the personal trauma, the stigma and discrimination attached to HIV adds to the sense of alienation felt by a PLWHA. These are perhaps the deterrents that prevent PLWHA from disclosing their status.

A cause for concern is the admission made by PLWHA that they face discrimination primarily from the family and the medical fraternity. This raises a question mark on the awareness campaigns run by various agencies. Given the quantum of resources available for HIV/AIDS prevention, agencies should have a sense of accountability with respect to the effectiveness of the programmes they run. Greater attention needs to be paid while designing sensitization campaigns targeting the medical fraternity.

A good majority of the respondents said they had taken preventive measures to protect their spouses from getting infected. Yet, in a contradictory finding, most of the PLWHA mentioned their spouses too were infected. Add to this the fact that the rate of new infections is continually rising. The nature of the virus is such that it can only be transmitted from an infected person. Hence, perhaps, AIDS prevention campaigns need to focus more on early detection of HIV+ status and to involve a greater commitment from PLWHA to ensure that HIV infection is not transmitted accidentally from them to a non-infected person. While the PLWHA are unanimous that they wouldn't take a chance in allowing their children to become HIV+ , the only preventive measure, the respondents speak about is not having a child. Advances in medical science, such as Nevirapine to prevent mother to child transmission, does not seem to be accessible or available to the common man in India as very few of the PLWHA interviewed mentioned the drug.

8. State report:

Assessing the Socio-economic impact of HIV/AIDS in Tamil Nadu*

Section I

8.1 Background of Positive Women Network (PWN+)

Positive Women Network of South India (PWN+) is a self-help organization of women living with HIV. PWN operates from its headquarters in Chennai, Tamil Nadu, India. PWN+ was registered as an organization in 1998 under the Tamil Nadu State Societies Registration Act.

An HIV+ diagnosis can give rise to a lot of emotions — shock, anxiety, grief, fear, uncertainty, anger, despair and more. It creates a sense of urgency, a pressing need to make decisions and changes. It can also create a need for support services and advocacy. Thus, there emerged a need to develop a network to deal with the complex situations arising in the lives of women living with HIV/AIDS (WLHA).

The goal of PWN+ is to provide an enabling environment for women living with HIV.

Our objectives are:

- To create an enabling environment for WLHA by de-stigmatising HIV/AIDS.
- To educate WLHA and their families in order to increase their awareness of issues affecting them.
- To establish a system of referral services.
- To work towards the empowerment of WLHA.

Activities: To:

- provide counselling to people living with HIV and their families.
- organize monthly support group meetings for women living with HIV.
- initiate self-help groups at district and state levels.
- conduct training programmes and workshops for WLHA.
- network with Government and NGOs, care centres, national and international agencies working on this issue and people from various other fields.

* Study undertaken by PWN+ with support from ILO.

- advocate issues concerning women living with HIV.
- train volunteers to enable them to comprehend the issues of HIV/AIDS.
- function as an information centre; and
- offer referral services.

8.2 Data Analysis and Interpretation

8.2.1 Demographic data of respondents

The data in Table 8.1 indicates that a majority of the respondents (66%) were female, while a sizeable percentage (34%) was male. This gender disparity in the number of respondents also succeeds in bringing out the socio-economic impact of HIV with reference to women.

Table 8.1: Gender distribution of respondents

Gender	Frequency	Per cent
Male	16	34
Female	31	66

The data shows (Table 8.2) that a majority of the respondents (51%) were in the 31–40 age group, while a large percentage was between 21 and 30 years. The ages between 31 and 40 are a vital period in a person's life, since this is the prime working age. Given that more than 90 per cent of the respondents were below 40 years, it's clear that HIV is affecting India's workforce in nearly every sector in a big way.

Table 8.2: Age distribution of respondents

Age (yrs)	Frequency	Per cent
21 – 30	20	42.6
31 – 40	24	51
41 – 50	3	6.4

Table 8.3: Education

Educational qualification	Frequency	Per cent
No formal education	4	8.5
School (up to 12 th std)	35	74.5
Graduate	4	8.5
Post graduate	4	8.5

A majority of the respondents (74.5%) had obtained basic education, having studied up to the school level (Table 8.3). An equal number of respondents were graduates and post graduates. It can, therefore, be concluded that awareness of HIV or becoming HIV+ may not have any correlation with the level of education.

A vast majority (78.7%) of the respondents were employed, either in the private or public sectors, or self-employed. Around 21.3 per cent of the respondents were unemployed (Table 8.4).

Table 8.4: Occupation

Occupation	Frequency	Per cent
Unemployed	10	21.3
Employed in private sector	25	53.2
Employed in public sector	2	4.2
Self-employed	10	21.3

Of the 47 respondents, 38 (80.9%) resided in their place of origin. Around nine had shifted to another district within Tamil Nadu citing marriage and employment as reasons (Table 8.5). One respondent refrained from providing a reason for shifting residence, while two others mentioned abandonment and death of spouse respectively as reasons for shifting. Therefore, there was no evidence of respondents shifting place of residence due to HIV-related discrimination.

Table 8.5: State of residence

State of residence	Reasons for shifting, if any			Frequency	Per cent
	Marriage	Work	Others		
Residing in place of origin	-	-	-	38	80.9
Shifted to current place	3	3	3	9	19.1

Table 8.6 reveals that almost half the respondents (46.9%) were widowed, while around 31.9 per cent were married and lived with their spouses. It is significant that among the 31 female respondents, 22 had been widowed. Only one woman was unmarried. It is, therefore, a major finding that among women, transmission of HIV predominantly occurs within the institution of marriage.

None of the men in the study were widowed. Though the representation of men in the study is less than half of females (only 16 men as compared to 31 women), this finding could also be indicative of a better physical and mental health status among women, with specific reference to the effects of HIV.

Table 8.6: Current marital status

Marital status	Gender distribution		Frequency	Per cent
	Male	Female		
Married	7	8	15	31.9
Widowed	-	22	22	46.9
Unmarried	5	1	6	12.7
Living together	3	-	3	6.4
Abandoned	1	-	1	2.1
Total	16	31	47	100

A majority of the respondents (53.2%) lived in joint families, while a sizeable percentage (29.8%) lived in nuclear families. Around 17 per cent lived alone (Table 8.7). This indicates that family ties are still strong in Tamil Nadu.

Table 8.7: Family status

Family status	Frequency	Per cent
Joint family	25	53.2
Nuclear family	14	29.8
Living alone	8	17

8.3 Issues in disclosure of HIV/AIDS status

Table 8.8 shows that nearly half the respondents (49%) had discovered their status by 'other' means. Significantly, it was revealed that of the 21 women in this category, 20 had undergone HIV tests only after their husbands had tested positive. Around 19.1 per cent of the respondents had discovered their status after prolonged illness, among whom a larger percentage was male. Three women (6.4%) had discovered their status during ante-natal check-ups.

Table 8.8: Mode of discovery of HIV status

Mode of discovery of HIV status	Gender		Frequency	Per cent
	Male	Female		
Voluntary testing	5	3	8	17
Donating blood	1	-	1	2.1
After prolonged illness	7	2	9	19.1
Ante-natal checkups	-	3	3	6.4
For employment	1	2	3	6.4
Others	2	21	23	49
Total	16	31	47	100

The findings from the data were supported by the observations that emerged from two focus group discussions held in urban and rural areas (Chennai and Erode). When the group was asked to discuss how most people discover their HIV status, the following points came out:

- Most men discover their HIV status after prolonged illness.
- In the case of married women, it is, most often, the husband's illness that prompts them to take a test.
- During pregnancy.
- After the husband's death.
- After husband's status becomes known.
- Due to peer educators' compulsion, especially among women who are commercial sex workers.

Table 8.9: Period of Detection

Period	Chennai	Namakkal	Erode
Before 1990	-	-	-
1990 – 1999	15	11	3
2000 -	6	7	5

A majority (61%) of the respondents had discovered their HIV status before 1999, while a sizeable percentage had discovered their status after 2000, indicating reduced new infections.

Table 8.10 reveals that a majority of the respondents had not had either pre-test or post-test counselling at the time of detection. Only about 31.9 per cent had been counselled out of which a majority of the respondents had been counselled post test alone. As most of the respondents had discovered their status before 1999, availability of counselling might have been an issue then. But, the quality of the counselling provided also needs to be taken into account here.

Table 8.10: Availability of Counselling

Pre – Post test counselling	Frequency	Per cent
Counselled	15	31.9
Not counseled	32	68.1

During the focus group discussions, most members pointed out that when tests are done during pregnancy, no counselling is given. The person is usually not even

informed about the test and consent is not taken. The authorities do it as mandatory testing. This practice is especially prevalent in government centres.

Table 8.11: Disclosure of HIV status

Persons to whom respondents disclosed their HIV status	Frequency	Per cent
Spouse	20	42.5
Parents	31	66
Siblings	25	53.2
Close friends	19	40.4
Co-workers	12	25.5
Neighbours	12	25.5
Others	6	12.7

It is interesting to note that all the respondents (100%) in the sample had revealed their HIV status to somebody or the other (Table 8.11). A large percentage of respondents had revealed their HIV status to their families, either to their parents, siblings or spouses. A sizeable percentage (40.4%) had revealed their status to their close friends. A small percentage had disclosed their status either to their colleagues, neighbours, employers or doctors.

To the question on what efforts they had taken to protect their spouse from getting infected, a majority of the respondents felt this question was not applicable. Among the 35 respondents who had not taken any preventive measures, around 28 women said this question was either not applicable to them or they had not taken any precautions as they themselves had discovered their HIV status only after their spouses (Table 8.12). The men who felt this question was not applicable were mostly unmarried.

Table 8.12: Precautions taken to protect spouse from HIV transmission

Precautions	Gender of respondents		Frequency	Per cent
	Male	Female		
Efforts taken	9	3	12	25.6
Efforts not taken/ not applicable	7	28	35	74.4

Among the 12 respondents (25.6%) who had taken precautions, abstinence from sex and condom usage were the common preventive measures employed. This was primarily to prevent re-infection and not to prevent the transmission of HIV, although one unmarried male respondent had started practising safe sex to prevent the spread of the infection to others.

The data clearly reveals the inability of women to protect themselves as the majority of women in India are not in a position to negotiate their reproductive rights. This was supported by the findings from the qualitative data also.

The general consensus during the focus group discussions was that protection of spouse is only possible in cases where the person comes to know about his/her status either before marriage itself, or before having unsafe sex with spouse after marriage. But in most cases, the HIV status was known only after prolonged illness, by which time he/she is already married.

A vast majority of the respondents (87.3%) felt that this question was not applicable to them. Some had no children while some were unmarried. The six respondents who had not taken precautions had been unable to do so as they too had discovered their HIV status after the birth of their child. For the five respondents who had taken precautions, the preventive measures taken included AZT, Nevirapine and avoiding breastfeeding (Table 8.13).

Table 8.13: Precautions taken to protect children from HIV transmission

Precautions	Frequency	Per cent
Efforts taken	5	10.6
Efforts not taken / not applicable	41	87.3
Decided not to have child	1	2.1

These findings when correlated with the data in Table 8.8 shows that most people go in for testing when they are either sick for a long time, or, in case of married women, when their spouse's status is discovered. Therefore, the concept of taking precautions to prevent transmission within the circle of marriage arises only when the persons involved are in a position to do so, which according to the data, they are not.

Table 8.14 reveals that a significant number of respondents (55.3%) had no other family members who were HIV+. However, this was because most of the respondents were women who had lost their spouses and did not have HIV+ children. Some of the male respondents were unmarried. An almost equal number of respondents (48.9%) had other members infected by HIV in their families. For some respondents, it was either their spouses or children, while in a few cases both spouses and children had been infected by HIV. One respondent was unable to answer the question as his wife had not been tested for HIV as she was not aware of his status.

Table 8.14: HIV+ family members in respondents' families

Presence of HIV positive family members other than respondent	HIV+ family members			Frequency	Per cent
	Spouse	Children	Others		
Present	14	8	1	23	48.9
Not present	-	-	-	26	55.3
Not aware	-	-	-	1	2.1

8.4 Issues in stigma and discrimination:

A majority of the respondents (53.2%) said that they had not experienced any stigma or discrimination as a result of HIV. However, around 46.8 per cent had experiences of stigma and discrimination, indicating that it is an issue that cannot be ignored (Table 8.15).

Table 8.15: Experience of stigma and discrimination

Stigma and discrimination	Frequency	Per cent
Experienced	22	46.8
Not experienced	25	53.2

Among the 22 respondents who had faced discrimination, many reported the source as families and care centres (Table 8.16), followed by neighbours and community representatives. Considering the fact that most respondents had revealed their status to their families, implying a feeling of trust in them, the fact that they faced HIV-related stigma and discrimination from them, is a cause of concern.

Table 8.16: Source of stigma and discrimination (multiple responses)

Source	Frequency
Family	11
Hospital	11
Neighbour	7
Community	5
Educational institution	1
Others	3

Another alarming statement that was made during the focus group discussions was: "Discrimination is strong in hospitals." Many respondents said that they did not reveal their HIV status during visits to private clinics for ordinary ailments like fever, cough, etc. Many felt that if they revealed their status, they would either be denied treatment, or excess money would be demanded.

During the group discussions the consensus was that stigma was more in villages than in towns. Discrimination was mostly in the form of moving away when the infected person passed by, or refusing to share utensils, clothes, using abusive language when referring to them, etc.

With regard to schools, none of the respondents had revealed their HIV status in their children's schools. They pretended that they were suffering from tuberculosis, jaundice or cancer as these illnesses don't have the stigma that HIV does.

From Table 8.17 it is evident that a vast majority of the respondents' families had exhibited initial reactions of shock and denial. Around 10 respondents felt that their families had been embarrassed to have an HIV+ person living with them. Only four respondents said that their families had empathized with them and understood them thoroughly.

Table 8.17: Initial reaction of family members to HIV status

Initial reactions	Frequency
Shocked	32
Denied	28
Empathized	4
Embarrassed	10
Not disclosed to family	5
Others	2

Among the 41 respondents who had revealed their status to their families, a sizeable majority (90.2%) had been accepted (Table 8.18). However, this did not imply that the entire family had accepted the respondents. Many of the respondents had revealed their status only to their parents, siblings or spouses and had been accepted by them alone. The other members in their families did not know the respondents' status. Also, only in a few cases did the families immediately accept their status. The time taken for acceptance varied from immediate acceptance to about a year, although, encouragingly enough, the former category was more.

Table 8.18: Acceptance by family members

Acceptance	Frequency	Per cent
Accepted	37	90.2
Not accepted	4	9.8

8.5 Impact of HIV on women and children

Around 83 per cent of the respondents felt that they needed somebody to take care of them when they fell sick, while around 17 per cent were confident that they could manage on their own. However, this did not imply that they had somebody to care for them (Table 8.19).

Table 8.19: Assistance required during sickness

Assistance	Frequency	Per cent
Required	39	83
Not required	8	17

Families played a major role in functioning as care-givers for people living with HIV. When looking at the gender distribution, it is interesting to note that a vast majority of the female respondents had predominantly cited parents as the care-givers, while for male respondents it was the spouses, siblings and parents who were the care-givers (Table 8.20).

Table 8.20: Relationship of caretaker to respondents (multiple responses)

Caretakers	Frequency
Spouse	8
Children	2
Parents	26
Siblings	10
Others	5

Around 38.2 per cent respondents said that their care-givers had lost income due to remaining absent from work to look after them.

Table 8.21: Loss of income of care giver

Loss of income	Frequency	Per cent
Income lost	18	38.2
Income not lost	15	32
Non earning member	4	8.6
NM	10	21.2

The average income lost by care-givers during the time they had taken off to look after the infected person was around Rs. 1,500 (Table 8.22). The respondents whose care-givers had not lost income were mostly from family businesses.

Table 8.22: Amount lost

Median (Average)	Rs. 1,500
Range	Rs. 200 – Rs. 10,000

As cited in Table 8.23 majority of the respondents (68%) felt that this question was not applicable to them as their spouses were no longer alive or were not in a position to take up additional responsibility. Some respondents felt that they were managing well and, therefore, there was no need for their spouse to take up additional responsibility. Those respondents who had children said they were too young to take up any responsibility.

Table 8.23: Additional responsibility taken by spouse/ children of the infected person to support the family

Additional responsibility	Frequency	Per cent
Quit job	-	-
Taken up job	6	12.7
Taken up additional job	4	8.6
Others	5	10.7
Not applicable	32	68

A majority of the respondents (55.4%) said that discrimination did not occur (Table 8.24). However, in many cases the respondents were either unmarried or their families were not aware of their status. In a few cases the families were aware but did not

Table 8.24: Attitude of family towards infected/affected spouses of respondents

Attitude towards spouse	Frequency	Per cent
Neglected	5	10.7
Verbally abused	4	8.7
Physically abused	3	6.3
Deprived	3	6.3
Property taken away	3	6.3
Asked to leave home	3	6.3
Never discriminated	26	55.4

discriminate, or the spouses had passed away. Many of the respondents were female and in their case, it was they who faced discrimination from their families and not their spouses. Those who said their spouses had been discriminated against reported verbal and physical abuse, neglect, deprivation of basic amenities, abandonment and denial of property.

A few shocking statements were heard during the focus group discussions. "As it is, women are treated badly in their husbands' homes. With HIV it is even worse as aspersions are cast on their chastity and they are blamed for their husband's illness." Apparently, even the women in the household were not sympathetic to women infected/affected by HIV.

Interestingly, except for three of the participants in the group discussions, all the others said they lived with their parents/ siblings. Two of them lived with their husbands while only one woman lived with her in-laws.

As Table 8.25 reveals, a majority felt this question was not applicable to them as they were unmarried, did not have children, did not live with their families, or had sent their children to be educated in hostels and homes. Some of the children though had faced discrimination such as being withdrawn from school, being forced to take up jobs, separate vessels being kept for them and not being allowed to play with other children.

Table 8.25: Treatment of children at home

Treatment of children	Frequency	Per cent
Withdrawn from school	1	2.2
Had to take up job	3	6.3
Denied basic amenities	1	2.2
Others	12	25.5
Not applicable	30	63.8

Around 10.6 per cent of the children were treated badly by the community, with discrimination taking the form of neglect, verbal abuse and other children not being allowed to play with them (Table 8.26).

Table 8.26: Treatment of children by community

Treatment of children	Frequency	Per cent
Badly treated	5	10.6
Treated well	16	34
Status not known	13	27.7
Not applicable	13	27.7

8.6 Issues of HIV/AIDS at the workplace

It is evident from Table 8.27 that about 40.4 per cent of the respondents had informed their employers about their HIV status. It is interesting to note that except for two respondents, all the others were from the private sector. Their job profile varied – some were employed as daily wage workers, others as coolies and drivers. Some worked for NGOs and networks, others in printing presses and hospitals. Both the respondents working in the public sector belonged to government undertakings and had not revealed their status to their superiors as they felt that they would not receive the support of their employers. Around 40.4 per cent felt that this question was not applicable to them as they were either unemployed or self-employed. One person whose employer had become aware of his status had removed him from his job and he is now unemployed.

Table 8.27: Employer's awareness about HIV status of respondent

Employer's awareness of HIV Status	Unemployed	Pvt sector	Public sector	Self-employed	Frequency	Per cent
A. Aware	1	18	-	-	19	40.4
Not aware	-	7	2	-	9	19.2
Not applicable	9	-	-	10	19	40.4

Out of the 19 respondents whose employers were aware of their status, only around 10 (21.3%) felt that their employers were supportive. This support, except for a few cases, was a general kind (psychological) and not anything specific. For 59.5 per cent of the respondents, this question was not applicable, as they were either self or unemployed or their employers were not aware of their status (Table 8.28).

Table 8.28: Availability of support from employer

Support	Frequency	Per cent
Available	10	21.3
Not available	9	19.2
Not applicable	28	59.5

Table 8.29: Form of employer support

Form of support	Frequency
Medical expenditure	6
Paid leave	9
Others	3

Of the 10 respondents who had received assistance from their employers, the support ranged from looking after medical expenditure (to treat opportunistic infections), paid leave, psychological support, extra salary, permission to use the office as a place to stay to providing opportunities for additional jobs in order to supplement their income (Table 8.29).

The respondents who did not have supportive employers had to cope by using their past savings, selling their assets, borrowing from others or stopping medicines (Table 8.30). Some respondents who were employed and had received assistance from their employers said that they still had to depend on NGOs or loans from others to supplement their incomes in times of difficulty.

Table 8.30: If not available, coping with increased expenditure (multiple responses)

Coping strategies	Frequency
Use past savings	3
Borrow from others	8
NGO support	4
Sale of assets	1
Stopped taking medicines	2
Others	1

Table 8.31 shows, around 10.6 per cent of the respondents felt that they were discriminated at the workplace. Three respondents said that benefits were not given and promotions were denied to them, while one respondent was forced to take voluntary retirement. One respondent was terminated from his job. About 55.4 per cent felt that they were not discriminated against. The reasons varied from a conducive workplace, supportive employers, co-workers who were not aware of their status to the fact that they were working in a network or with an NGO.

Table 8.31: Discrimination at workplace

Discrimination	Frequency	Per cent
Discriminated	5	10.6
Not discriminated	26	55.4
Not applicable	16	34

Around seven respondents felt that their co-workers were not very sensitive and neglected them, verbally abused them, refused to co-operate with them and talked among themselves about the respondents' HIV status. A few respondents felt that their co-workers were generally supportive and did not abuse them. For about 74.4 per cent this question was not applicable as they were either unemployed, self-employed or their co-workers were not aware of their HIV status (Table 8.32).

Table 8.32: Attitude of co-workers

Attitude	Frequency	Per cent
Neglected	4	8.6
Verbally abused	1	2.1
Others	7	14.9
Not applicable	35	74.4

Around 10.6 per cent of the respondents had changed jobs in the last six months. About 21.4 per cent were unemployed and, therefore, this question was not applicable to them. A majority of respondents (68%) had not changed jobs (Table 8.33). The five who had changed jobs had moved from one to two jobs on an average. Of these, three had been asked to quit, one person had been sacked and one respondent had changed jobs because of ill-health.

Table 8.33: Change of job in the last six months

Change of job	Frequency	Per cent
Changed job	5	10.6
Did not change job	32	68
Not applicable	10	21.4

As Table 8.34 shows, almost an equal percentage of respondents had remained absent and not taken any leave from work during the last six months. But many of the unemployed came under the category of being absent from work as they had no work. The period of absenteeism varied from two days to seven months.

Table 8.34: Absenteeism from work during last six months

Absenteeism	Frequency
Not Absent	23
Absent	24
Median (Absent)	20
Range (Absent days)	2 days – 7 months

Around 58.3 per cent of the 24 respondents who had taken time off from work lost income, while around 41.7 per cent had not because they were either in family businesses, so others took care, or their employer was supportive and so they got paid leave (Table 8.35).

Table 8.35: Loss of income due to absenteeism

Loss of income	Frequency	Per cent
Lost income	14	58.3
Did not lose income	10	41.7

The amount lost by respondents during the last six months due to absenteeism varied from Rs. 500–Rs. 20,000.

Table 8.36: Amount lost

Median	Rs. 2,500
Range	Rs. 500 – Rs. 20,000

8.7 Economic impact of HIV on PLWHA and their families

Respondents mainly depended upon their families for support. NGO support and community support was also available in a few cases (Table 8.37). The respondents felt that they depended on family and NGOs even when they were employed to augment the increased expenditure after HIV infection.

Table 8.37: Source of support for expenses, if unemployed (multiple responses)

Support	Frequency
Family support	14
NGO support	4
Others	1
Not applicable	28

The monthly income of respondents was around Rs. 400–Rs. 15,000 with Rs. 2,000 as the average (Table 8.38). Around seven respondents did not respond to this question as they were totally dependent on their families for support. Many of the other respondents depended on external support, personal savings and borrowings to meet their basic needs.

Table 8.38: Monthly income of respondents

Information given	40
Median	Rs. 2,000
Range	Rs. 400 – Rs. 15,000

Around five respondents were not aware of their families' income, while the others said the income ranged between Rs. 100 and Rs. 25,000, with the average around Rs. 3,000 (Table 8.39).

Table 8.39: Monthly income of the family

Information given	42
Median - average	Rs. 3000
Range	Rs. 100 – Rs. 25,000

A vast majority of the respondents (80.9%) said that their family members did not have to take up any extra work due to their illness, while around 17 per cent said their family members had taken up extra work to support their expenditures (Table 8.40). Among the 17 per cent, five respondents felt that the additional work covered only part of their expenses, while one respondent felt that it fully covered all the expenses. The others could not really say whether it had made any difference.

Table 8.40: Extra work by household member

Work by Household member	Frequency	Per cent
Did extra work	8	17
No extra work	38	80.9
Not applicable	1	2.1

8.8 A Prior to HIV status

To estimate any increase on household expenses, questions were asked on how much was spent on some of the common household expenses prior to the HIV infection. However, not all the respondents answered all questions, as some said they could not afford to spend money on certain items while others stated that certain expense items were not applicable to them. As shown in table 8.41 the monthly expenses on food prior to the discovery of HIV status ranged between Rs. 200 and Rs. 3,000, with the average being Rs. 1,000. The monthly expenses on clothing for 42 respondents

Table 8.41: Monthly household expenses

Expenses on	No. of respondents	Median (in Rs.)	Range (in Rs.)
Food	47	1000	200-3000
Clothing	42	250	50-1500
Education	32	200	50-3600
Accommodation	29	500	120-2000
Medicine	40	300	50-2000
Entertainment	44	300	100-2000
Other expenses	33	300	50-7000
Total expenses	44	2800	400-7800

averaged around Rs. 250. The other five respondents felt that they were not in a position to spend money on clothing and, therefore, said the question was not applicable to them.

Thirty-two respondents said the question on education was not relevant to them as they did not have children or their children were too young for them to incur any educational expenditure. For those who had incurred expenses, the average amount spent to education worked out to Rs. 200 per month.

Eighteen respondents said they were living in their families' own homes and so incurred no expenses on accommodation. For the remaining 29 respondents, the amount averaged around Rs. 500 per month, the maximum being Rs. 2,000. Ten respondents did not experience any need for medicines and so there were no medical expenses. For the other respondents, the amount averaged around Rs. 300 per month.

It is a common notion that whenever there is need for more money, people tend to curtail expenses on entertainment. Keeping this in mind an attempt was made to probe into the expenditures made on entertainment before the HIV infection. To this 44 respondents responded and the average worked out to Rs. 300 per month, the minimum being Rs. 100 and the maximum Rs. 2,000.

On the question of other petty expenses, 14 respondents said they were totally dependents on their families for even their daily living, and so felt that there was no other expenditure, which would warrant a monthly average. For the rest, other expenses averaged around Rs. 300. When asked about the total household expenses, the average expenditure was reported to be around Rs. 2,800 per month.

Table 8.42: The income that would have been gained if free from illness during last six months

Not applicable	19
Information given	28
Median	Rs. 12,000
Range	Rs. 500 – Rs. 30,000

Nineteen respondents said they were unaffected – they did not suffer from illness or their illness had not had any impact on their income. For the 28 respondents who suffered losses due to sickness, the monthly average that could have been earned if they had been fit worked out to around Rs. 12,000 (Table 8.42).

8.9 After the detection of HIV status

About 80.9 per cent of the respondents felt that after the detection of HIV their household monthly expenditures on food and medicines had increased. The increase in spending averaged around Rs. 500 per month for both categories. On entertainment spends, there was a mixed response. About 49 per cent reported a decrease in entertainment expenses, while around 46.8 per cent of the respondents felt that even after the discovery of HIV status there was no difference in this expenditure.

With regard to education, about four per cent each reported an increase and decrease in the expenditure. Around 59.6 per cent of the respondents said their debts had increased after the detection of HIV with the borrowings averaging around Rs. 20,000 (Table 8.43).

Table 8.43: Household monthly expenditure

Expenditure	Increased	Decreased	No difference	Not applicable
Food	38 (80.9%)	6(12.8%)	3(6.3%)	-
Entertainment	2(4.2%)	23(49%)	22(46.8%)	-
Medicines	38(80.9%)	-	9(19.1%)	-
Education	2(4.2%)	2(4.2%)	11(23.6%)	32(68%)
Debts	28(59.6%)	-	15(31.9%)	4(8.5%)

8.10 Medical expenditure

Thirty three respondents had suffered from opportunistic infections during the last six months and spent an average of Rs. 2,500 on treatment (Table 8.44). The other 14 respondents were not affected.

Table 8.44: Cost incurred on treatment of opportunistic infections in the last six months

Not applicable	14
Median – Average	Rs. 2,500
Range	Rs. 250 – Rs. 15,000

Table 8.45: Cost incurred on checkups of viral load and CD4 / CD8 count

Not applicable	43
Median – Average	Rs. 2,500
Range	Rs. 1,000 – Rs. 6,500

The data in Table 8.45 reveals that around 43 respondents had not undergone any kind of viral load, CD4 or CD8 testing. It is important to note that a majority of people living with HIV do not have access to health care in the country.

The data shows (Table 8.46) that 41 respondents had not had any ART, while those who had undergone treatment spent an average of Rs. 4,750 per month on it. And among those who spent on viral load check, the average was Rs. 2,500.

Table 8.46: Cost incurred on anti-retroviral treatment (ART)

Not applicable	41
Median – Average	Rs. 4,750
Range	Rs. 1,400 – Rs. 16,000

The average cost incurred on tests and other medicines was around Rs. 2,000 per month. In some cases, the amount spent was as much as Rs. 50,000 because those respondents experimented with expensive alternative remedies such as Siddha trials (Table 8.47).

Table 8.47: Cost incurred on other medicines and tests

Not applicable	10
Median	Rs. 2,000
Range	Rs. 50 – Rs. 50,000

8.11 Major findings

8.11.1 Demographic details:

1. A majority of the respondents (66%) were female, while a sizeable percentage (34%) was male.
2. A majority of the respondents (51%) were in the 31-40 age group, while a large percentage was between 21 and 30 years.
3. A vast majority of the respondents (74.5%) had been educated up to the school level and had thus received basic education.
4. A sizeable majority of the respondents were employed, either in the private or public sectors, or self-employed
5. A vast majority (80.9%) of the respondents resided in their place of origin
6. Almost half the respondents (46.9%) were widowed.
7. A majority of the respondents (53.2%) lived in joint families.

8.11.2 Information on HIV/AIDS status:

1. Nearly half the respondents (49%), especially the female respondents, discovered their HIV status only after their spouses tested positive.
2. A majority of the respondents had discovered their HIV status in the 1990s.
3. A majority of the respondents had not had pre/post-test counselling at the time of detection.
4. All the respondents (100%) in the sample had revealed their HIV status to somebody or the other.
5. A majority of the respondents said they could not take precautions to prevent new infections as they had not been in a position to even protect themselves. Women, especially, had discovered their status only after their spouses had tested positive, so the question of them taking responsibility to prevent new infections did not arise.
6. A vast majority of the respondents (87.3%) said they were not in a position to protect their children from HIV transmission as by the time they learnt their status their children had already been born.
7. A significant number of respondents (55.3%) had no other family members who were HIV+ because many of them were widows and had no children.

8.11.3 Stigma and discrimination:

1. A majority of the respondents (53.2%) said that they had not experienced any stigma or discrimination as a result of HIV.
2. Of the 22 respondents who had faced discrimination, many reported facing it within their own families and care centres, followed by their neighbours and community representatives.
3. A vast majority of the respondents' families had exhibited initial reactions of shock and denial.
4. Among the 41 respondents who had revealed their status to their families, a vast majority (90.2%) of them had been accepted.

8.11.4 Impact on women and children

1. A vast majority (83%) of the respondents felt that they needed somebody to take care of them when they were sick.
2. Most of the female respondents cited their parents as the predominant care givers.

3. A sizeable percentage of care-givers had lost income averaging around Rs. 1,500 while looking after the HIV patient.
4. A majority of the respondents (68%) felt that the question on additional responsibilities taken to support family by spouse/ children of the infected was not applicable to them as their husbands had died and their children were too young to support them.
5. A majority of the respondents (55.4%) revealed that they had not faced discrimination.
6. Most of the respondents did not have children and, hence, the question of how their children were treated at home was not applicable.
7. Around 10.6 per cent of the respondents said that children were treated badly by the community, with discrimination taking the form of neglect, verbal abuse and not being allowed to play with other children.

8.11.5 HIV/AIDS and employment:

1. About 40.4 per cent of the respondents had informed their employers about their HIV status.
2. Of the 19 respondents whose employers were aware of their status, only around 10 (21.3%) felt that their employers were supportive
3. For a vast majority (74.4%) of respondents, the question of their co-workers' attitudes towards them was not applicable as many of them were either unemployed, self-employed or had not disclosed their status to their co-workers.
4. Around 10.6 per cent of the respondents had changed jobs in the last six months.
5. An equal number of respondents had been forced to remain absent from work and not missed work in the last six months.
6. A majority (58.3%) of those respondents who had remained absent lost income.
7. The amount lost during the last six months due to absenteeism varied from Rs. 500 – Rs. 20,000.
8. Most of the respondents predominantly depended on their families for support.

8.11.6 Indirect expenditure/support:

1. The monthly income of respondents ranged between Rs. 400 and Rs. 15,000, with Rs. 2,000 as the average
2. A negligible percentage was not aware of their families' income, while the others said it ranged between Rs. 100 and Rs. 25,000, with the average around Rs. 3000.

3. A vast majority of the respondents (80.9%) said that their family members did not take up any extra work due to their illness.

8.11.7 Impact of HIV on household expenditure:

A. Prior to HIV status:

1. Before they discovered their HIV status, the respondents spent on an average around Rs.1,000 on food per month.
2. A vast majority of the respondents had incurred an average expenditure of Rs.250 per month on clothing.
3. A majority of the respondents did not have to spend on education as they did not have children.
4. For the 29 respondents who had to pay for their accommodation, the average expenditure was around Rs. 500 per month.
5. A majority of the respondents had medical expenses prior to the discovery of their HIV status, with the average expense per month working out to Rs. 300.
6. On entertainment, 44 respondents had an average monthly expense of Rs. 300.
7. Fourteen respondents were totally dependent on their families for their daily sustenance.
8. The average total monthly expenditure of 44 respondents was Rs. 2,800.
9. Twenty eight respondents felt that if they had been free of illness during the last six months, they would have earned an average of Rs. 12,000.

B. After the detection of HIV status:

1. About 80.9 per cent of the respondents said that after the detection of HIV their household monthly expenditures on food and medicines had increased by an average of about Rs. 500 per month.

C. Medical expenditure:

1. The average cost incurred on treatment of opportunistic infections for 33 respondents was Rs. 2,500.
2. A vast majority of the respondents had not undergone any kind of viral load, CD4 and CD8 testing.
3. A majority of the respondents had not had any anti-retroviral treatment. For those who had, the average spent on treatment was around Rs. 4,750 per month.

4. On an average, respondents incurred a cost of Rs. 2,000 per month on tests and medicines.
5. Some respondents had spent as much as Rs. 50,000 on medical care, because they had experimented with expensive alternative therapies such as Siddha trials.

8.12 Conclusion

The ages between 31 and 40 years are a vital period in a person's life as it is the prime working age. With more than 90 per cent of the respondents below 40 years, it is evident that the workforce is being affected in a big way. The impact of HIV in relation to the nation's economy thus needs to be examined.

It can be concluded that awareness on HIV or becoming HIV+ may not have any correlation with the level of education.

There was no evidence that HIV-related discrimination had led to the shifting of residence.

It can be concluded that among women, transmission of HIV predominantly occurs within the institution of marriage.

None of the men in the study were widowed. Though the representation of men in the study is less than half of the female representation, this finding could also be indicative of a better physical and mental health status among women, with specific reference to the effects of HIV.

The data clearly indicates the lack of the ability of women to protect themselves as the majority of women in India are not in a position to negotiate their reproductive rights. This was supported by the findings from the qualitative data also.

Most people go in for testing when they are either sick for a prolonged period or, in case of married women, only when their spouse's status is discovered. Therefore, the concept of taking precautions to prevent transmission within the institution of marriage arises only when the persons involved are in a position to do so, which according to the data, they are not.

It was found that stigma and discrimination was widely prevalent in care centres and family set-ups, although support from families also ranked high.

With reference to acceptance by family, many of the respondents had revealed their status only to their parents, siblings or spouses and had been accepted by them alone. The other members in their families did not know the respondents' status.

The impact of HIV on women and children was much more drastic when compared to its impact on men.

Some respondents who were employed, and for whom support was available, felt that even with employer support, they still had to depend on borrowings from others and on NGOs to supplement their incomes in times of difficulty.

8.13 Recommendations

A committee sensitive to the issues of people living with HIV needs to be set up to monitor the quality of counselling provided – both pre-test as well as post test.

People living with HIV should be involved as peer counsellors in providing counselling.

The business sector needs to be sensitized to the issues of people living with HIV in order to render their support to them.

The business sector needs to be fully involved in a sustained manner in HIV prevention and care issues to address and reduce the impact of the epidemic.

Strong existing legal policies need to be implemented to address issues of stigma, discrimination and HIV-related human rights violations.

More and more people living with HIV need to be involved in programmes addressing HIV/AIDS issues in a sustained and participatory manner.

Trained medical personnel skilled in HIV medicine should be placed in ESI hospitals and treatment for people living with HIV, not only for opportunistic infections, but also for ARV therapy made available.

Provident fund and gratuity should be automatically made available to the spouses of those who die of HIV-related causes to reduce the economic impact of HIV on women.

Section II

A. Affected families

Sample size: 13

I. General Information

- The 13 respondents who were part of this study were all female, except for one respondent.
- Among the 13 respondents, 10 (76.92%) were the wives of the deceased, two (15.38%) were parents and one respondent (7.7%) was the son of the deceased.
- 76.9 per cent of the respondents were educated up to the 10th standard, two respondents had no formal schooling while one was a graduate.
- A vast majority of the respondents (84.6%) had not shifted their place of residence and had been living in the same area since their birth.
- There was an almost equal divide between respondents from rural (53.8%) and urban (46.2%) areas.
- A majority of the respondents (61.6%) lived in nuclear families.
- A sizeable percentage of the respondents (46.2%) were employed in private/public sectors, while 38.5 per cent were unemployed. Two respondents were self-employed.

II. Stigma and discrimination

- A majority of the respondents (69.3%) expressed that they had faced instances of stigma and discrimination due to the presence of a person living with HIV in the family.
- These respondents (30.8%) had predominantly experienced stigma and discrimination from their own families. An equal percentage (23% each) faced discrimination in hospitals, from neighbours and community. Only one respondent faced discrimination in an educational institution. (multiple responses).
- The respondents said that initial reactions of the family towards the infected when the HIV status was revealed ranged from shock, denial, to disappointment to a greater degree, and embarrassment and empathy to a lesser extent.
- A vast majority of the respondents (84.6%) felt that that their families had accepted the deceased.

III. Impact on other family members

- The deceased were primarily taken care of by their spouses (76.9%), with parents being mentioned by four respondents.(multiple responses)

- A sizeable percentage of respondents (53.8%) said that the caretakers had lost income due to loss of work time.
- The loss of income ranged between Rs. 500 and Rs. 12,500 per month approximately.
- A vast majority of the respondents (76.9%) had to take up a job to support themselves and their families.
- A vast majority (76.9%) felt that their children were treated as usual at home and were not discriminated against.
- A sizeable majority (76.9%) felt that neither they nor their children faced any discrimination from the community.
- The respondents who had been discriminated by the community mentioned that they had been neglected, verbally abused, avoided, isolated, and their children were not allowed to play with others.

IV. HIV/AIDS and economic status

Part A – Past economic status

- A vast majority (76.9%) of the deceased had been the sole breadwinners of the family.
- A sizeable majority (84.6%) of the deceased had not obtained any specific support from their employer as their status had not been revealed to the employers.
- The respondents who had not received employer support coped with the increased expenditure mainly by borrowing from others and mortgaging assets.
- All the respondents (100%) said that the deceased had not faced any discrimination at the workplace.
- The attitude of the co-workers towards the deceased was supportive and helpful as the HIV status had not been revealed at all.

Part B – Current economic status

- A majority of the respondents (69.2%) had gone back to their parents and were supported by them, while a sizeable percentage was self-employed.
- A majority of the respondents (69.2%) felt that only part of their expenditure was met by the income available/earned.

V(a). Household expenditure:

- The monthly household expenditure was as follows:
 1. **Food** - Range (Rs.500–Rs.3,000)
 2. **Clothing** – Range (Rs. 100 – Rs. 500)

3. **Education** – Range (Rs. 100 – Rs. 800)
 4. **Rent/Accommodation** – Range (Rs. 300 – Rs. 500). Around 53.8 per cent owned their place of residence.
 5. **Medicine** – Range (Rs. 50 – Rs. 5,000)
 6. **Conveyance/ entertainment** – Range (Rs. 100 – Rs. 1,000)
 7. **Other expenditures** – Range (Rs.100 – Rs. 1,000)
 8. **Total monthly expenditure** – Range (Rs.1,450 – Rs. 9,000)
- The respondents said that the loss of income due to AIDS-related death in the family ranged between Rs. 3,500/- and Rs. 1,20,000/- for one year.

(b) After detection of HIV status:

- **Food:** A majority of the respondents (61.5%) felt that the expenditure on food had increased because of HIV.
- **Entertainment:** A vast majority of the respondents (92.3%) said that the expenditure on entertainment had decreased.
- **Medicines:** For a sizeable majority of the respondents (92.3%), expenditure on medicines had increased.
- **Education:** Around 46.15 per cent of respondents felt that the expenditure on education had increased, while for four respondents, it had decreased.
- **Debts:** Around 92.3 per cent said that debts had increased, while one respondent said that it had remained the same.

VI. Medical expenditure:

- The approximate yearly cost on treatment of opportunistic infections of the deceased had ranged between Rs. 4,000 and Rs. 40,000.
- Only three respondents said that the deceased had undergone checkups for viral load / CD4 etc. One was given treatment free of cost. For the others the cost averaged around Rs. 4,650.
- None of the deceased had taken anti-retroviral therapy (ART).
- The general medical costs ranged between Rs. 2,000 and Rs. 88,000.

VII. Key concerns for future:

The key concerns for the future of the respondents centred around the following:

- Availability of ART free of cost.

- Children's future – education, security and marriage.
- Economic security.
- Society becoming free of HIV-related stigma and discrimination.

9. State report:

Assessing the Socio-economic impact of HIV/AIDS in Maharashtra*

9.1 Profile

Network of Maharashtra by People Living with HIV/AIDS (NMP+) is a movement of People Living with HIV/AIDS (PLWHA), registered under the Societies Registration Act in 2001. NMP+ is the state-level network of, for and run by PLWHA in Maharashtra.

9.1.1 Background

NMP+ was created to provide a sense of belonging and togetherness to people living with HIV/AIDS in Maharashtra and aims to improve the quality of life of affected people. Volunteers from the organization work in the districts of Mumbai, Thane, Pune, Sangli and Pimpri Chinchwad (Asia's largest industrial area) in an attempt to build the self-esteem of PLWHA and to support their affected families. The membership is open to all PLWHA in the jurisdiction of the state of Maharashtra, irrespective of gender, caste, religion, etc and the confidentiality of members is ensured. From a group of nine members in 2001, the network has grown into a family of 413 PLWHA (as of May 2003).

Since 2001, when NMP+ came into existence, it has been actively empowering PLWHA by teaching them skills, building capacity, and giving a face and voice to the movement. It provides care and support to the affected members. NMP+ also focuses on the control of HIV/AIDS and attempts to prevent the spread of the infection. NMP+ is affiliated to the Indian Network for People Living with HIV/AIDS (INP+)

9.1.2 Ideology

Ours is a movement and we believe all PLWHA are equal. We work for the social acceptance of PLWHA who are at the centre of the epidemic and at the same time part of the solution. We respect the self-esteem of PLWHA and believe in a co-operative work culture.

* Study undertaken by NMP+ in collaboration with ILO.

9.1.3 What are our objectives?

1. To provide access to information to people living with HIV.
2. To promote social acceptance of people living with HIV and to end stigma and discrimination.
3. To provide opportunities of networking for people living with HIV.
4. To raise awareness among people emphasizing, in particular, the vulnerability of women to HIV.
5. To facilitate and improve access to treatment for people living with HIV.
6. To promote and protect the human rights of people living with HIV.
7. To promote Greater Involvement of People Living with HIV/AIDS (GIPA) at all levels of decision making.
8. To promote, through advocacy efforts, an atmosphere conducive to research, not only in the medical field but also in different areas that will benefit society.
9. To promote opportunities for skill building of its members, in order to achieve the objectives of the organization.
10. To promote and advocate drug/vaccine trials. To make sure that they are ethical, clearly explained, strictly monitored and that trial participants are fully insured against negative drug effect, through participatory involvement.

9.1.4 Present activity

1. Counselling
2. Skill and capacity building of PLWHA.
3. Referral services
4. Technical assistance to develop district-level networks and support groups in other parts of Maharashtra.
5. Facilitating treatment of opportunistic infections of PLWHA (through PATHWAY project)
6. Hospital admission/home visit as and when required.
7. Nutrition support for the most needy
8. Advocacy
9. Networking
10. Providing correct information on life after infection.
11. Motivating PLWHA to speak in public as a positive speaker.
12. Forum development.
13. Support group meetings.
14. Awareness among PLWHA, affected families, health care providers (HCP) and the general population.

9.1.5 Background and need for a study

A lot is being done to ensure that infected persons and affected people can lead normal lives. Yet there is lots more that needs to be done in order to create an atmosphere of 'live and let live' in society.

It was essential to talk to people and find their problems, their thoughts and to understand their feelings to come up with ways to create an enabling environment. Hence, we planned to conduct a survey where those who are infected and affected by HIV/AIDS would give their true opinions on this sensitive issue.

We are thankful to all those who joined hands in this task including our respondent friends and other affiliated organizations.

We hope to achieve success in the form of adoption of policies at national, international NGO, government and all possible levels.

9.1.6 Methodology

1. Quantitative – structured questionnaire (with PLWHA and their families)
2. Qualitative
 - (a) Focus group discussions (with PLWHA)
 - (b) In-depth interviews (key informants — community leaders and NGOs engaged in care and support)

One of the hurdles in collecting information was to get true insights from people affected by HIV/AIDS. Due to the sensitivity of the subject, it was difficult to obtain answers on various critical issues. Secondly, there was a need to get information from other states as well as from different districts within the state since geographical factors play a part in the spread of the virus.

In view of the above, the decision was taken to mobilize members of the network to collect information from friends and relatives where due to the familiarity between the investigator and the respondent there was greater chance of getting accurate details. Two categories of respondents were contacted. The first category included either the infected person himself/herself or a member of the immediate family who necessarily stayed with the infected person and knew the details of the patient. There were 97 such respondents in three districts of Maharashtra — Mumbai, Pune and Satara. Data was collected during July-August 2002.

In the second category, a close relative, mostly the spouse, of a person who had died due to HIV/AIDS-related causes was interviewed. There were only 20 such respondents from Maharashtra. Since the number was very small, no separate report was prepared from the second type of data. However, it is worth mentioning that the analysis of this data substantiates the findings of the first set of respondents.

9.2 Data analysis and interpretation

9.2.1 Demographic data of respondents:

Table 9.1 indicates that a majority of the respondents (62%) were male, while a sizeable percentage (38%) was female.

Table 9.1: Gender distribution of respondents

Gender	Frequency	Per cent
Male	60	62
Female	37	38
Total	97	100

The data in Table 9.2 reveals that a majority of the respondents (54%) are in the age-group of 20–30 years, while a large percentage was between 31 and 45 years. Given that these two age-groups are the most productive ones, it is evident that the state's workforce is being affected. Thus, the impact of HIV in relation to the nation's economy needs to be examined.

Table 9.2: Age distribution of respondents

Age (yrs)	Frequency	Per cent
20 – 30	52	54
31 – 45	45	46
Total	97	100

A vast majority of the respondents (69%) had been to school and had basic education (up to 12th standard). A sizeable percentage (13.5%) was graduates (Table 9.3). There were no postgraduates in the study. It can, therefore, be concluded that awareness of HIV or becoming HIV+ may not have any correlation with the level of education.

Table 9.3: Education

Educational qualification	Frequency	Per cent
No formal education	17	17.5
School (up to 12 th std)	67	69
Graduate	13	13.5
Post graduate	—	—
Total	97	100

A majority (44%) of the respondents were employed (see Table 9.4), either in the private or public sectors, or self-employed. Around 34 per cent of the respondents were unemployed. Most had become jobless after the detection of their status, some due to depression, some because of health problems and a few due to discrimination.

Table 9.4: Occupation

Occupation	Frequency	Per cent
Unemployed	33	34
Employed in private sector	39	40
Employed in public sector	4	4
Self employed	21	22
Total	97	100

Among the total 97 respondents, 86 per cent resided in their place of origin. Around 14 per cent said they had shifted to Maharashtra for reasons of marriage, work or poverty (Table 9.5). Thus, there was no evidence of anyone shifting place of residence due to HIV-related discrimination.

Table 9.5: State of residence

State of residence	Reasons for shifting, if any			Frequency	Per cent
	Marriage	Work	Poverty		
Residing in place of origin	-	-	-	83	86
Shifted to current place	2	9	3	14	14

The data in Table 9.6 shows that the majority of the respondents (75%) were from urban settings. Very few were from rural areas. However, most of the respondents in rural areas reported that they feared discrimination against their entire family.

Table 9.6: Location of current residential area

Residential status	Frequency	Per cent
Rural	18	18.5
Urban	73	75
Semi urban	6	6.5
Total	97	100

The data reveals that almost half the respondents (52%) were married and lived with their spouses, while around 22 per cent were widowed and 20 per cent were unmarried. Taken in combination with the data in Table 9.7, the inference, thus, is that 74 per cent of the respondents had been married and almost 25 per cent had lost their spouse while they were still in the early and productive age. Since the data shows that most of those interviewed were married or widowed, this means that HIV is not a problem of high-risk groups alone.

Table 9.7: Current marital status

Marital status	Frequency	Per cent
Married	51	52
Widowed	21	22
Unmarried	19	20
Living together	-	
Separated	5	5
Abandoned	1	1
Total	97	100

As depicted in Table 9.8 a majority of the respondents belonged to the Hindu religion (92.7%) while muslims and christians were three and two per cent respectively.

Table 9.8: Religion

	Frequency	Per cent
1) Hindu	90	92.7
2) Muslim	03	3.0
3) Christian	02	2.0
4) Others	02	2.0
Total	97	100

Table 9.9: Family status

Family status	Frequency	Per cent
Joint family	69	71
Nuclear family	9	9
Living alone	19	20
Total	97	100

A majority (71%) of the respondents lived in joint families, while 20 per cent lived alone, mostly compelled by their HIV-status to stay on their own (Table 9.9).

9.3 Issues in disclosure of HIV/AIDS status

Table 9.10 indicates that an equal percentage of people found out their HIV status through voluntary testing (34%) and prolonged illness (34%). About six per cent came to know their status during ante-natal check-ups. This clearly indicates that HIV infection is no more restricted to targeted groups alone.

Table 9.10: Discovery of HIV status

How HIV status was discovered	Frequency	Per cent
Voluntary testing	33	34
Donating blood	4	4
After prolonged illness	33	34
Ante-natal checkups	6	6
Pre-employment tests	2	2
Others	19	20

In the group discussions too, the responses obtained were similar. The respondents described the various reasons they decided to go in for testing. Some got it done during pregnancy, others during surgery. Still others went for tests when they began feeling weak and, thus, got to know about the infection. One respondent was surprised when the diagnosis revealed that he had HIV instead of tuberculosis as suspected.

A majority of the respondents discovered their HIV status after 1999, while a sizeable percentage had got to know their status before 1998. According to Table 9.11, 34 per cent of the respondents found out their status only after prolonged illness. This means that the epidemic is probably undetected at a very high level (95% people don't know about their HIV status - NACO statistics).

Table 9.11: Period of Detection

Period	Mumbai		Pune		Satara	
	Freq	Per cent	Freq	Per cent	Freq	Per cent
Before 1990	2	2.0	-	0	-	0
1990-1998	11	11.3	6	6.1	3	3.0
1999 and after	22	22.6	39	40.2	14	14.4

It is evident from Table 9.12 that a large number of respondents had not received pre/post-test-counselling at the time of detection. This is an area of concern as it shows that the national policy on pre-and-post-test counselling is still not being implemented thoroughly. About 60 per cent of the respondents had received counselling, of which a large majority had been counselled post-test alone. Since many of the respondents had discovered their status in the 1990s, availability of counselling might have been an issue. The quality of counselling provided also needs to be taken into account here.

Table 9.12: Availability of Counselling

Pre – Post test counseling	Frequency	Per cent
Counselled	59	60
Not counselled	38	40

From the focus group discussions, it emerged that most of the group members had got their tests done either after suffering from prolonged illness or during pregnancy at which time no counselling was given. In many cases, the person was not even informed about the test and his/ her consent not taken. The authorities often include HIV tests as part of mandatory testing. This practice is especially prevalent in government centres.

The data in Table 9.13 clearly shows that a majority (80%) of the respondents had disclosed their status. Around 20 per cent had not disclosed their status due to fear of stigma and rejection, which occurs due to misconceptions about the disease, specially its mode of transmission.

Table 9.13: Disclosure of HIV status

Disclosure of status	Frequency	Per cent
Yes	76	80
No	21	20

Table 9.14: People to whom status was disclosed (multiple responses possible)

Persons to whom respondents disclosed their HIV status	Frequency	Per cent
Spouse	38	40
Parents	92	94
Siblings	35	36
Close friends	30	31
Co-workers	10	10
Neighbours	15	16
Others	12	12

It is interesting to note that a majority of the respondents (Table 9.14) in the sample had revealed their HIV status to parents, siblings and spouses. This shows that they feel more comfortable and free with family members than with outsiders. A large percentage of respondents had revealed their HIV status to their close friends. A very small percentage had revealed it to either co-workers or neighbours, which shows that fear of stigma and discrimination is still very high. From the data, the inference is that PLWHA disclose their status when there is an enabling environment. The data shows that disclosure was usually made to family members and relatives, thus reiterating the need for a psycho-social support.

A majority (43%) of the respondents had taken efforts to protect their spouse, while 45.5 per cent fell in the 'not applicable' category. Among the 42 respondents (43%) who had taken precautions, abstinence from sex and condom usage were the common measures employed (Table 9.15).

Table 9.15: Precautions to protect spouse from HIV transmission

Precautions	Frequency	Per cent
Efforts taken	42	43
Efforts not taken	11	11.5
Not applicable	44	45.5

A majority of the PLWHA appeared to be protective towards their spouse and the common preventive practice was to use condoms or abstain from sex (Table 9.16).

Table 9.16: Ways of protection

	Freq	Per cent
(1) Abstaining from sex	21	21.6
(2) Using condom	21	21.6
(3) Stopped sharing needles	0	0
(4) Stopped donating blood	1	1.0
(5) Others	0	0
(6) Not mentioned	2	2.0
(Multiple response possible)		

9.17: Precautions to protect children from HIV transmission

Precautions	Frequency	Per cent
Efforts taken	29	30.0
Efforts not taken / not applicable	4	4.1
Decided not to have child	1	1.0
Not applicable	46	47.4
Not mentioned	17	17.5

When asked what efforts they had taken to protect their children a majority of the respondents (65%) said, this question was not applicable to them as they had come to know about their status after the birth of their children or they were still unmarried. The four respondents who had not taken precautions had been unable to do so as they had discovered their HIV status after the birth of their child or were helpless. Among the 29 respondents who had taken precautions, AZT and not breastfeeding were cited as the precautionary methods taken.

In group discussions too the respondents' protective attitude was observed. Group members were by and large aware of the need to observe safe sex. They also mentioned avoiding blood donation. It was also pointed out that in case of ill health, sex should be avoided. Some of the group members stressed the need for greater knowledge on the subject, especially the significance of the use of condom. For many, gaining the confidence of the spouse was important. Regarding protection of children, most participants felt that the infected parent should take maximum efforts, such as taking extra care if injured. The general consensus was that infected parents should not give birth to a child.

Participants did not mince words when they spoke about how children get affected when a parent or both parents are HIV+. They mentioned the tensions that get created in the family, the neighbours' attitude of ignoring or neglecting the child, teachers' discriminatory behaviour, etc. Group members appeared quite worried about their children's education and their future.

The financial contribution made by children was also discussed. Some of the group members pointed out how children are often compelled to get engaged in income-generation activities where there are chances of developing bad habits like alcoholism, drug addiction, etc.

Table 9.18 reveals that a significant number of respondents (65%) had no other members in their family who were HIV+. However, 18.5 per cent of the respondents had other people living with HIV in their families and mostly it was their spouses.

Table 9.18: HIV+ family members in respondents' families

Presence of HIV positive family members other than respondent	Frequency	Per cent
Present	18	18.5
Not present	63	65.0
Not tested	16	16.5

9.4 Issues relating to stigma and discrimination:

A majority of the respondents (57%) (Table 9.19) said that they had not experienced any stigma or discrimination as a result of HIV. But this was mostly because they had not disclosed their status at their workplace or at hospitals. Around 43 per cent had experienced stigma and discrimination, either because they themselves had disclosed their status or there was breach of confidentiality. This shows that stigma and discrimination is a problem that cannot be ignored.

Table 9.19: Experience of stigma and discrimination

Stigma and discrimination	Freq	Per cent
Experienced	42	43
Not experienced	55	57

As evident in Table 9.20, among the 42 respondents who were victims of discrimination, most faced it within their families (20.6%) and in hospitals (25.7%), rather than from neighbours and community representatives. Given that most respondents had revealed their status to their families, implying that they trusted them, the fact that HIV-related stigma and discrimination took place here, is a major finding.

Table 9.20: Source of stigma and discrimination (multiple responses)

Source	Freq	Per cent
Family	20	20.6
Hospital	25	25.7
Neighbour	8	8.2
Community	5	5.1
Educational institution	0	0
Others	3	3.0

Focus group discussions were useful in obtaining insights into this aspect. Group members revealed that neighbours avoided inviting infected persons and their families on social occasions like marriage, birthday, death rites, etc. As a result, tense relations developed with neighbours. Some also mentioned that they, along with their family, were compelled to leave their residence as they found it difficult to live in such a non-cooperative environment.

9.4.1 Some instances of discrimination

- a. Thrown out of home
- b. Deprived of basic amenities at home/property taken away

- c. Discrimination at workplace/ terminated from job
- d. Neighbours behaviour/ isolated by relatives
- e. Discrimination by medical fraternity/ denied treatment
- f. Wife labelled as spouse of HIV+
- g. Not allowed to touch their own children

The data (Table 9.21) reveals that a vast majority (39%) of the respondents' families had exhibited initial reactions of shock. The families of 18.5 per cent respondents did not accept them. However 43 per cent empathized with the HIV+ member. About four per cent said that their families had been embarrassed to have a person living with HIV with them. But about 12 per cent respondents did not disclose their status to their family due to fear of rejection, or to spare them worries.

Table 9.21: Initial reaction of family members to HIV status (multiple responses)

Initial reactions	Freq	Per cent
Shocked	38	39.1
Denied	18	18.5
Empathized	42	43.2
Embarrassed	4	4.1
Not disclosed to family	12	12.3
Others	7	7.2
Not Applicable	1	1.0

Among the respondents who had revealed their status to their families, a vast majority (63%) of them had been accepted. However, this does not mean that the entire family had accepted the respondents. About 29 per cent did not accept them initially (Table 9.22). Also, many of the respondents had revealed their status either to their parents, siblings or spouses or others within the family, and had been accepted by them alone. The other members in their families did not know the respondents' status.

Table 9.22: Acceptance by family members

Acceptance	Frequency	Per cent
Accepted	61	63.0
Not accepted	28	29.0
Not Applicable	8	8.0

The acceptance period varied from immediate acceptance to as long as a year, although the former categories were more.

9.5 Impact of HIV on women and children

Around 75 per cent of the respondents felt that they needed somebody to take care of them when they fell sick, while around 25 per cent were confident that they could manage on their own (Table 9.23). Many of the respondents said that they did not fall sick at all and could manage by themselves.

Table 9.23: Assistance required during sickness

Assistance	Freq	Per cent
Required	73	75.2
Not required	24	24.8

Families played a major role in functioning as care-givers for people living with HIV. Most of the care-givers were women — either wife, mother or sister (Table 9.24).

Table 9.24: Relationship of care taker with respondents (multiple responses)

Caretakers	Freq	Per cent
Spouse	37	38.1
Children	5	5.1
Parents	41	42.2
Siblings	23	23.7
Others	9	9.2

Table 9.25 shows that around 32 per cent reported that their care-givers had lost income as they had remained absent from work in order to look after them. There's urgent need to provide HIV education to correct the existing situation. The findings revealed that due to HIV/AIDS many middle-class families were falling below the poverty line and, especially women and children were facing lots of problems.

Table 9.25: Effect on income of care giver

Effect on income	Freq	Per cent
Income lost	31	32
Income not lost	44	45.5
Non earning member	21	22.5
Not mentioned	0	0

Table 9.26: Extent of loss

Loss in income	Loss (in Rs)
Median (average)	2,000
Range	100-18,000

It was found that a sizeable percentage of care-givers had lost income averaging around Rs. 500 to Rs. 1,500 per month. Among those who had been earning, 32 per cent said that they had lost income. Though the average monthly loss reported was Rs 2,000, in some cases the extent of loss was as much as Rs. 18,000, indicating very serious repercussions (Table 9.26). Four people did not respond to the question.

A majority of the respondents (64%) felt that this question was not applicable to them, as their spouses had either passed away, or were not in a position to take up additional responsibility. Among those who had children, many said their children were too young to take up any responsibility. Wherever the need arose, family members had to take up a new or an additional job. Financial crisis appeared to worry them more than physical crisis (Table 9.27).

Table 9.27: Additional responsibility taken to support family by spouse/children of the infected

Additional responsibility	Freq	Per cent
Quit job	1	1.0
Taken up job	11	11.3
Taken up additional job	4	4.1
Others	3	3.0
Not applicable	64	65.9

Encouragingly enough 55.4 per cent of the respondents felt that they were never discriminated against within the family set-up. However, ten per cent did say that they felt neglected. And, nearly six per cent were even asked to leave home (Table 9.28).

Table 9.28: Attitude of family towards infected/affected spouses of respondents (multiple responses)

Attitude towards spouse	Freq	Per cent
Neglected	14	10.7
Verbally abused	7	8.7
Physically abused	1	6.3
Deprived	3	6.3
Property taken away	4	6.3
Asked to leave home	9	6.3
Never discriminated	68	55.4

A majority of respondents, said, the question on treatment of children at home was not applicable as they were unmarried, did not have children, or did not live in joint families. Among those who had children, some did report various forms of discrimination such as being forced to withdraw children from school, separate vessels for children, not being allowed to play with other children, and in some cases being forced to take up jobs (Table 9.29).

Table 9.29: Treatment of children at home

Treatment of children	Freq
Withdrawn from school	2
Had to take up job	1
Denied from basic amenities	8

Around six per cent (Table 9.30) of the children were treated badly by the community, discrimination taking the form of neglect, verbal abuse and not being allowed to play with other children.

Table 9.30: Treatment of children by community (multiple responses possible)

Treatment of children	Freq	Per cent
Badly treated	6	6
Treated well	36	38
Status not known	44	45

9.6 Issues of HIV/AIDS at the workplace

The data shows that about 22 per cent of the respondents had informed their employers about their HIV status. But, of these, many were working for NGOs, networks and care homes. Around 56 per cent felt this question was not applicable to them, as they were either unemployed or self-employed (Table 9.31).

Table 9.31: Employer's knowledge of respondents' HIV status

Employer's knowledge of HIV status	Freq	Per cent
Aware	21	21.6
Not aware	22	22.7
Not applicable	54	55.7
Total	97	100

It is interesting to note that out of the 21 respondents whose employers were aware of their HIV status, only around nine (43%) respondents felt that their employers were supportive. In general, the support was psychological and rarely was there anything more specific. Many of the respondents avoided mentioning whether the employer had given any support or not, which indicates they might have faced an unpleasant situation (Table 9.23).

Table 9.32: Availability of support from employer who was aware of the HIV status

Support	Freq	Per cent
Available	9	43
Not available	12	57
Total	21	100

The respondents who received support from the employer were the ones who worked for NGOs or networks. The form of employer support was medical expenditure (6%) and paid leave (3%) (Table 9.33).

Table 9.33: Form of employer support (multiple responses)

Form of support	Freq
Medical expenditure	6
Paid leave	3

The 12 respondents who said their employers were not supportive coped by using their past savings (35%), borrowing from others (20.3%), mortgaging assets (18.5%), taking a loan from employer (11%) or discontinuing their medicines (9.2%) (Table 9.34). Some respondents who were employed and had received support from their employers said that they still had to borrow from others or depended on NGOs to supplement their incomes in times of difficulty.

Table 9.34: If not available, coping with increased expenditure (multiple responses)

Coping strategies	Freq	Per cent
Used past savings	19	35
Borrowed from others	11	20.3
Mortgaged assets	10	18.5
NGO support	5	9.2
Sale of assets	1	1.8
Took loan from employer	6	11.1
Stopped taking medicines	5	9.2
Others	6	11.1

At the workplace, a majority of the respondents (both employed and self-employed) said they did not face discrimination. However, the reason for this could be that a large number of them did not disclose their status (Table 9.35).

Table 9.35: Discrimination at workplace

Discrimination	Freq	Per cent
Discriminated	4	4
Not discriminated	48	49.5
Not applicable	45	46.5

A majority (32.9%) of the respondents who had jobs had not changed it, either because most were working for NGOs or had not disclosed their status at workplace (Table 9.36).

Table 9.36: Change of job in the last six months

Change of job	Freq	Per cent
Changed job	11	11.4
Did not change job	32	32.9
Not applicable	54	55.6

Those who had changed jobs said either they were forced to quit (36%) or had to leave because of ill health (27%). One person reported being terminated from the job specifically because he had HIV. About 27 per cent quit their jobs on their own as they felt they that would not be able to work and went into isolation (Table 9.37).

9.37: Reason for change/loss of job

	Freq	Per cent
(1) Asked to Quit	4	36.0
(2) Discrimination by co-workers	0	0
(3) Terminated	1	9.0
(4) Ill-health	3	27.2
(5) Others	3	27.2

Table 9.38: Absenteeism from work during last six months

Absenteeism	Frequency	Per cent
Not Absent	62	63.9
Absent	35	36.0
Median (Absent)	20	—
Range (Absent days)	2 days – 6 months	—

A large number of the respondents (36%) were absent from work during the last six months. The period of staying absent from work varied from two days to the entire six months (Table 9.38).

Table 9.39 shows that a majority (62.8%) of those who had been absent from work reported loss in income.

Table 9.39: Loss of income due to absenteeism

Loss of income	Freq	Per cent
Lost income	22	62.8
Did not lose income	13	36.2

As indicated in Table 9.40 amount lost during the last six months due to absenteeism varied from Rs. 100 to Rs. 30,000.

Table 9.40: Amount lost

Median (Rs)	1500
Range	Rs. 100 – Rs. 30,000

9.7 Economic impact of HIV on PLWHA and their families

The predominant support came from family for most respondents (Table 9.41). There was also NGO and community support in a few cases. Even if they were employed, the respondents turned to family and NGOs first for support.

Table 9.41: Source of support for expenses, if unemployed (n=54) (multiple responses)

Support	Freq
Family support	30
NGO support	2
Community Support	2
Others	13
Not mentioned	54

Table 9.42: Monthly income of respondents

	No. of People	Income	Per cent
Information given	80	—	82.4
Not mentioned	17	—	17.6
Median – average		Rs. 2,500	—
Range		Rs. 300 Rs. 20,000	—

The monthly income of respondents ranged around Rs. 300–Rs. 20,000 with Rs.2,500 as the average. Around 17 respondents did not respond to this question, as they were totally dependent on their families for support and were not in a position to even calculate their average expenditure versus support. Many respondents depended on external support, personal savings and borrowings from others to meet their basic needs (Table 9.42).

Some respondents were not aware of their family income, while for others the amount varied from Rs. 500–Rs. 35,000, with the average around Rs. 4,000 (Table 9.43).

Table 9.43: Monthly income of the family

Information given	70
Median - average	Rs. 4,000
Range	Rs. 500 – Rs. 35,000

A vast majority of the respondents (70 per cent) said that their family members did not take up any extra work due to their illness, while around 23 per cent said that members of their families had taken up extra work to support their increased expenditures (Table 9.44). Of these, 11 respondents felt that it covered only part of their expenses, while 10 respondents felt that it fully covered all the expenses. One respondent could not really say whether the additional work had made an impact.

Table 9.44: Extra work by household member

Change of job	Freq	Per cent
Did extra work	22	23
No extra work	68	70
Not applicable	7	7

9.8 Prior to HIV status

Table 9.45: Monthly household expenses

Expenses on	No. of respondents	Median (in Rs.)	Range (in Rs.)
Food	93	1000	200-3000
Clothing	66	250	50-1500
Education	44	200	50-3600
Accommodation	36	500	120-2000
Medicine	65	300	50-2000
Entertainment	41	300	100-2000
Other expenses	29	300	50-7000
Total expenses	68	2800	400-7800

To estimate any increase on household expenses, questions were asked on how much was spent on some of the common household expenses prior to the HIV infection. However, not all the respondents answered all questions, as some said they could not afford to spend money on certain items while others stated that certain expense items were not applicable to them. As shown in Table 9.45 the monthly expenses on food prior to the discovery of HIV status ranged between Rs. 200 and Rs. 3,000, with the average being Rs. 1,000. The monthly expenses on clothing for 66 respondents averaged around Rs. 250. The remaining 31 respondents felt they were not in a position to spend money on clothing

Fifty-three respondents said the question on education was not relevant to them as they did not have children or their children were too young for them to incur any educational expenditure. For those who had incurred expenses, the average amount spent to education worked out to Rs. 200 per month.

Sixty-one respondents said they were living in their families' own houses and so incurred no expenses on accommodation. For the remaining 36 respondents, the amount averaged around Rs. 500 per month, the maximum being Rs. 2,000. Thirty-two respondents did not experience any need for medicines and so there were no medical expenses. For the other 65 respondents, the amount averaged around Rs. 300 per month.

People often tend to curtail expenses on entertainment whenever there is need for extra money. With this assumption in mind, an attempt was made to probe into the expenditures made on entertainment before the HIV infection. To this 41 respondents responded and the average worked out to Rs. 300 per month, the minimum being Rs. 100 and the maximum Rs. 2,000.

Asked about other petty expenses, 29 respondents provided information and the average expenses were around Rs. 300, the maximum being Rs. 7,000.

When asked about the total household expenses, the average expenditure was reported to be around 2,800 per month.

Table 9.46: If free from illness during last six months, the amount that could have been earned

Not applicable	32
Information given	65
Median – Average	9,000
Range	Rs. 600 – Rs. 60,000

Thirty-two respondents did not figure in this category as they either did not suffer from illness, or their illness had no impact on their income. For the 65 respondents in this category, the monthly income that they could have earned had they been fit averaged around Rs. 9,000 (Table 9.46).

9.9 After the detection of HIV status

After the detection of HIV, most respondents reported an increase in the household monthly expenditures on food (Rs. 345), medicines (Rs. 370) and debts (Rs. 3,086), while spends on entertainment (Rs. 82) and education (nominal) had decreased. Two respondents said that the expenses on food had decreased, while one said that entertainment expenses had increased. Five respondents said that their medical expenses had decreased as they didn't have money to buy medicines (Table 9.47).

Table 9.47: Household monthly expenditure

Expenditure on	Increased/ Decreased	Mean Amt. Increase/ decrease (in Rs.)
Food (increased)	47	345.00
Entertainment (decreased)	37	82.00
Medicines (increased)	62	370.00
Education (decreased)	12	—
Debts (increased)	32	3,086.00

9.10 Medical Expenditure

As shown in Table 9.48 the average cost incurred on treatment of opportunistic infections for 70 respondents was Rs. 4,100. The other 27 respondents did not suffer from any opportunistic infections or had not taken any medicine during the last six months.

Table 9.48: Cost incurred on treatment of opportunistic infections in the last six months

Not applicable	27
Median – Average	Rs. 4,100
Range	Rs. 200 – Rs. 35,000

Table 9.49: Cost incurred on checkups of viral load and CD4/CD8 count

Not applicable	74
Median – Average	Rs. 1,600
Range	Rs. 20 – Rs. 40,000

It is vital to note that a majority of people living with HIV do not have access to health care in our country. The data in Table 9.49 clearly shows that around 74 respondents had not undergone any kind of viral load, CD4 and CD8 testing.

The data in Table 9.50 shows that 95 respondents had not had any ART. The cost of treatment for two respondents averaged around Rs. 2,700 per month.

Table 9.50: Cost incurred on anti-retroviral-therapy (ART) per month

Not applicable	95
Median – Average	Rs. 2,700
Range	Rs. 2,700

The 20-odd respondents who had incurred medical expenditure spent an average of Rs. 460 per month (Table 9.51). One of the respondents reported an expenditure of Rs. 1,25,000 on treatment, but this could be because the patient had taken treatment from quacks.

Table 9.51: Cost incurred on other medicines and tests

Not applicable	77
Median – Average	Rs. 460
Range	Rs. 100 – Rs. 1,25,000

Table 9.52 gives an indication of how HIV patients are exploited. On an average, tests should not cost more than Rs.10. However, there are people who have spent as much as Rs. 3,700, indicating that it is a very serious matter.

Table 9.52: Cost of testing

Free	46
Average cost	Rs. 622
Median cost	Rs. 300
Range	Rs. 50-Rs. 3,700

More worryingly, people faced discrimination from hospital staff. At times they were refused treatment. At times they were the butt of sarcastic remarks by the medical and para-medical staff. Often no concern was shown as to whether a patient could get the medicine or not. They also mentioned that sometimes hardly anybody would turn up to remove the dead body of an HIV-infected person in the hospital and in the neighbourhood.

Lastly, the group discussion also touched upon gender-specific problems. Most of the group members felt that women — whether infected or affected — had to face far more problems than men.

9.11 Key concerns

Almost all the respondents expressed apprehensions and concerns about the future. Most had worries about whether they could afford the medicines and treatment once their condition deteriorated. Here are some of the key concerns as voiced by the respondents:

- (1) The prime worry of the respondents was the availability of affordable medicines and treatment. Many felt that medication should be free.
- (2) Those who had children or dependents were worried about the fate of their wards.
- (3) Monetary concerns were very high. Would they be able to afford treatment? Would they have enough savings to meet their basic livelihood needs when their condition deteriorated?
- (4) Employment was a major concern. Many said that employment opportunity for HIV+ people should be provided
- (5) Some respondents said that condoms should be easily available at places like government hospitals, etc.
- (6) Most of the respondents also expressed concern over stigma and discrimination in society and felt that something should be done to reduce this.

9.12 Discussion

The ages between 20 and 45 years are a vital period since these are the most productive stages in a person's life. Since more than 90 per cent of the respondents were below 40, it is evident that India's workforce is being significantly affected. The impact of HIV in relation to the nation's economy needs to be examined.

It can be concluded that awareness on HIV or becoming HIV+ may not have any correlation with the level of education.

Shifting place of residence due to HIV-related discrimination was not visible.

From the data, it is clear that transmission of HIV among women predominantly occurs within the institution of marriage.

None of the men in the study were widowed. Though the representation of men in the study is less than half of the female representation, this finding could also be indicative of a better physical and mental health status among women, with specific reference to the effects of HIV.

The data clearly indicates the lack of the ability of women to protect themselves, as the majority of women in our country are not in a position to negotiate their reproductive rights. This was supported by the findings from the qualitative data also.

It can be concluded that most people go in for testing when they are either sick for a prolonged period or, in case of married women, when their spouse's status is discovered. Therefore, the concept of taking precautions to prevent transmission within the circle of marriage arises only when the persons involved are in a position to do so, which the data clearly shows, they are not.

It can be concluded that stigma and discrimination was widely prevalent in care centres and families, although support from families also ranked high.

With reference to acceptance by family, many of the respondents had revealed their status either only to their parents, siblings or spouses or others within the family, and had been accepted by them alone. The other members in their families did not know the respondents' status.

The impact of HIV on women and children was much more drastic, when compared to its impact on men.

Some respondents who were employed, and for whom support was available, felt that even with employer support, they still had to depend on loans from others, or on NGOs to supplement their incomes in times of difficulty.

The study has revealed the following facts:

- HIV/AIDS is still seen as a threat by many in the public.
- This has caused stigma and discrimination towards people living with HIV.
- Proper and right information on HIV should be provided during counselling so as to prevent new infections, especially among children.
- Advocacy strategies have to be initiated on human rights issues, especially on care and support issue and employment.
- There is practically no information on life after infection. This is forcing PLWHA to stay in isolation thereby increasing the chance of the epidemic going underground. As this study was completed with the involvement of PLWHA networks, it indicates that involvement of positive networks is very important in responding to the pandemic. Therefore, PLWHA networks should be supported and strengthened. Meaningful involvement of PLWHA at all possible levels is one of the main and effective strategies in the response to the pandemic.

9.13 Conclusions

- From the findings it emerges that there are more women being widowed than men.
- The major mode of transmission is through sexual mode and in heterosexuals.
- The most affected group of the HIV epidemic is the age group around 20-45.
- Employer support is important in protecting the lives & livelihood of PLWHA.
- Data shows that PLWHA are taking precautions to protect their partner and spouses from getting infected after they discovered their HIV + status.
- Apart from personal trauma, the stigma and discrimination attached to HIV add to the alienation of PLWHA.
- From the one-to-one interviews, it has emerged that there is lack of information on leading life after infection, particularly on how to cope up with the HIV status.

9.14 Recommendations

- Meaningful GIPA should be implemented at all levels.
- NACO's policy on counselling needs to be implemented.
- ILO code of practice has to be followed at the workplace.
- Health insurance policy for HIV+ people is needed.
- A committee sensitive to the issues of people living with HIV needs to be set up to monitor the quality of counselling provided – both pre test and post test.
- Enabling environment needs to be created.
- Family members are supportive. Others in the society should also come forward to contribute.
- Counselling services should be made available at every testing centre and should be monitored properly to give the desired result
- There is increasing sense of responsibility of infected towards the spouse, children and society
- Employment opportunity for PLWHA should be provided and advocacy efforts should concentrate on this
- Formation and strengthening of PLWHA networks is very important to respond to the epidemic.

- The business sector needs to be sensitized to the needs of people living with HIV in order to render their support to them.
- Strong legal policies need to be formed and implemented to address issues of stigma, discrimination and HIV-related human rights violations.
- The concept of involving people living with HIV in programmes addressing HIV/AIDS issues needs to be implemented in reality.
- Effect on children appears to be more serious. The impact on them needs to be probed in more detail.

Annexure 1



ILO HIV/AIDS PREVENTION PROJECT

Interview Schedule for the Study:

"Assessing the Socio-economic Impact of HIV/AIDS on
Families of People Living with HIV/AIDS"

Classification Data

01. Respondent ID#		
02. Area ID#		
03. Interviewer ID#		
04. Date of Interview		
05. Sex	1. Female	2. Male

Section - I: General Information

101. Age	Yrs. D.O.B: (/ /)	
102. Educational Qualification	01. No formal school 02. School upto_____(standard/level) 03. Graduate 04. Post-graduate+	
103. State of Residence	Origin 01. Delhi 02. Tamil Nadu 03. Maharashtra 04. Andhra Pradesh 05. Karnataka 06. West Bengal 07. Nagaland 08. Imphal (Manipur) 09. Churachandpur (Manipur) 10. Others 11. Don't know	Current 01. Maharashtra 02. Tamil Nadu 03. Manipur 04. Delhi 05. Others
104. Since when you are staying _____(current place)	Yrs. (if staying since birth skip to 106)	

105. What are the reasons for coming to _____ (place)	
106. Location of Current Residential Area	01. Rural 02. Urban 03. Semi-urban
107. Religion	01. Hindu 02. Muslim 03. Christian 04. Others
108. Current Martial Status	01. Married 02. Separated/Divorced 03. Abandoned 04. Widowed 05. Living together 06. Unmarried/No live-in partner
109. Family Status	01. Living with parents/joint family 02. Living separately with spouse/partner 03. Living alone
110. Occupational Status	01. Employed a. Public b. Private 02. Unemployed 03. Self employed

Section - II : Information on HIV/AIDS Status

201. How did you discover your HIV Status?	01. Voluntary testing 02. While donating blood 03. After prolonged illness, symptomatic 04. During pregnancy 05. While seeking employment abroad 06. Others (specify_____)
202. When was it detected?	(/ /)
203. Where was the test done?	1. Govt. 2. Private Place:_____

204. Did you have pre and post test counseling?	1. Yes 2. No
205. What was cost of testing	Rs. _____ No cost involved
206. Have you disclosed your HIV status to others?	01. Yes 02. No (skip to q. 208)
207. If yes, to whom?	01. Spouse 02. Parents 03. Siblings 04. Close friends 05. Co-workers 06. Neighbours 07. Others (specify _____)
208. If no, what are the reasons for not disclosing your HIV status?	01. Stigma and discrimination 02. Rejection 03. Others (specify _____)
209. Did you take any precaution to protect your spouse/ partner from getting infected?	1. Yes 2. No (Skip to q.211) 3. Not Applicable (Skip to SECTION III)
210. If yes, what efforts did you take?	01. Abstain from having sex 02. Started using condom consistently 03. Stopped sharing needles 04. Stopped donating blood 05. Others (specify _____)
211. Did you take any precaution to protect your children from getting infected?	1. Yes 2. No 3. Decided not have a child (skip to SECTION III) 4. Not applicable (skip to SECTION III)
212. If yes, what efforts did you take?	01. AZT/Nevropine during pregnancy 02. C-section during delivery 03. AZT to the infant 04. No breastfeeding 05. Decided not to have a child

213. Apart from you, are there other family members who are HIV+ ?	1. Yes 2. No (Skip to SECTION III)
214. If yes, who are they?	1. Spouse 2. Siblings 3. Children – Age Sex 1. 2. 4. Others (Specify _____)

Section - III: Stigma and Discrimination

301. Have you faced any discrimination or stigma?	1. Yes 2. No
302. If yes, then from whom/where?	1. Family 2. Hospital 3. Neighbour 4. Community 5. Educational Institution 6. Others (specify _____)
303. Please mention three instances when you faced discrimination?	1. 2. 3.
304. What was the initial reaction of your family members to your HIV status?	01. Shocked 02. Denied/Disappointed 03. Empathized 04. Embarrassed 05. Not disclosed to family (Skip to SECTION IV) 06. Others
305. Did your family accept you?	01. Yes 02. No
306. If yes, how long did they take to accept?	

Section - IV: Impact on Women and Children

401. Have you needed anyone to take care of you, while you were sick?	1. Yes 2. No
402. If yes, who takes care of you?	01. Spouse 02. Children 03. Parents 04. Siblings 05. Others
403. Did your care giver lose income due to lose of work time? (in case if they have one)	01. Yes 02. No 03. Non-earning member (Skip to q.405)
404. If yes, how much income did they lose?	Rs. _____
405. What additional responsibilities were taken to support the family by the spouse/ children of the infected?	01. Quit job in order to take care 02. Had to take-up job in order to support the family (wife/children) 03. Had to take up additional job to meet the increasing expenditure 04. Others 05. Not applicable
406. What was the attitude of the family members towards the infected/ affected spouse?	01. Neglected, isolated, avoided 02. Verbally abused, teased 03. Physically abused 04. Deprived of using basic amenities at home 05. Property taken away 06. Asked to leave home 07. Never discriminated
407. How were the children treated at home?	01. Withdrawn from the school 02. Had to take up job 03. Were denied basic amenities 04. Others 05. Not applicable

408. Were you or your children treated badly or differently by others in the community because of having HIV/AIDS in the family?	01. Yes 02. No 03. Status not known to others (Skip SECTION V)
409. If yes, how did they treat you or your children differently	01. Neglected, isolated, avoided 02. Verbally abused, teased 03. Did not allow your children to play with their children 04. School authorities were compelled to expel the child from the school 05. Others

Section - V: HIV/AIDS and Employment

A - Only if employed

501. Does your employer know about your HIV status	1.Yes 2.No 3. Self-employed (skip to q. 504)
502. Do you get support of your employer?	01. Yes 02. No
503. If yes, specify the form of employer support	1. Medical expenditure 2. Paid leave 3. Others (Specify _____)
504. If no support of employer / self-employed, how do you cope with the increased expenditure on medicines, maintenance etc?	01. Use past savings 02. Borrow from others 03. Mortgage assets 04. Sale assets / durable 05. Loan from employer 06. NGO supports 07. Stopped taking medicines 08. Others
505. Did you face any discrimination at the workplace?	1. Yes 2. No

506. If yes, how were you discriminated?	<ol style="list-style-type: none"> 1. Promotion denied 2. Forced to take-up voluntary retirement 3. Benefits were not given 4. Others
507. What was the attitude of co-workers at the workplace?	<ol style="list-style-type: none"> 1. Neglected, isolated, avoided 2. Verbally abused, teased 3. Others
508. Did you change your job in the last six months	<ol style="list-style-type: none"> 01. Yes 02. No
509. How many jobs have you changed in last six months	Nos. _____
510. What was the reason for change / loss of job?	<ol style="list-style-type: none"> 01. Was asked to quit job 02. Discrimination by co-workers 03. Terminated 04. Ill health 05. Others
511. How many days were you absent from work in the last six months due to illness?	Days/months:
512. Did you lose wage/income due to leave/absence?	<ol style="list-style-type: none"> 01. Yes 02. No (Skip to q.601) 03. Not applicable (Skip to q.601)
513. If yes, how much wage/income did you lose?	Rs. _____
514. What was the amount of fringe (over time, paid leave etc.) benefits lost, if any? Please specify the nature of fringe benefits?	<ol style="list-style-type: none"> 1. 2. 3. Rs. _____ (Approx)

B – Only if Un-employed

515. How do you support your expenses?	1. Family support 2. NGO/Network support 3. Community support 4. Others (Specify_____)
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Section - IV: Indirect Cost

601. What is your monthly income?	Rs. _____
602. What is the source of income?	
603. What is the monthly income of the family?	Rs. _____
604. Did any of your household member (spouse/ children) do extra work to compensate the loss of income/time due to your illness	01. Yes (Specify_____) 02. No
605. If yes, how much of current expenditure does it cover?	01. Covers only part of increased expenses 02. All increased expenses are covered

Section - VII: Household Experience**A-Prior to HIV Status**

701. What are the household monthly expenses on food?	Rs. _____
702. What are the household monthly expenses on clothing?	Rs. _____
703. What are the household monthly expenses on education?	Rs. _____
704. What are the household monthly expenses on rent/accommodation?	Rs. _____
705. What are the household monthly expenses on medicine?	Rs. _____

706. What are the household monthly expenses on conveyance, entertainment etc?	Rs. _____
707. Other expenditures	Rs. _____
708. Total monthly expenditure	Rs. _____
709. How much would you have earned if you were free from illness during the last six months	Rs. _____

B-After the Detection HIV Status

710. How has HIV/AIDS impacted on the following: a. Expenditure on food has increased b. Expenditure on entertainment has decreased c. Expenditure on medicines has increased d. Expenditure on education has decreased e. Debts have increased	<i>If. YES</i>	
	1. Yes 2. No	Increased from Rs.____ to Rs.____
	1. Yes 2. No	Decreased from Rs.____ to Rs.____
	1. Yes 2. No	Increased from Rs.____to Rs.____
	1. Yes 2. No	Decreased from Rs.____ to Rs.____
	1. Yes 2. No	Approx Amt. _____

Section VIII: Medical Expenditure

801. What is the cost incurred on treatment of opportunistic infections in the last six months?	Rs. _____
802. Cost incurred on checkups of viral load & CD4/ CD8 Count	Rs. _____
803. Cost incurred for ART	Rs. _____
804. Other general medical costs/tests (specify)	Rs. _____

Section IX:**Key Concerns for Future**

- 1.
- 2.
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Annexure 2



ILO HIV/AIDS PREVENTION PROJECT

Interview Schedule for the Study:

"Assessing the Socio-economic Impact of HIV/AIDS on
Families of People Living with HIV/AIDS"

Schedule for Affected Families
(Where an adult HIV/AIDS death has occurred)

Classification Data

01. Respondent ID#		
02. Area ID#		
03. Interviewer ID#		
04. Date of Interview		
05. Sex	1. Female	2. Male

Section - I: General Information

101. Age	Yrs. D.O.B: (/ /)	
102. Educational Qualification	05. No formal school 06. School upto _____(standard/level) 07. Graduate 08. Post-graduate+	
103. State of Residence	Origin 12. Delhi 13. Tamil Nadu 14. Maharashtra 15. Andhra Pradesh 16. Karnataka 17. West Bengal 18. Nagaland 19. Imphal (Manipur) 20. Churachandpur (Manipur) 21. Others 22. Don't know	Current 06. Maharashtra 07. Tamil Nadu 08. Manipur 09. Delhi 10. Others

104. Since when you are staying _____(current place)	Yrs. (if staying since birth skip to 106)
105. What are the reasons for coming to _____ (place)	
106. Location of Current Residential Area	04. Rural 05. Urban 06. Semi-urban
107. Religion	05. Hindu 06. Muslim 07. Christian 08. Others
108. Family Status	04. Extended family 05. Nuclear family
110. Occupational Status	04. Employed c. Public d. Private 05. Unemployed 06. Self employed

Section - II: Stigma and Discrimination

201. Have you faced any discrimination or stigma?	1. Yes 2. No
202. If yes, then from whom/where?	1. Family 2. Hospital 3. Neighbour 4. Community 5. Educational Institution 6. Others (specify _____)
203. Please mention three instances when you faced discrimination	1. 2. 3.
204. What was the initial reaction of the family towards the infected, when the HIV status was known?	01. Shocked 02. Denied/Disappointed 07. Empathized 08. Embarrassed 09. Not disclosed to family (Skip to SECTION IV) 10. Others

205. Did the family accept him/her?	01. Yes 02. No
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Section - III: Impact on Other Family Members

301. Who took care of the deceased?	06. Spouse 07. Children 08. Parents 09. Siblings 10. NGO 11. Hospital 12. Others
302. Did the care giver lose income due to lose of work time?	04. Yes 05. No (Skip to q.304) 06. Non-earning member (Skip to q.304)
303. If yes, how much income did they lose?	Rs. _____
304. What additional responsibilities were taken to support the family by the parent/ spouse/ children of the deceased?	06. Had to take-up job in order to support the family 07. Had to take up additional job to meet the increasing expenditure 08. Others 09. Not applicable
305. How were the children of deceased treated at home?	06. Withdrawn from the school 07. Had to take up job 08. Were denied basic amenities 09. Others 10. Not applicable
306. Were you or the children of deceased treated badly or differently by others in the community because of HIV/AIDS death in the family?	04. Yes 05. No 06. Status not known to others (Skip SECTION IV)

307. If yes, how did they treat you or the children of deceased differently?	06. Neglected, isolated, avoided 07. Verbally abused, teased 08. Did not allow your children to play with their children 09. School authorities were compelled to expel the child from the school 10. Others
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Section - IV: HIV/AIDS and Economic Status

Part - A (Past Economic Status)

401. What was the employment status of the deceased?	1. Was the only bread winner of the family 2. Was a earning member in the family 3. Was self-employed (Skip to q.404) 4. Was a non-earning member (Skip to PART-B)
402. If, only bread winner or an earning member of the family did he/she get support of the employer?	03. Yes 04. No (Skip to q.404)
403. If yes, specify the form of employer support	1. Medical expenditure 2. Paid leave 3. Others (Specify _____)
404. If no support of employer / self-employed, how did the family cope with the increased expenditure on medicines, maintenance etc?	09. Use past savings 10. Borrow from others 11. Mortgage assets 12. Sale assets / durable 13. Loan from employer 14. NGO supports 15. Family supports 16. Stopped taking medicines 17. Others
405. Did the deceased face any discrimination at the workplace?	1. Yes 2. No

406. If yes, how was he/she discriminated?	<ol style="list-style-type: none"> 1. Promotion denied 2. Forced to take-up voluntary retirement 3. Terminated 4. Benefits were not given 5. Others
407. What was the attitude of co-workers at the workplace?	<ol style="list-style-type: none"> 1. Neglected, isolated, avoided 2. Verbally abused, teased 3. Supportive/helpful 4. Others

B – Current Economic Status

408. How does the family support expenses?	<ol style="list-style-type: none"> 1. Other siblings support the family 2. NGO/Network support 3. Community support 4. Children work to earn money to support the family 5. Parents of deceased work to earn to support the family 6. Others (Specify_____)
409. How much of current expenditure does it cover?	<ol style="list-style-type: none"> 03. Covers only some part of expenses 04. All expenses are covered 05. Have reduced the household expenses

Section - V: Household Expenditure

A-Prior to HIV Status

501. What are the household monthly expenses on food?	Rs. _____
502. What are the household monthly expenses on clothing?	Rs. _____
503. What are the household monthly expenses on education?	Rs. _____

504. What are the household monthly expenses on rent/ accommodation?	Rs. _____
505. What are the household monthly expenses on medicine?	Rs. _____
506. What are the household monthly expenses on conveyance, entertainment etc?	Rs. _____
507. Other expenditures	Rs. _____
508. Total monthly expenditure	Rs. _____
509. How much of income you think the family has lost due to the AIDS death?	Rs. _____

B-After the Detection HIV Status

510. How has HIV/AIDS impacted on the following:	<i>If. YES</i>
a. Monthly expenditure on food increased	1. Yes 2. No Increased from Rs. ____ to Rs. _____
b. Monthly expenditure on entertainment decreased	1. Yes 2. No Decreased from Rs. ____ to Rs. _____
c. Monthly expenditure on medicines increased	1. Yes 2. No Increased from Rs. ____ to Rs. _____
d. Monthly expenditure on education decreased	1. Yes 2. No Decreased from Rs. ____ to Rs. _____
e. Debts have increased	1. Yes 2. No Approx Amt. _____

Section VI: Medical Expenditure

601. What was the approximate yearly cost on treatment of opportunistic infection of the deceased?	Rs. _____
602. What was the yearly cost incurred on checkups of viral load & CD4/ CD8 Count	Rs. _____
603. What was the yearly cost incurred for ART	Rs. _____
604. What was other general medical costs/tests (specify)	Rs. _____

Section VII: Key Concerns for Future

- 1.
- 2.
- 3.

