Both biological and social reasons make women more vulnerable to HIV infection and these factors need to be taken into account when planning strategies against HIV/AIDS. Many of the HIV positive women in India are single-partner married women, who have little control over their bodies, placing them at risk of contacting the infection. The research found strong gender differences in the impact of the disease. It also found that, perhaps for different sets of reasons, simple awareness of about HIV/AIDS does not necessarily translate into changed behaviour for either sex.

The basic research for this book was carried out in 1999-2000 in Delhi. Focusing on the household and the community, the study included interviews with HIV positive persons and their family members as well as focus group discussions with men, women, adolescent boys and girls in a slum cluster in Central Delhi.

Swapna Mukhopadhyay is the Director of Institute of Social Studies Trust, New Delhi. Rajib Nandi, Madhurima Nundy and Jyotsna Sivaramayya are Research Associates at Institute of Social Studies Trust, New Delhi.

The Institute of Social Studies Trust (ISST), is a non-profit, non-governmental organisation. ISST conducts research and action programmes to promote social justice and equity for the underprivileged with a focus on women. In recognition of its work, ISST has been conferred the NGO Consultative Status (II) by the United Nations.

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GENDER AND HIV/AIDS IN DELHI

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Institute of Social Studies Trust
New Delhi

Dedicated to
all those affected families and individuals
who are coping with HIV/AIDS

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Gender and HIV/AIDS in Delhi

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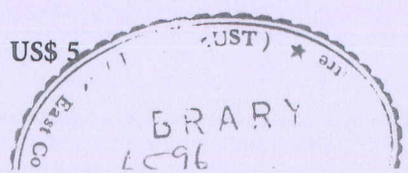


Contents

Preface and Acknowledgement

The basic field research for this document was carried out in various locations in Delhi between June 1999 and January 2000 for a project sponsored by UNIFEM. The primary purpose had been to study the gendered impact of HIV/AIDS within the family and the community. The study findings are based on personal interviews with PLWH/A and their family members. Meeting were also held with bereaved families who have lost their main earning member to the epidemic. Focus Group Discussions were held separately with married men and women as well as with adolescent boys and girls, in order to gain insight into their perception about HIV/AIDS and the factors that make them vulnerable to the infection.

ISST has had long experience of research in the area of reproductive health from a gender perspective. Until now, we had shied away from researching HIV/AIDS primarily because we felt the challenge to be much too overpowering. Colleagues at the Bangalore unit of ISST who have been involved in field-based training programmes in rural Karnataka for long have been reporting the devastation caused by the steady spread of HIV/AIDS cases in the villages and townships within their area of operation, and the social stigmatisation of the affected families that it brings in its wake. By the time the Delhi office of UNIFEM came up with the proposal for doing a few pilot studies on the gender dimensions of HIV/AIDS, we were mentally prepared to take the plunge.

ISST is grateful to UNIFEM, for sponsoring the original study. In particular, we would like to thank Ms. Chandni Joshi, South Asia Regional Director and Ms. Suneeta Dhar of UNIFEM Delhi office, who went way beyond the call of duty to help us break into this challenging area of research. Nobody knows better than us how invaluable that help was for our team.

We are highly indebted to Dr. D. Sengupta, National Consultant of NACO, for providing us with access to affected individuals and families. Organizations like Nav Jeevan Sewa Mandal, Salaam Baalak Trust and Sahara helped us to carry out the study. We would like to extend our sincere thanks and gratitude to them.

We would also like to thank all our colleagues at ISST for providing logistic support during the work. We would like to thank Talha and Maisra Malik, Veenu Singh, Vishal Goyal, Sudhir Miglani and Nidhi Arora, among others.

Finally, our thanks and gratitude to the PLWH/A and their family members who have spent time talking to us, and without whose support and co-operation it would have been impossible to carry out this study. We hope that the results of this work will contribute in some small measure towards changing the difficult environment within which they struggle and survive today.

Swapna Mukhopadhyay
Director, ISST
May 2001

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
BSF	Border Security Force
CSW	Commercial Sex Worker
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
ITBP	Indo-Tibetan Border Police
IDU	Intravenous Drug User
NACO	National AIDS Control Organisation
NGO	Non-Governmental Organisation
PLWH/A	People Living With HIV/AIDS
SBT	Salaam Baalak Trust
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNIFEM	United Nations Development Fund for Women
WHO	World Health Organisation

CHAPTER I

Introduction

1.1 Background

For quite a while after AIDS virus was 'detected' for the first time in the USA in 1981, there was a general feeling in India that AIDS was after all a problem of the 'promiscuous' and 'degenerate' West, and that in India, one is relatively safe from its reaches. However, one did not have to wait too long before the first case of AIDS surfaced in the country. In 1986, AIDS cases were reported in Mumbai and later on in Chennai among female sex workers. As these came to light, sheer panic and fear gripped people's minds. Anyone even with a suspicion of harboring the virus was immediately isolated and was treated like a pariah. A judgement passed by the Bombay High Court in 1989, while rejecting a petition by two mothers for the release of their HIV positive sons detained in Goa under Public Health Law, noted that although isolation results in social ostracism and encroaches on individual liberty, it is necessary due to the fear of spread of the virus.

It is hard to imagine the agony and the suffering of scores of HIV/AIDS affected individuals and their families who are shunned by the community and turned away even today by public authorities. Despite recent media–based advocacy attempts, these individuals and their families continue to be subjected to every form of social discrimination, stigma and blame. HIV/AIDS is labeled as a 'dirty disease'. It is believed by many to be brought on as a legitimate punishment for sins committed. Pervasive misinformation about the nature of the ailment and how it spreads is primarily responsible for the fear psychosis that it has generated, and this has been proving to be the biggest hindrance in tackling the challenge of containing it and of ensuring proper care for those who have contacted it already.

The fact that sexual contact is the most common mode of transmission makes the task infinitely more complicated. In India, society's response to sexual matters is anything but open and receptive. Ours also happens to be one of the most hierarchical societies in the world, what with sharp divisions along caste, class and gender lines. As a rule one could surmise that, ceteris paribus, the more hierarchical a society is, the greater is the probability that any external shock will have a strong group-differentiated impact. In particular, in a highly patriarchal society like India, the social and economic effects of a sexually transmitted infection like HIV/AIDS is likely to be worse for women. The fact that treatment is very expensive and at the present state of knowledge the disease is 'incurable', are factors that only make the problem even more intractable.

Research all over the world indeed does suggest that the HIV epidemic affects men and women differently. The differences are seen both in terms of greater biological vulnerability of women, as well as in terms of non-biological, social impact of the infection. In order to understand the nature and extent of the gender differentiated impact of HIV/AIDS, one has to study it in the context of the household and the community where gender relationships, roles, expectations etc., are played out according to prescribed societal norms. There are not too many research studies in India that are currently available on this subject. This work is an attempt to fill a bit of that void.

The basic research for the study was carried out in 1999-2000 in Delhi. The study examines two aspects of the epidemic: first, the societal norms that influence 'risk behaviour' of men and the resultant increase in women's vulnerability, and second, the gender differentiated impact of the illness within the family. The study focuses on the consequences of the epidemic for the average Indian woman, not necessarily belonging to the 'high risk groups' that are generally targeted by the many national and international HIV/AIDS intervention programmes. Such an approach is justified by the significant incidence of disease prevalence in single partner married women as revealed by the several sentinel surveys carried out by the National AIDS Control Organization in anti-natal clinics in different locations in India.

1.2 Gender and HIV/AIDS

According to the UNAIDS figures, women constitute 41 percent of the population that are currently living with HIV/AIDS around the world. While there are no firm figures, it is believed that the rate of new infection is higher among women, especially in developing countries. In these countries, the awareness level about the disease is far lower among women as compared to men, as are the levels of literacy. The data reveal that over 90 percent of women carrying the infection in developing countries are unaware that they are HIV positive[1]. Figures also show that where the prevalence of HIV/AIDS is higher in the overall population, the percentage of sero-positive women is also high.

One of the most alarming features of the pattern of spread of the infection is the changing age profile of the infected population. As the epidemic progresses, younger population is being increasingly infected. It is reported that 50 to 60 percent of HIV infection occurs in young people aged between 15 and 24, most of them girls and young women[2]. Young women are more vulnerable to the infection for various reasons. In many societies including Indian, a belief exists that having sexual relationship with a virgin girl would cure an infected male of STIs including AIDS. Also, to protect themselves from the possibility of getting infected, men often tend to seek out younger women who are believed to be less likely to carry the infection. These factors add to the vulnerability of younger women, who in any case are also less likely to be able to negotiate in sexual matters, or have control over the circumstances in which sexual intercourse takes place[3].

Biological factors also predispose women to greater risk of contacting the disease. It is a well-known fact that where heterosexual transmission dominates, women are at a greater risk of being infected by men[4]. It is recorded in a number of studies that due to a variety of biological factors, the virus spreads more easily from men to women than

[1] UNAIDS June 1998 cited in Baden
[2] Chowdhury, 1996, p.6
[3] Baden, 1998, p.14
[4] Baden, 1998, p.6

vice versa.[5]. Biologically, women are more likely to suffer from STIs as they have greater chance than men do, to be infected from a single sexual act with partners who have STIs[6].

In countries like in India where gender disparities show up in many different forms, including unequal distribution of food and nutrition within the household, and where young girls are married off at an early age to fulfil their societal obligation to procreate as early as their young bodies will take, it is small wonder that a very large number of women tend to suffer from serious nutritional deficiencies. Major nutritional deficiencies found in Indian women are iron-deficiency related anemia and low levels of Vitamin A. As it happens, both these nutritional deficiencies play a role in increasing the risk of contracting HIV/AIDS. Women with anemia are more likely to require blood transfusions, especially after delivery, raising the probability of infection through transfusion. Vitamin A plays a vital role in upholding the immune system and in keeping mucous membranes in function[7]. Thus absence of adequate levels of iron and Vitamin A translate into higher risks of being infected.

That the average Indian woman is likely to be vulnerable to HIV infection is not very surprising in view of the fact that that all STIs are a major risk for women in India. While there are no large-scale data available, various independent studies show that up to 90 percent of Indian women suffer from one or more STIs[8].

However, far from being mitigated by countervailing measures, the higher biological vulnerability of women is compounded by a variety of ways in which are discriminated against in Indian society. Societal norms place all kinds of barriers on women from seeking treatment for STIs. The ingrained sense of shame and taboo linked to anything relating to sex and sexuality, especially for women, strong notions of feminine propriety in general, lack of access to adequate treatment facilities, lack of mobility and social stigma associated with sexually transmitted diseases are some of the barriers women face for seeking

[5] Baden, 1998, p.11; Pavri, 1996, p.10
[6] McNamara,1993, p.4
[7] Baden, 1998, p.17
[8] Bang et al, 1989, p.85

timely treatment of STIs. There is also the fear that if and when the knowledge of the ailment becomes public, they may be accused of being unfaithful and sent back to their natal homes[9], a contingency which can spell disaster for the young woman. She may be equally unwelcome in her natal home as somebody who has been already 'given away' to her marital family. It is believed that a daughter belongs to her marital family and is '*paraya*' in her place of birth. The care that men are automatically entitled to within the family, be it though their wives, their mothers or their sisters, is not generally available to their women. An infected woman cannot expect to get the kind of care that a man would be entitled to. She may be blamed even for the disease that her husband may have picked up in sexual encounters outside the home. It is not uncommon for widows of infected men, even if they themselves are not infected, to be thrown out of their marital homes.

Women appear to be at a greater disadvantage not only when they themselves are infected, the impact is greater on women but also when somebody else in the family is infected. In most societies women are the primary care givers, which places an additional burden on them in case of sickness in the family. In many instances where the husband has been infected earlier, and has been forced to drop out of the labour market, the wife has the dual responsibility of caring for the sick and working for pay to keep starvation at bay. Also, one of the first casualties of sickness in the average Indian family is the education of the girl child, who is the first to be pulled out of school to take care of household duties and even join the mother to provide for the maintenance of the family[10].

Marriage and procreation define the two main concerns around which the life of the representative Indian woman is woven. Marriage is seen as an alliance between two families rather than individuals. There is hardly any cultural space for an unmarried woman. A woman's identity is linked to her marital status and her reproductive role. For a woman, marriage and sexuality are defined in terms of her ability to procreate. A woman's fertility and relationship to her husband are the source of her social identity.

[9] Mukhopadhyay & Sivaramayya, 1999, p.337
[10] Whelan, 1999, p.17

Thus, for a married Indian woman, sexual activity is not a matter of choice but her sacred duty. Indian law does not even recognise non-consensual sex with the wife. Marital rape is yet to be recognised by the Indian penal code. Women's social and economic dependency on the husband deprives them of the power to negotiate within the marriage. Since for the majority of Indian women, staying single is not an option that is socially acceptable, there is virtually no alternative support structure outside the marriage for the women themselves and their children.

A majority of Indian women are either unaware or too shy to talk about 'safer sex' practices. And if the information from micro studies are to be believed, the idea of condom use for safe sex is not very popular with the average Indian male. Since a married woman has little power to negotiate in sexual matters with her husband, even if condoms were available, most women would not be able to ensure that their husbands use them. Unequal power relations within marriage renders completely infructuous, whatever awareness of safe sex practices women may have acquired, if indeed they have.

Indian society idealises femininity marked by innocence, virginity and motherhood in women while men are expected to be experienced and sexual decision-makers. Women are supposed to be faithful to their husbands, while multi-partner relationships for men are condoned and sometimes even seen as a sign of masculinity and machoism. Male sexuality is seen as more powerful, as something that needs frequent outlets, while female sexuality is rigidly controlled. Society places a high value on the virginity of an unmarried girl, while turning a blind eye to pre-marital sexual activities of the men. The relative powerlessness of women within and outside marital relationships, the importance society places on marriage and child-bearing for women, and societal latitude towards the sexual irresponsibility of the Indian male are all factors that pre-dispose the Indian woman to added vulnerability.

Stigmatisation and discrimination against people of both sexes living with HIV/AIDS (PLWHA) in India is well known. It is also quite likely that the extent stigmatisation for people of both sexes may vary across economic classes and /or social strata. But given the way

the die is cast against the woman it is highly probable that on an average women face greater discrimination than men in the context of most Indian families.

1.3 Methodology

It is no wonder that researching a topic like gender dimensions of HIV/AIDS in a highly patriarchal society where sex is a taboo subject, and that too using community-based data, is fraught with problems. There is a high degree of secrecy and shame associated with the ailment, as is the case with all sexually transmitted diseases. Also, because of the relatively recent advent of HIV/AIDS in the country as compared to other STI's, there is no firm estimate of the incidence of the disease even at the national level, not to speak of sub-national or community level estimates. Given the stigma and secrecy that surrounds the ailment, locating infected individuals or affected families can be difficult: finding those that are willing to talk are obviously even more so. As first time entrants to this difficult field of social research, the ISST research team had encountered enormous problems of access. Much time was spent in establishing one's credentials. Clearly under such conditions, choice of sample can neither be random nor representative.

Given the nature of the problem, it was decided that the requisite information would be collected using a variety of methods of qualitative research. Focus Group Discussions (FGDs) would be used for gathering information on the levels of awareness about the ailment in the community, and attitudes towards it. FGDs would also be used to garner information on perceptions on gender relations and sexuality within various groups in the community. Since age and sex are two important differentiating criteria in Indian society, it was felt that, to ensure relative homogeneity among group members, it would be proper to conduct the FGDs separately among adult men and women and adolescent boys and girls. Given the fact that the study was meant to be in the nature of a pilot, a decision was taken to contextualize these group discussions and hold them in a few select communities, especially those that are relatively poor and presumably more vulnerable to all health hazards including HIV.

The information collected through FGDs was to be supplemented by some intensive case studies of infected individuals. Given the time constraint, and the difficulties of access, it was decided to carry out the case studies among HIV/AIDS patients coming for treatment in a government hospital in the city of Delhi. While this did solve our access problem, resorting to this method meant that in the case of many of these patients who were coming for treatment from outside Delhi, we had to forego the opportunity of meeting their household members, which was a loss we had to live with, given the constraints under which the work was undertaken. The case studies were meant to provide us with personal experiences, attitudes and problems of infected persons, which would supplement the societal level attitudinal data gathered from FGDs.

A third method of collecting information has been the key informant interviews, whereby selected NGO activists working in this area as well as care givers and medical personnel have been interviewed to gather their impressions, experience of individual cases and their general assessment of the gender dimension of the affliction.

Given the restrictions under which the study was carried out, the results should be taken as indicative. However, it may be mentioned that the findings of the study are consistent with those from the handful of field-based research in the area that are currently available in India.

This study is concerned with the impact as well as the factors that increase the vulnerability of men and women to the infection. The study also examines the level of awareness, perceptions, norms and values that govern vulnerability to the infection and also the impact of the epidemic.

The methodology adopted for collection of data had four components.

- *Individual interviews (PLWH/A)*
- *Household interviews and case studies*
- *Focus group discussions (FGDs)*
- *Key informants*

Case studies: Initially, most of the people the research team met, were through a doctor in the outpatient department (OPD) of a

government hospital in Delhi. The HIV positive cases, referred to the hospital are treated by him. The doctor also treats other ailments. Generally one cannot identify an HIV case among other cases those are treated by him in the OPD. There is no counselling centre in the hospital and the doctors are unable to provide any counselling services due to the rush of people coming for treatment. The doctors just provide with the medical prescription and clinical details. On an average, seven new HIV cases come every week (personal communication with the doctor).

The researchers had undergone training in counselling PLWH/A. It was decided that the researchers would also counsel PLWH/A visiting the doctor. Due to the lack of space, counselling cum interviews were conducted in the lobby of the hospital. In few occasions, the interview was conducted inside the chamber of a doctor who was on leave on those days. Even though a lot is being talked of pre-test and post-test counselling, except for one government hospital none of the others provide this facility in Delhi.

In the later phase of data collection, interviews were also conducted at an NGO in Delhi, which provides counselling and palliative care for the PLWH/A and also runs a care home.

Household interviews: Household interviews need not imply visiting the home of PLWH/A, but refers to cases where other members of the household apart from the PLWH/A have been spoken to whether at home or in a hospital setting. A few household interviews were conducted in the hospital setting. Home visits were made to three affected household with the help of a Delhi based NGO, which provides institutional and home based support to children affected by HIV/AIDS.

Focus group discussions (FGDs): Focus Group Discussions were carried out in collaboration with an NGO in two settlement pockets in Delhi. Discussions were held with different categories of the population, one each with adolescent boys and married men, four with married women and three discussions with adolescent girls. The FGDs were conducted to understand the nature and extent of awareness about HIV/AIDS, perceptions of various groups about the infection, and to examine gender differentiated norms of behaviour that influence vulnerability.

Nodal informants: Interviews were conducted with key informants such as doctors and medical personnel, NGO personnel involved in the care and counselling of HIV/AIDS affected.

Ethical considerations: The methodology adopted has been consistent with ethical guidelines essential for such a community-based research. The purpose of the research was explained to all the individuals. The interviewees were assured of confidentiality and any person who showed unwillingness to speak to the researchers was not probed further. While documenting the cases, strict anonymity was observed. No real names appear in the book. When visiting households, the researchers went with NGO workers who were part of organisations providing psychosocial support and care to the affected families. Every individual was given the organisation address and contact number so that they could get back to the researchers if they wanted to. During the interviews the PLWH/A were briefed about the general objective of the research and they were told that any queries they had would be answered. In most of the cases the PLWH/A would be interested in knowing more about HIV/AIDS, and they would just feel happy to talk to someone who was willing to listen to them without any discrimination or bias. Providing counselling services was an essential part of the entire process and often counselling took precedence over research prerogatives. Rapport was formed during the process of counselling. Since the study had been initiated, a number of interviewees have gotten back to the research team, some seeking further information and some seeking counselling.

1.4 Researching HIV/AIDS: Some lessons and some caveats

Conducting research on the social dimensions of a serious health problem like HIV/AIDS had not been an easy proposition. Apart from the inevitable psychological pressure associated with studying the impact of a terminal disease on the affected families, one of the major problems the research team faced was getting access to PLWH/A. During the discussions with other organisations and several other key informants, it emerged that the problem of establishing contact was more acute in Delhi than in other cities.

Lack of space and privacy in the hospital were among some of the problems faced by the research team in the process of conducting the

study. Interviews had to be carried out in the crowded and noisy corridors of a hospital OPD, definitely not the right kind of setting for counselling or intimate conversations.

To the extent the cases were being taken from the hospital, there was obviously a selection bias. These were cases that are being reported, cases that have scaled the barrier of silence and secrecy. Most of the patients were accompanied by relatives or friends, suggesting that here is some kind of support, psychological and material, that has been garnered. It is quite possible that this may not be representative of the situation faced by patients who have not had the courage to come out in the open to seek treatment or who have nobody to share their troubles with.

The other problem of a sample chosen largely from people coming for treatment in a Delhi hospital has been that for those patients who are not ordinarily residents of Delhi, it has not been possible to investigate the home situation. Some of the married men who were tested positive had left their wives in the villages. It could not be ascertained as to whether these husbands were reporting their positive status to their wives. If the cases interviewed for the study are anything to go by, it is quite likely that irrespective of what they say, many husbands prefer not to divulge their HIV status to their wives, thereby exposing them to the danger of infection.

The book is organized into six sections. The next section discusses some quantitative estimates of infected individuals world-wide and within India, by region and by gender. The following chapter is based on the Focus Group Discussions (FGD) that were carried out with married men and women and with adolescent boys and girls in the various communities in Delhi in order to explore the level of awareness and knowledge among various categories of the population on HIV/AIDS. This chapter also examines the prevailing socio-cultural factors that increases the vulnerability of women, and also of men to HIV/AIDS. The next chapter illustrates the main issues that emerge from the individual and household interviews. This is followed by a section that summarizes the study by highlighting the main findings. Details about the cases that were interviewed during the study are provided in the Appendix.

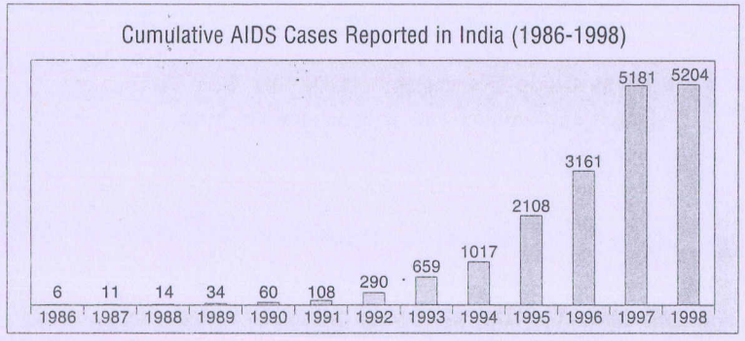
CHAPTER 2

Indian Scenario

The estimates of HIV affected population in the country are anything but firm. A number of organisations and individuals working in the field of HIV/AIDS hold an opinion that actual figures might be much higher than NACO figures.

However, NACO is the one organisation which have been involved in generating regular estimates pertaining to special groups and in different parts of the country. The figures quoted here are largely based on NACO estimates.

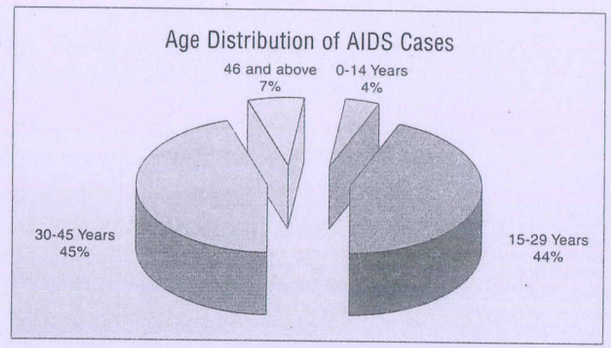
The estimated number of adults (15- 49 years) and children living with HIV/AIDS, at the end of 1999 was 37 lakh. These estimates include all people with HIV infection, whether or not they have developed symptoms of AIDS. The estimated number of adults and children who died of AIDS during 1999 was 3.1 lakh[11].



Source: NACO, Country Scenario 1997-98.

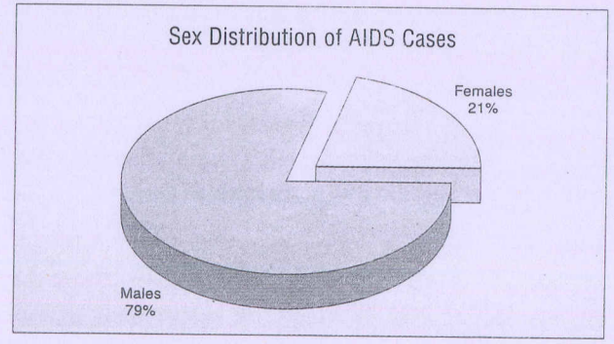
[11] UNAIDS, 2000 update

In India, majority of AIDS cases (89%) are among the sexually active and economically productive age group of 15-45 years (NACO, Country Scenario, 1997-98).



Source : NACO, Country Scenario 1997-98.

The Male - Female ratio of cases reported to NACO is 4:1[12]. Sex wise distribution of cases is given below.



Source : NACO, Country Scenario 1997-98.

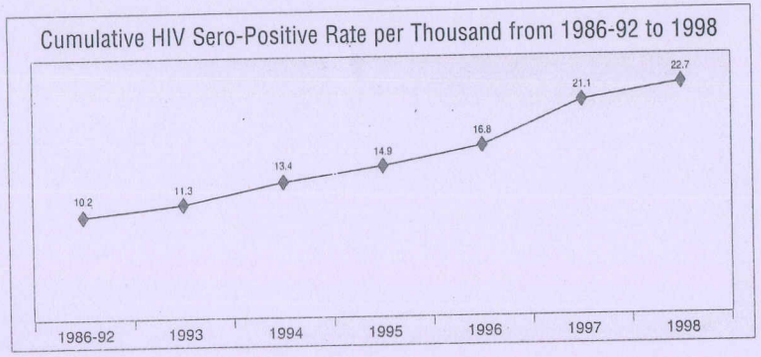
2.1 Types of surveillance to assess the epidemiological situation

Most of the data collected by NACO are obtained on the basis of various surveillance activities carried out in different locations of the country. Surveillance is defined as a continuous scrutiny of all aspects of occurrence and spread of disease and/or its infectious agents that are pertinent for prevention and control of the disease phenomena in the

[12] NACO, Country Scenario, 1997-98

country[13]. The following section provides some estimates of HIV prevalence obtained from different surveillances.

- HIV Sero-surveillance - Out of 3.29 million persons screened, 74 960 persons were found to be HIV positive with a sero positive rate of 22.73 per thousand as on March 31, 1998. The comparative growth in sero-positive cases in the country from 1986 to 1998 is shown in the following graph. It shows that the sero-positive cases have doubled within a brief span of six years[14].



Source : NACO, Country Scenario 1997-98.

- STD surveillance – Surveillance of sexually transmitted infections is based on reporting of syndromic cases in district and reporting of STD cases by specific diagnosis from STD clinics.

- Behavioural surveillance – A number of KABP (knowledge, attitude, behaviour and practice) studies have been carried out during the past years. During 1997-98 a high risk behaviour study was carried out in 36 cities with the objective to understand the pattern of risk behaviour, to map out the areas having concentration of population having high risk behaviour, to estimate the population of each type of high risk group and fix priority for targeted intervention. A summary of the findings from 18 cities was published by NACO. The groups studied were commercial sex workers, men having sex with men, eunuchs, frequently travelling males and intravenous drug users.

[13] *Ibid*
[14] *Ibid*

Different scenarios about the impact of HIV/AIDS on population size illustrate the significance of age specific sexual behaviour. Anderson et al puts it as "theoretical developments have outpaced data availability, given the many practical difficulties associated with the study of sexual behaviour and in particular networks of sexual contact". In general there is a lack of knowledge in this area and a need for more systematic and detailed research, with the focus on age and gender differences. This should incorporate attention to gendered beliefs and norms surrounding sexual behaviour, as well as attempts to 'quantify' and charecterise sexual interactions, both for men and women (Baden, 1998).

- Sentinel surveillance – After the establishment of the fact that HIV infection is present in wide geographical area, the objective of surveillance was redefined to monitor the trends of HIV infection. The objective of the surveillance is achieved by annual cross sectional survey of the risk group in the same place over few years by unlinked serological testing procedures by two Elisa tests. The high risk groups of population is represented by patients attending STD clinics and intravenous drug users while low risk of population includes mothers attending antenatal clinics (ANCs), (NACO, Country Scenario, 1997-98).

2.2 Biases in data collection for capturing the incidence among women

Even though today the HIV virus is spreading amongst women at a rapid rate, they tend to be undercounted in data regarding spread of HIV/AIDS. Over 90 percent of women in developing countries are unaware that they are HIV positive. This stems from lack of education, awareness, information and mobility. Baden points out three areas where women are under counted. The first relates to diagnosis of AIDS and AIDS related deaths. The cause of death among female AIDS sufferers for both social and health reasons, is more likely to be attributed to maternal mortality or other opportunistic infections that accompany HIV/AIDS rather than AIDS itself. It may also be underreported by women because of the stigma attached and more so because most cultures are sexually restrictive for women. The second gender bias is in the sample selection for sentinel surveillance. A

major source of information for these surveys is pregnant women reporting to antenatal clinics. Often these groups are chosen for pragmatic reasons (e.g. anonymous testing of women in ANCs is relatively easy to organise and can be justified on medical and ethical grounds) as much as representativeness for surveillance purposes. However, research has shown that prevalence rates are likely to be higher for females in the reproductive age in the general population than for women reporting to antenatal clinics, for populations with low contraceptive use over all. Baden also points out that certain assumptions about sexual behaviour govern sample selection, which do not necessarily hold up as the epidemic develops. For instance pregnant women may be 'low risk' in the early stages but as the epidemic spreads, their exposure to the infection increases. Similarly, risk behaviour among sex workers may decrease as awareness spreads and behavioural changes occur. The third bias concerns inaccurate knowledge and assumptions about sexual behaviour. Women are likely to under report extra marital or multi-partner relationships where sexual norms are restrictive for women, while men may exaggerate sexual activity where permissiveness is the norm for men[15].

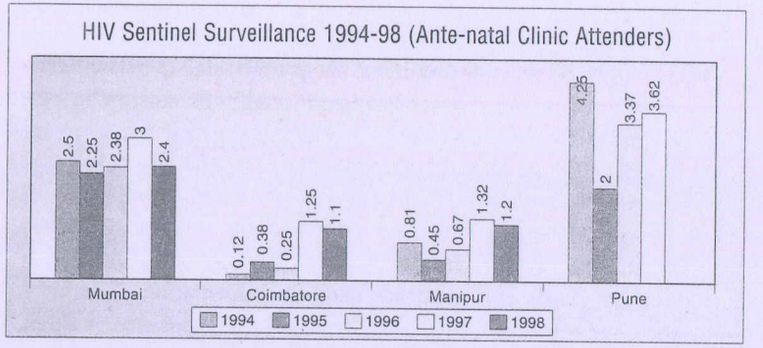
There is a clear indication that the progression of the epidemic has gradually spread from the so-called 'high risk groups' to the general population. The different parts of the country and different groups of the population are in different stages of the epidemic.

Based on the HIV sero positivity rates among different groups the states have been classified according to the following criteria by the National Aids Control Organisation.

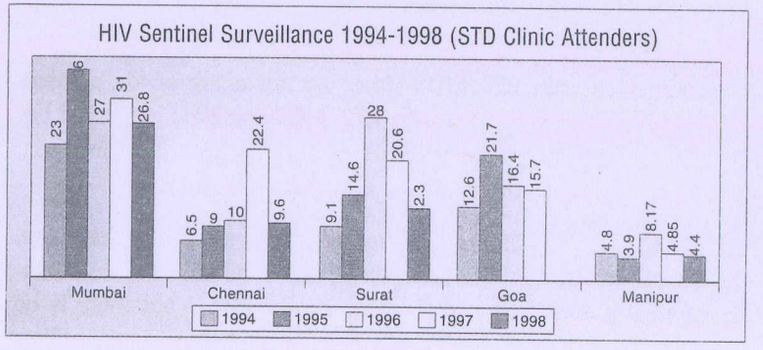
- Generalised epidemic- Ante-natal HIV prevalence of more than 5 per cent, no state has yet recorded such a large prevalence rate.
- Concentrated epidemic I- Ante-natal prevalence more than 1 per cent in states like Maharashtra, Karnataka, Andhra Pradesh, Tamil Nadu, and Manipur.
- Concentrated epidemic II- Ante-natal prevalence less than 1 per cent like Gujarat, West Bengal and Nagaland.

[15] Baden, 1998, p.10-12

- Low level epidemic- STD/ HRG HIV prevalence of less than 5 per cent like Punjab, Haryana, Himachal Pradesh, Uttar Pradesh, Madhya Pradesh, Rajasthan, Orissa, Assam, Kerala, Meghalaya, Sikkim, Arunachal Pradesh.



Source: NACO, Country Scenario 1997-98.



Source: NACO, Country Scenario 1997-98.

2.3 Response of the State

The initial response of the Government was to deny that AIDS was a problem in India. It was believed that so called traditional socio-cultural norms of monogamy, universal marriage and the societal proscriptions against homosexual behaviour and discussion of sex and sexuality in public provided the necessary shelter from a predominantly sexually transmitted disease. Further the strong association in India of HIV with CSWs has led to the widespread belief that the epidemic was not a problem in India. However, by early 1990s denial had given way to an attempt to contain AIDS and viewing it as a medical problem.

The National AIDS Control Organisation (NACO) was set up in 1992 with an aim to develop a comprehensive multi-sectoral programme for the prevention of HIV/AIDS in India. The plan included improving levels of knowledge among medical personnel, to ensure HIV-free blood products through blood safety programmes and to run public information campaigns. Though the plan was comprehensive it failed to generate a sense of urgency. Denial of the problem has persisted even as the number of reported cases has been steadily increasing[16].

Although the creation of awareness about HIV/AIDS was a primary goal, the overall awareness of HIV/AIDS in various sections of the population still remains very low. This could be due to cultural sensitivity and inhibitions to open discussions about sexuality and limitations of the methods and materials used for information dissemination and communication. The socio-cultural contexts, values, socialisation process and the concept of sexuality were not adequately addressed[17].

Part of the problem is because the epidemic is still hidden. Many of those suffering from HIV/AIDS either are not aware of the problem themselves and in many cases the HIV/AIDS epidemic is masked behind the symptoms of other diseases like tuberculosis, diarrhoea etc., which the person contracts.

Although the HIV/AIDS programme is designed to be comprehensive, there is no involvement of other government departments. The Ministry of Health and Family Welfare constituted NACO but there is no visible link with other health-related issues that have serious implications for the success of the programme.

Low priority accorded to health generally in national health and research allocation and the relative neglect of primary health care and the resultant weak health infrastructure in the states has not been addressed. There are no links with the reproductive health programme even when sexual transmission is the predominant route of spread. The fact that STIs are the third most important group of diseases in the country next to TB and malaria has been glossed over[18].

[16] Sethi,1999, p.386
[17] Sethi,1999, p.389
[18] Ramasubban, 1998, p.2865

The programme has also laid a lot of emphasis on advocacy for behaviour change and condom usage. However, without a sea-change in the unequal gender relations and powerlessness of Indian women in negotiating safe practices with their partners, such advocacy is not likely to bear any fruit. As mentioned earlier, the largest number of newly infected are monogamous married women who do not have the powers to negotiate about sexual matters in the marriage. Studies with CSWs also reveal that very often they are powerless to negotiate condom usage with their clients[19]. For women, simple advocacy on condom usage does not help in reducing their vulnerability to the HIV virus. The HIV programme needs to develop strategies that will also address the lack of negotiating power of women in society. The programme has not addressed issues of male and female exuality. In a context where men are the sexual decision-makers, the programme has failed to address links between notions of masculinity and safe sexual practices.

[19] Jana *et al* 1998, p.S104

CHAPTER 3

Community Perceptions
Focus Group Discussions

India has the largest number of people living with HIV/AIDS in the world. And yet there is very little information on the level of knowledge about HIV/AIDS in the country. This chapter collates the information on community perceptions about HIV/AIDS. The main methods used for collating this information are focus group discussions (FGDs) with different groups of people categorized by age and sex in study sites. While the focus group discussions were conducted to gauge the level of awareness about HIV/AIDS in the community and people's perceptions about it.

The FGDs also give a picture of the reality of women's everyday lives that render them vulnerable to the infection. Seven focus group discussions with females and two with men were held in the community centres run by Salaam Baalak Trust (SBT) in two different locations: in a squatter settlements near New Delhi Railway Station and, in the Railway Colony.

Table 1: Number of Focus Group Discussions

Location	Females		Males	
	Adolescents	Married women	Adolescents	Married men
Settlement near Railway Station	2	3	1	1
Railway Colony	1	1		

Five FGDs with female and two FGDs with males were held in the squatter settlements. This settlement consists of a thousand families

by the side of the New Delhi railway station. The settlement is illegal and the residents have been served eviction notice by the Delhi High Court. Some of the men here are employed by the railways and have been given government accommodation but they have in turn rented that out. The settlement is located near the biggest wholesale market of Delhi. It is also placed at a stone throw distance from the oldest red-light area of the town. The majority of men are daily wage labourers, fruit vendors, cycle rickshaw pullers, auto-rickshaw drivers etc. The women are basically home bound. Many of them are engaged in some home based seasonal jobs like making of *rakhis*, candles, *Diwali* lamps and packaging of spices, salt etc.

Most of the people are migrants from UP, Bihar and Bengal. Muslims are the dominant group in the area with a sizeable Hindu population. Segregation on the basis of religion is quite evident in the area. Salaam Baalak Trust (SBT) runs two community centres in the area which provide pre-school activities and mid-day nutrition to the children. SBT conducts classes for school drop outs. They also conduct sewing and craft classes for adolescent girls. The SBT workers also help the community women in matters of family planning.

The second SBT centre where FGDs with adolescent and married women were conducted is situated in the railway colony. In most of the cases, the head of the family living here is employed with the railways; a few are in private sector jobs. While some of the families are in the lower income group, others are lower middle class. The SBT centre provides space for school children to do their homework and provides tutorial lessons for those who need help. They also hold sewing classes especially for adolescent girls, both school going girls and who have dropped out of school.

The FGDs were carried out to gauge people's understanding, perception, awareness and attitudes to HIV/AIDS. The discussion centred on the following key themes- the social behaviour of the community, their perceptions and attitudes towards sexual behaviour and sexuality, perception and knowledge about HIV/AIDS/STIs and sense of responsibility in care and support to HIV/AIDS people. The discussions also

focused in the context of their being which affects their vulnerability and the impact the epidemic is likely to have on their lives. The men were less inhibited in talking about sex, visiting commercial sex workers (CSWs), their relationships with their wives etc. On the other hand the women were unwilling to discuss sex or their relationships with their husbands. One major draw back was that the researchers were viewed as outsiders and the women felt shy in discussing the relationship with their husbands. Similarly adolescent girls also were unwilling to talk about interactions with boys. The research team had a feeling that the girls are unwilling to share their knowledge about sex as the dominant norm places value on sexual innocence of women. The team held a number of FGDs with females to understand the nature of marital relationships and the extent of sexual knowledge.

The use of FGDs for such a study has both its benefits and drawbacks. One of the major drawbacks is that the 'idealised' or 'norm' is emphasised by the group while actively downplaying the digressions from these norms. On the other hand, at times discrepancies in stating facts were also pointed out by others in the group.

The number of group members in each group discussion varied from eight to twelve. The language used was Hindi and the expression used by the group members was mostly colloquial.

3.1 Focus Group Discussions with Women

All the married women, who took part in the FGDs, were in the age group of 18-40 years and adolescents were in the age group of 12-18 years. All of them live in nuclear households as only the couple has migrated to the city with the children. On certain occasions, women and children keep shifting between the in-laws in the village and the city. One adolescent girl said.

"They call the wives in winters (when it is cold) because it is more cosy. In winters you need (them) to do the housework. In summers they manage the work themselves."

Quite a few adolescent girls, who have dropped out of school, also divide their time between the village and the city.

Education

The level of education is very low among the married women. A few had completed primary school, but they have forgotten everything due to long detachments with reading and writings. The rest of adult women had never been to school.

The level of schooling is higher amongst the adolescent in both the locations. In the settlement all adolescent girls had finished primary school. Most had dropped out of school after that. A few were continuing their schooling and one was in the 10th standard, however none was sure whether they would be able to continue. They said that after a girl 'grows up' she stops going to school. Even if the parents do not mind sending the girl to school, the neighbours start pointing out that the girl has now grown up. If they (girls) say that they want to study further, the parents say, "*What's the use? You aren't going to take up a job.*"

The girls said that they (girls) should definitely be educated so that they 'won't be taken for a ride' (*"koi hamara fayada nahin uthayega"*). Shopkeepers would not cheat them. One said you can even help your children with homework if you are educated. The girls did not view education as giving them jobs. They did not think they would get jobs in offices because they did not have that kind of education. They did not want to take up other types of work. They would like to take up some work that can be done at home.

The adolescent girls who participated in the FGD in the railway colony were all going to school and had finished primary schooling. These girls were economically better off and had a higher level of education than the girls at nearby settlement on an average. In this group all wanted to study further and take up jobs. All the girls here too did a lot of work in the house after their schools. A few said they liked doing it, while most said they had to do it.

Differential Treatment

The girls felt that they get the same food as their brothers do and sometimes are even pampered more than the boys do. However they admitted that the girls do all the work at home and help their mothers. The boys do not look after any household work.

"They can't even take a glass of water by themselves. Whatever the situation girls have to work at home".

One of the girls whose mother had expired had to drop out of school and take over all the work at home. Few also said that their brothers had dropped out of school and were not doing anything else, they vile away their time with peers.

The married women reported that they have to do all the housework even if they are sick. Many women said that when they are ill, they take medicines to control the fever and do all the household chores including preparation of food. One woman told, *"Moreover we have to bear with the complaints if the food tastes bad."* Even when specifically asked would their husbands help if they were bedridden, they said that their husbands were the breadwinners and worked so hard, they wouldn't possibly tell them to help at home too. Few said if it was a necessity, then the husbands would help out, but ultimately, those willing to help will help and those who are unwilling won't. Men could not afford to take care of them in case they fell ill, as it would mean a day's loss of earnings.

Adolescent girls also reported that even if unwell they have to do the household works. Only if they are laid up in bed they won't do any work.

Marriage

Some adult women said that they were married around 12-16 years of age but most said that they were married so young that they could not remember their weddings. They were sent to their marital homes (*gauna*) when they were about 16 years old.

"Nowadays girls are married when they are 18-20 years old, they are mature and get spoilt. They do everything according to their own wishes. If you get married when you are younger, you do not even realise what is happening. That is much better."

A FGD was held with a group of young married girls who had been married within past two years. All these girls were also married around 14-16 years of age. All women reported that their fathers had a major role to play in arranging their marriage, the mother did not have much say in it. A 35 year old woman reported.

"After my marriage was fixed we got to know that he drinks a lot but my father said it is my fate (kismat)."

Women also reported that dowry was a common practice. They said dowry was given according to the family's ability.

The group of women living in the railway colony reported that,

"When we were married, we were not allowed to see the boy but we would definitely want our daughters to see their would be husbands. But even if we want it like that, they (husbands) won't agree. Men will after all do things the way they like."

The adolescent girls reported that they do not have any say in their marriage. The parents decide whom they will marry. The parents and younger siblings see the boy and the boy's parents and relatives come to see the girl. However, the boy and girl are not allowed to see each other.

The girls reported that the boys come and have a look at the girl without anyone knowing as they can go anywhere. But it is impossible for the girls to do this as they do not know how and where to go.

A few girls from the better off families in railway colony said that in their family the boy does come to see the girls. However everyone said that even if a girl gets to know he is not 'good' or likes someone else or does not want to marry him, she has no choice. They would not be able to tell their parents if they liked someone else. They would like to have say in the choice of bridegroom but were unable to express their opinion. It all depends on your fate (*kismat*).

Sexuality

A number of married women reported that after they started menstruating, they were told about this by their mothers. Others got to know about it from older sisters. There is absolutely no communication between mother and daughter about issues relating to reproductive functions. All of them reported that they got to know about all this only after marriage from their husbands.

In the settlement, the adolescent girls' knowledge about their anatomy was very low. They got to know about menstruation from older girls

or their mothers after they started the menstruation cycle. They were told that it happens to all girls. Some were told that it was bad blood, which needs to come out. They all know that it stops when a woman is pregnant or when she grows old.

The girls at railway colony were more aware of anatomy, reproductive functions and menstrual cycle. The level of knowledge of girls studying in secondary school was visibly higher. They were aware of female contraceptives and condoms and also a contraceptive that is injected. They also spoke about STIs including HIV and white discharge. They had acquired most of their knowledge from peers and senior girls in school and training programmes at SBT. They got to know about the modes of transmission of HIV/AIDS through school textbooks. In this group the older school going girls also asked us a lot of questions about male sexuality, masturbation, etc.

Almost all women who participated in FGDs in the settlement and railway colony live in nuclear households. Some said that they preferred this independence but at times felt that the extra helping hand that was available in a joint family was missing.

Pregnancy and Child Birth

Some of the women who had daughters as their first child reported that they had to hear barbs from their in-laws and they have to keep trying for a son. At the same time women said that a girl is also necessary since she is '*Lakshmi*'. In case of a female child they do not receive any moral support from anyone around. One participant from the railway colony reported.

"*Even during pregnancy you have to listen to a lot of things from their relatives. Some suggested that she should get an ultra sound done and if it is a girl, then should get the child aborted.*"

In the settlement all the women said that their children were born at home which is preferred. The hospital staff treats them very badly, they are abusive and even hit them during labour. There are two trained dais who live near the community and are called for delivery. The *dai* (midwife) is paid more for the birth of a boy than of a girl. In the

railway colony some visit Lady Hardinge Hospital and some call the *dai* at home.

Contraception

All married women reported that they were aware of contraceptives but few used any. Oral pills, CopperT (IUD) and tubectomy were the modern methods reported by women. Many also reported that as long as they were feeding the child they did not need any other contraceptive method. They are unable to take any contraceptive without the consent of their husbands. Many women wanted to go in for tubectomy but need the consent of their husband. Some also reported that they would like to use contraceptives but their husbands refused. One woman, who wanted to use contraceptives, was asked by her husband, "*Why do you want to use them? I would like to have more children.*"

None of the participants reported condom use by their husbands. Some said they had heard about them but were unable to tell their husbands, as they do not talk about it. They are unable to negotiate with their husbands. The few women who were using contraceptives felt that as they themselves were using contraceptives there was no reason for their husbands to use anything.

Some women had gone in for sterilisation. Many others were interested but had not spoken to their husbands about it. The women said that they prefer to get themselves sterilised than their husbands because he will not be able to go out and do his job after that. They believe that sterilisation makes the man weak.

Sexually Transmitted Infections

Boils and white discharge also came up during discussions but only a few reported having sought treatment. Many of them believe that these problems do not require any treatment. Women do not discuss these issues among themselves. Some have gone for treatment but they do not feel comfortable discussing this with a male doctor. Their husbands communicate with the doctor but it is difficult to talk about the problem clearly. They feel easier talking to a female doctor however she is not available easily.

When discussing the use of condoms for preventing STIs, one woman reported.

"Men don't carry condoms in their pockets (jeb mein rakh kar to ghoomte nahin hain). And even if he has them, he won't use it. He says we'll see to it when it happens (jo hoga dekha jayega). When he wants to do it he just tells me to come aside."

Some women also said that their husbands came drunk and won't listen to anyone.

While discussing the use of condoms for preventing STIs including AIDS, women said *"how can you tell him to use a condom if you are pregnant."*

Condom is viewed as a contraceptive devise only. Similarly it would be difficult for a women having undergone sterilisation also to bring up the issue of condom use.

What emerged from the discussions was the lack of decision making or negotiating power women have in sexual matters.

Awareness about HIV/AIDS

Awareness about HIV/AIDS amongst both married women and adolescent girls found to be extremely low. The exception was the adolescent girls in railway colony who were school going and also had been given information about HIV/AIDS by SBT.

Of the rest amongst both married women and adolescent girls very few had heard about AIDS on television and that there is no cure for AIDS. Others said that, as they did not have television how could they know about it. But even those who had heard about it did not know what the infection did to the person. The women wanted to know about symptoms of the infection. Some of those who had heard about AIDS said that it spreads through blood and relationships with 'bad' women.

The women said that they knew of neighbours who regularly visited sex workers on GB road and that even young unmarried men visited them. They were quite keen to know about HIV/AIDS and said that since husbands go out and give the infection to their wives at home.

At the same time added that they knew that their husbands would not indulge in such things.

One woman reported: *"I used to watch a serial on TV about AIDS. The woman got it from her husband and after he died they (in-laws) threw her out of the house. This happens in real life".*

One woman also said, *"it will be good if all those (sex workers) who have it die then the disease also will be wiped out".*

When asked how would they react if someone in the community heard it. Women reported it was a 'dirty disease' (*gandi bimari*) and if someone had it, the person will not tell anyone. If the community came to know, the person would be isolated and would be taunted by the community. People around would be scared of getting infected.

3.2 Focus Group Discussions with Men

FGDs were held with married men aged 30 to 45 years and adolescent boys between 14 and 19 years of age. The men who participated in the discussions have been residing in this settlement for the past five to ten years. They are all first generation migrants and have come from the states of Uttar Pradesh, Haryana, Bihar and Rajasthan.

Education

Many of the men, who took part in the FGDs, are illiterate. Few of them are just literate. Among the boys, a couple of them are studying in school while the rest dropped out after seventh or eighth standard in the school. A few among them are totally illiterate. The boys dropped out from school due to economic pressure from the family. At an early age, they are engaged in different economic activities, to earn money for the family.

Economic Activities

The men are engaged in economic activities like *rehriwala, thelawala,* porter, *rikshaw* puller etc., though nothing is fixed. Many a time they are just unemployed. Their wives are housewives and sometimes they take up home based work like jewellery polishing, packing spices, salt,

candle making etc. Most of the adolescent boys came to the area in their childhood days and only a few are second generation residents.

All these boys including the school going ones are involved in some kind of economic activity like vending, *presswala*, home based work including making packets of spices and salt and polishing jewellery etc. A few of them were involved in a particular job at some point of time, that is selling boiled eggs and porno graphs in the red light areas, the customers were the clients of the sex workers. They say that they get a better price from the customers. But no body is involved in any permanent or regular job. Their fathers have irregular employment - *reriwala*, construction labour, *rikshaw*-puller, railway porter etc., but few of them have anything permanent.

Health Status

Incidences of T.B and STIs have been reported in the area. People do not discuss these health problems openly, but every body knows that many around them are suffering from these health problems. Generally, they do not visit hospitals. They try to solve the problem through consulting the local doctors, who most of the cases are not registered practitioners. Two such clinics are located in this settlement. Some in the group were suffering from genital infections.

Sexuality

As the settlement is very near G.B Road, the oldest red light area of Delhi, a number of men of the settlement are regular visitors of those sex-workers. Use of condom is low, both in brothel and at home. Many of them never used a condom. The incidence of homosexuality is also not uncommon.

Many adolescent boys visit sex-workers. According to them, the condom use is higher in this age group. The sex-workers do not have sex without condoms. Some times the sex-worker herself forces the client to use a condom. The new comers cannot bargain in favour of not using condoms, as they are *'anari'* (inexperienced) in sex in front of those sex workers. They say that boys have a curiosity for going to sex workers as they hear stories from older boys and also want to have

some experience with sex. Among peers, it is related to their prestige and status in the group. Friends laugh at the boys, who do not have any experience in sex. They do not reveal these facts to the older members of the community. They always hide these facts from their guardians. The incidence of homosexual activity and bisexual activity is high among boys. Boys complained that older boys and men force them to have sex sometimes.

Awareness about HIV/AIDS

All of them had heard about HIV/AIDS. They do not know much about the difference between HIV and AIDS. Though they know the ways it spreads, they have some other misconceptions and fear about this infection. They have a belief that it may spread even from close association with the infected person, so it is better to avoid them. They know very well that AIDS is not curable. They wanted to know what are the probable early symptoms of HIV/AIDS. They believe it comes from the sex-workers. They believe that the sex-workers are polluted and are the 'store house' of many diseases.

When they were asked, why people still go to them, the answer was, *"they cannot control the heat of the body and they do not have a control over their sex desire"*.

Men in the FGD, told that the rich men are more vulnerable to HIV/AIDS.

"They spend much money and are more frequent visitor to the sex-workers. Poor people cannot go to sex-workers very often, as they have neither enough money nor time. Poor people have to do more laborious jobs to earn money, they do not have time to relax like them (rich men)."

But they do not blame those men in the settlement who visit sex-workers. Many of them believe that housewives if they are pure, cannot contract those *'dirty diseases'*. When they were told that when somebody gets AIDS he becomes very sick and weak after a few years they were not surprised. They replied that many other diseases make people weak, and they are not able to do any work. In such a situation the lady and other members of the house start doing some job to cope-up with the problem.

When asked about what happens if the wife becomes very sick, they replied that she would be provided medical treatment. But if it continues to worsen the lady might be sent to her parents. It is also probable that the man may run away from the house.

"Its no surprise if one runs away from home to some other city when the burden becomes too heavy".

Boys said they had seen it happen. The running away from house is not new. In those cases, where the husband has run away from the house due to some reason, the woman is blamed and abused by the community.

The boys had heard about HIV/AIDS from T.V, government billboards and senior boys, but the information is neither complete nor correct. The boys are confused about HIV/AIDS. They do not have any idea about opportunistic infections due to HIV/AIDS.

The boys told us that women are totally unaware of HIV/AIDS and the use of condom. A few of them would not even know what a condom is. When asked about the probable impact of HIV/AIDS on women in the community, they said,

"There will be an adverse impact on women if HIV/AIDS spreads in the settlement as an epidemic. They will have to bear the entire financial burden of the family. If the economic condition becomes worse at home the woman has to go to work outside the house. Generally women think about the savings in the family. Already women face a lot of discrimination in the community. There are instances in the settlement, where the lady has received severe criticism and abuse both from inside the house and outside, because she could not give birth of a child or a male child".

3.3 Conclusion

The FGDs bring to light the extreme vulnerability of the women to HIV infection. And this vulnerability is due to their lack of decision making and negotiating power even for matters that threaten their lives. The inability to take decisions without the consent of their husbands - whether it is in the marriage of their daughter, number of children to have, the use of contraceptives or sexual relations within the marriage - is the most important factor that places them at risk.

Negotiation in sexual matters becomes more difficult when the husband is drunk. Many women do not feel empowered to raise the issue of condom use. It was pointed out, even if they are able to ask their husbands to use condoms, it is impossible for those women who are pregnant, as condoms are only seen as contraceptives. The same also applies to women who have undergone sterilisation.

There also does not seem to be any positive link between level education and decision making. Among women, younger generation is better educated than the older generation. However, in many respects the adolescent girls too displayed a lack of options and a lack of power to decide about their lives like the older generations. A comparison of the findings of girls with high school education shows that education does not lead to greater autonomy. These girls do not have a say in spouse selection as lesser educated girls. There is also no difference in the amount and type of household work that was done by the girls in their homes.

People's awareness and understanding about HIV/AIDS is very limited. Those who have heard about AIDS have done so on television but did not know what the infection was about. Amongst women most of whom are illiterate, those who did not have a television had never heard about AIDS. Even men who had heard about AIDS or read messages on government billboards did not have adequate understanding of the infection and also a lot of myths and misunderstandings.

Adolescent boys and girls seemed more aware about gender relations that their older counter parts. Awareness about AIDS also was greater amongst adolescents than older men and women. But their understanding of the infection is very limited. Among adolescent boys peer group pressure has a greater impact on sexual behaviour than messages on the roadside. This raises the question whether awareness is enough to bring about behaviour change, as it is evident that awareness does not imply that the messages have been internalised.

There are also many misconceptions, myths and lack of knowledge about health, especially reproductive health, anatomy and sex amongst both adult and adolescent females and males. This also increases the risk of HIV infection.

At the same time women are also unable to access health care for the treatment of STIs. Many feel uncomfortable talking to a male doctor while others convey through their husbands which results in miscommunication. A lot of STIs therefore remain untreated increasing women's vulnerability to HIV infection.

Women's vulnerability stems not only from gender norms and roles but also from a sense lack of access to essential medical facilities. It is clear that the present interventions for reducing the spread of HIV are based on a lot of assumptions, which do not match ground reality. There is therefore an urgent need to use strategies that take into account the societal vulnerability of women.

Many of the taboos surrounding HIV/AIDS emanate from the strong and resilient hold of patriarchy in Indian society coupled with the mystic secrecy and stigma surrounding all matters relating to sex, especially where women are concerned. The strong patriarchal traditions of Indian society leave very little space for women to negotiate on sex within marriage, or to have much say in the selection of their marriage partners. There are separate sexual norms for men and women while premarital sex is taboo for young girls it is not so for young boys, and our research clearly indicates that there is strong pressure on the latter from peer groups for acquiring sexual experience fairly early in life. Since there is virtually no intergenerational communication on sexual matters, young women generally enter marriage without any knowledge or preparations and are open to coercive sex within marriage. For men, the norms are different. Masculinity is equated with a macho image. Indulging in sex outside marriage by men is ignored by the society.

For women the rules of the game are different. A 'deviant' woman is branded as 'fallen' for all times, independent of the circumstances. There is a strong dichotomy between good women and bad women. In the communities researched by ISST the idea that the infection is transmitted through "bad women" has been widely reported by both men and women. Almost all married positive men referred to their wives as pure and good outside the ambit of *'dirty diseases'* like HIV/AIDS. However, when the wife gets the infection, in-laws would normally tend to castigate her as the primary culprit.

CHAPTER 4

Perceptions and Experiences of the Affected Population– Interviews with PLWH/A

This chapter is based on personal interviews of a number of people living with HIV/AIDS. In some cases household members of the infected persons have also been spoken to. Thus the chapter draws on the perceptions and experiences of both the infected and the affected categories.

Introduction to the Cases Interviewed

The total number of people living with HIV/AIDS (PLWH/A) interviewed was 25 belonging to 24 households. Among these 25 persons, one married couple was there. Out of 25 people, 16 were males and 9 were females. Among 16 males 10 were married and 6 were unmarried persons. And among 9 females, we found 5 widows and 4 married. The age group of the PLWH/A was between 21-56 years. Out of these 24 households, in eight cases the household members were also interviewed along with the positive persons. We have referred to them as household interviews. Apart from these cases we also interviewed members of four affected households. So altogether, members from 28 households were spoken to.

Table 2: Interviews with PLWH/A

	Female	Male	Total
Individual Interviews	4	13	17
Household Interviews	5	3	8
Total	**9**	**16**	**25**

Taking all the infected and affected cases into consideration, our aim was not to show any co-relation between HIV/AIDS and income level. However, the research team realised that the cases belong to different income levels. Although they are from varied social backgrounds and different income groups, they were facing same kind of treatment from their family members and relatives. Among the cases, 11 were from the lower income group, 4 from the lower middle income group, 9 from middle income group and 4 from the upper middle/higher income group. In most cases, except four cases from upper middle income group financial constraints would be evident if costs are to be borne by individuals or the family.

Questions were not asked regarding source of infections. Whatever information was gained on this was spoken out voluntarily by the individuals without probing into the details. Out of the 16 males, 10 admitted to have visited commercial sex workers (CSWs), one said he had contracted it while working in the operation theatre and rest did not reveal anything about it during the interview process. Among nine females, five of them were widows. In all five cases, the woman contracted the virus from her husband. Among the rest four, two contracted the virus from their respective husbands; one presumably from her client and final one, is an IV drug user. In the report, in all cases it has been put as likely source of infection.

In most cases, the individuals had got over the initial shock and depression but life had definitely changed for them. Some underwent phases of depression on and off and few were coping well. For all the HIV positive widows the main concern was finances, most were financially dependent and had young children who needed to be supported.

The reason behind HIV testing for the male interviewees was prolonged fever, diarrhoea, loss of weight, tuberculosis, genital ulcers and in some cases skin infections. For most HIV positive females it was because their spouses had tested positive or died of AIDS. Few of them are on anti-retroviral treatment. These are the ones who have managed the finances on their own. One of the PLWH/A is employed with ITBP and is being provided with anti-retrovirals by the organisation.

The ISST research team had taken interviews of 25 PLWH/A coming from all age groups, of both sexes, and spanning different economic classes. Most of these people are at various stages of the infection. The sample is not representative of the base population since one suspects that there are many more who have neither the will nor the wherewithal of treatment. However, coming as it does from a wide spectrum of background the sample does bring out the vulnerability and various forms of discrimination that AIDS affected persons and their family members have to cope with.

Economic Impact of the Infection

In some ways the economic impact of HIV/ AIDS on families and individuals is similar to that of any debilitating disease. It reduces the ability of the affected person for sustained work. It makes demands on the time of the care givers and for the health care that needs to be provided to the affected person and it impinges on the economic viability of household because of the expenses that need to be incurred for treatment, which in case of HIV/AIDS is very high. As in the case of other diseases, the economic impact of HIV is more severe for poorer families as compared to affluent ones.

"We'll sell some portion of our agricultural land, to face the extra economic burden for her treatment" (Father-in-law of a positive woman, Interview 19)

"I don't have any job now... no money to continue the treatment." (Positive man, Interview 10)

"I can very well bear the cost of anti-retroviral treatment. I'm not at all worried for that." (Positive man from affluent class, Interview 9)

The additional problem that HIV/AIDS inflicts on the affected person derives out of the stigma associated with the infection, aggravating the impact. And almost invariably on an individual basis, the impact is more severe for the women within the households as compared to their male counterparts. An AIDS affected male is more likely to receive the care/support from the family that is needed for sustenance as compared to an AIDS affected woman. In cases where an

HIV positive man expires, survived by his HIV positive widow, the widow is subjected to severe social discrimination and economic deprivation and is likely to be thrown out of the marital family. Many of the case studies conducted by the ISST research team brings out this added vulnerability:

"All my jewellery were taken back by my in-laws to bear the cost of my husband's treatment. After my husband's death they were unwilling to spend a penny on me, as I am an HIV positive...I'm looking for a job since I can't stay in this care home for long. I do not know if it is possible for me to get a job as I'm not literate...but I've to look after my son." (22 year old positive widow, Case 6).

"Nobody is there to take care of the expenditure for my treatment. They are planning to sell my husband's share in landed property. I do not know who will take care of my children." (30 year old positive widow, Interview 18)

If the woman is educated she still has some chance of finding a job and supporting herself economically. For poor and illiterate women, the burden is doubly severe. Support, if at all, may come from the natal family as the following cases interviewed by us suggest:

"...though I'm HIV negative, my husband died of AIDS. None of my husband's family members is helping me to bring up my three children. My brother is supporting me with some help...I've a doubt how long it will continue ...educational support for my children is coming from a support organisation." (38 year old widow, case 1)

"After my husband's death, I was asked by my in-laws to vacate the house...I had to take a job in a school. It will be better if I get some support for my children's education...it is not possible to stay in Delhi (for treatment) for a long duration. Yes, my sisters are helping me but that is not enough" (32 year old positive widow, case 3)

Sometimes the groom's family may extract treatment cost for their daughter-in-law as well as for their own affected son from the parents of the girl almost like dowry demands that continue years after the daughter's marriage on one pretext or another.

"Though my daughter is living with her in-laws, we are providing the entire economic assistance. We, even provided financial assistance for her husband's treatment" (Mother of a positive widow, case 2)

When the infection brings about job loss it can spell disaster. For a widow with children this results in total disruption of family life.

"I was working as a domestic-maid, but as my positive status was revealed to my employers, they sent me to this care home before telling it to me...my previous employers are good people, so far they have been paying for my treatment. Now I'm jobless, I do not know where to go. I have sent my son to my parents." (22 year old married woman, Case 4)

Discrimination

The case studies suggest that there is discrimination against affected and infected people within all structures. Discrimination is faced by HIV positive persons and their relatives within the family, in the community, in the work place and in hospitals and dispensaries in the process of accessing medical services. These people at all levels face stigma and isolation.

"We had to vacate the in-laws house as soon as my husband developed TB due to HIV infection. We did not receive any financial assistance from them. Later, after my husband's death, they provided me a shelter, but neither financial support nor moral." (32 year old positive widow, case 3)

"After the death of my son-in-law, my daughter was sent back by her in-laws, they didn't want to take up her responsibility and the fear of infection was very high. I had a lot of discussion with my daughter's in-laws. I told them that my daughter got the infection from their son, it was no fault of hers, why won't they keep her with them. At last they accepted her...My neighbourhood people have isolated us, mainly due to the fear of infection. They have stopped interacting and say that our house is infected. A few said that they want to visit our place but since our daughter has this deadly virus they feel scared." (Mother of a positive widow, case 2).

"After my husband's death, if any support I'm getting, that's only from my brother, nothing from my in-laws, in-laws have cut-off all relations with us... When my neighbours came to know about my husband's status, they

started passing comments, few of them started to isolate us from the community." (38 year old female, case 1).

"*All my jewellery were taken back by my in-laws to bear the cost of my husband's treatment. After my husband's death they were unwilling to spend a paisa on me, as I am an HIV positive. I left my marital home.*" (22 year old positive female, case 6)

"*When my sister fell ill due to infection, which she had got from her husband only, she sent her children to us, because there was no support for them. We are supporting her and her kids. They are only taking care of their son (sister's husband).*" (Unmarried brother of a positive woman, Case 8).

When the doctor, who was treating me disclosed the fact (my HIV status) to some of my friends and colleagues, they isolated me totally. I had to leave the course half way through." (24 year old positive unmarried man, Interview 14)

"*In my village people know about my disease. Whenever my wife goes there, she has to hear sarcastic comments from the neighbours.*" (29 year old married man, Interview 4)

"*The person in the laboratory, always creates problem for us. Each time he asks us to come on next day, though he knows that we come from such a far off place.*" (Brother of a positive man, Interview 3)

The fear of losing the job in case of disclosure is pervasive and in some cases such fears have been found to be vindicated.

"*I'm always in fear, if I fall sick, my job won't be there.*" (30 year old positive married man, Interview 7)

"*I was told by my organisation's doctor that if I fall sick, my job will be at stake.*" (23 year old positive unmarried man, Interview 1)

"*I was working as a domestic-maid, but as soon as my positive status was revealed to my employers, they sent me to this care home before telling it to me...*" (22 year old positive married woman, Case 4)

The Nexus of Secrecy

Thus, from the point of view of the positive persons and their families, the rationale of secrecy surrounding the infection is obvious. The

fear of discrimination and isolation was there in every single case studied by us. The urge for secrecy is doubly strengthened, because of the stigma that is associated with the infection, and this is especially so if there is a marriageable girl in the family.

"*My mother knew my status, but nobody else...no, not even my brothers. When I fell sick, became unable to do any job, my brothers threw me out of the house. Even my mother did not object to it. You know why? She is worried about my sister. A good family has to be found out for her marriage. But my presence in the house may create some problem. I'm an AIDS affected person.*" (Unmarried positive man in mid-twenties, Interview 10)

"*Nobody knows about my status except my wife and brother among my family members... I've to arrange marriage for two of my daughters before I die, this is my prime concern.*" (45 year old positive married man, Interview 2)

"*Nobody knows in this world (about my status), except the doctors. I don't feel like telling it to any body, not even to my family. ...Five more unmarried sisters are there, who'll look after them...tell me?*" (26 year old unmarried positive man, Interview 11)

"*They see this disease as 'ganda bimari'. I'm not much worried about myself, my prime concern is my younger sister's marriage*" (24 year old unmarried positive man, Interview 14)

The danger that such secrecy may imply is also not far to seek. The husband keeps it secret from the wife, thereby increasing the risk of transmission. Families keep it secret from neighbours thereby adding on to the level of stress and anxiety they are already subjected to. The problem is that much of the secrecy is propelled by factors that are avoidable. Much of it originates from the knowledge and understanding of the infection that is incomplete, inadequate and even patently incorrect.

Inadequate Awareness of the Infection

Knowledge about the infection is surprisingly low in the communities in which Focus Group Discussions were held, as also among many

infected and affected individuals and households. The ignorance cuts across all social groups and both genders.

"*Will there be any problem, if she moves around in the house freely?*" (A relative of HIV positive woman, Case 3)

"*We have small kids in the house. We are scared if an HIV positive person lives in the house.*" (A relative of an HIV positive person, Case 8)

"*My husband died of AIDS... I'll die very soon, because I've also got HIV. If some body touches me, he or she will also get the virus.*" (30 year old positive widow, Interview 18)

"*A nurse in my locality told me that, though I'm HIV negative at this moment, I'll get the infection within ten years from now, because my husband died of AIDS. I'm worried about my children.*" (38 year old widow, Case 1)

"*So I've got only HIV, not AIDS...that means nothing to worry about it.*" (26 year old positive unmarried man, Interview 11)

"*Could you tell me what are the probable indications for low CD4 count?*" (A medical practitioner from U.P., he is HIV positive, Case 7)

Factors Leading to Behavioural Change

One of the major findings from the case studies is that the sexual norms and belief systems in the communities studied by ISST are much too strongly entrenched to allow for behavioural changes through superficially designed strategies. More knowledge and awareness about some aspects of the infection and its transmission process is inadequate to change behavioural patterns. For insistence, thanks to media efforts, there is some degree of awareness about contraceptive devices. However, the more knowledge of condom use generally does not lead to their actual use by the potential user in most cases. For women, even if they are aware of the protective potential of condom use, they can hardly ever negotiate with their husbands or their actual use. Insistence of condom use by married women is seen as a sign of their infidelity. Most women dare not suggest it to their husbands for fear of physical violence.

CHAPTER 5

Conclusion

Summary of findings

Limited in size and scope as it has been, the study has come up with a whole range of findings — vindicated some established facts while revealing some new ones — and has raised some interesting questions as well. Subject to the caveat that the findings are bound to be coloured to some extent by the specificities of the study locations, our findings corroborate the following relatively established 'ground realities' among others:

Knowledge and Attitudes about HIV/AIDS

- Knowledge about HIV/AIDS was found to be surprisingly low both among the participants who attended the Focus Group Discussions and the positive people and their family members in Delhi. The levels of ignorance seem to cut across all social groups. Moreover, there is a huge gap between exposure to knowledge on HIV/AIDS and the internalization of such knowledge, and consequent behavioral change.
- The findings from Focus Group Discussions highlight gender differentials in the levels of awareness - low among women and girls as compared to boys and men. There was a positive co-relation between the level of education and awareness about HIV/AIDS. Adolescent girls who have a higher educational level than adults seemed more informed.
- In the FGDs, some men said that they did not know much about the differences between HIV and AIDS. Though they knew the mode of spread, misconceptions, fears and beliefs accompanied it. Many

of them believe that, it spreads through relationships with *"bad women"*. Many men in Delhi believed that HIV/AIDS was not their problem and that it was a problem of *"the other"* or *"the rich men"* who could afford to go to sex workers.

- Adolescent boys in the slums of Delhi learnt about HIV/AIDS from the TV and the billboards. However, the information they possessed was found to be incomplete. They also had no idea about opportunistic infections due to HIV/AIDS.

Knowledge of Sex and Sexuality

- It was found that most women and young girls were non-literate about their bodies. In some cases the younger girls were more aware about the reproductive functions, especially those attending secondary school, though it cannot be generalised for all the study sites.
- Adolescent boys in the settlements of Delhi are sexually quite active. There is considerable peer pressure for acquiring sexual experience fairly early in life. Visits to sex workers are proof of manhood, and provide ticket to peer acceptance. Boys and men shared that both bisexual and homosexual activity takes place as well as sexual abuse of younger males.
- Young girls are generally a "protected" lot, and sex is a highly taboo subject for them. However, girls who attend school are more open about sex and more aware about sexual matters. This is more so in communities, which have some NGO presence actively, involving both sexes.
- Gender balance in the family is extremely skewed. Adult women have little negotiating powers about sexual matters within marriage. Young girls have little choice in spouse selection.
- Women found it difficult to access health care for treatment of sexually transmitted infections. Many felt uncomfortable in talking to male doctors and while women wished to be seen by a female doctor, their husbands usually mediated such appointments. This in turn discouraged women from seeking further treatment, as a result, it is possible that a lot of STIs perhaps remain untreated.

- There is virtually no inter-generational communication over sexual matters. This is true for both sexes.

Issues of Prevention and Care

- In the FGDs all married women reported that they were aware of contraceptives but few used them. In FGDs with men, it was reported that condom use at the brothels and homes was low, though the adolescent boys said that they were in use.
- Education did not result in greater autonomy, thus leaving little space for women to negotiate on safe sex within marriage or even have say in selection of spouse for marriage.
- None of the women, who participated in FGDs, reported condom use by their husbands. Women further expressed that men were generally uncooperative when condoms were suggested. Therefore they felt that they would like to use contraceptives themselves. Thus women felt that in cases of pregnancy and in cases where they were sterilised bringing up the issue of condom use with the husband was impossible.
- Men who were HIV positive also said that they had difficulty in initiating the use of condoms especially since they had not used protection previously and they did not want their wives to become suspicious.
- A key observation was that men were torn between feelings of responsibility, on the one hand, a desire to protect their partners on the other, as well as a desire to maintain secrecy.

Economic Impact on Affected Households

- There are some features of HIV/AIDS that make it different from other illnesses in its socio-economic impact. These include the extended and very high treatment costs and it affects adults in their economically productive years.
- It was noted that at the individual family level the impact is quite evident and that only very few families that were economically better off could absorb the costs incurred. Some of the positive

men - the key bread earners in the family - lost their jobs, when their employers gained knowledge about their sero positive status.

- In most cases the HIV positive women were financially dependent on their spouses and did not have any source of independent income. This has intensified their feelings of insecurity. In many a case, women have no choice but to augment the family income. Women who are educated manage to find some work, in most cases they did not have sufficient skills to gain employment.

- In several cases, the natal family provided the much-needed economic support to their daughter and son-in-law, rather than the marital family. This seem some in line as an extension of the 'dowry demands' made on the wife's family. As such the economic costs incurred by the natal family remain invisible in the social context

- In cases where both the husband and wife are ill, they have been totally dependent on the families. To raise money families have sold their land, jewellery and valuable things at home.

Gendered Impact

The findings do reveal that women are worse affected. Impact of HIV/AIDS on the affected families corroborate similar findings from earlier studies in India. Among these are the following:

- The worries and apprehensions of men in such families are more centred around the self, while women worry much more about children and the family.

- A man suffering from AIDS is cared for by his wife or other female members of the family, while an AIDS-affected married woman is generally shunned. More often than not, their husbands desert them. In almost all the cases of AIDS- affected married women studied by ISST, it is the natal family that is providing economic support and also health care. In poor, especially landless families with an AIDS-affected woman who may not have any place to go to, it is not altogether unexpected for the man to leave the house, leaving his sick wife to her fate.

- The most striking feature is that on the death of the husbands, the wives have been either thrown out or sent back to their natal families.

- Fear of social ostracism prevented HIV infected people from confiding in family members and neighbours. There were many cases when both positive men and women suffered rejection and isolation from the family.

- There is a pervasive sense of guilt and fear around the ailment, resulting in a high degree of secrecy among many. In several cases, men did not inform their wives of their sero positive status even when they had informed other male members of their families. There was a desire to protect the wife on the one hand and keep the so-called honour of the family intact on the other. This was particularly the case where female members of the family (sisters/daughters) were yet to be married.

- It seemed that in affluent and educated sections of society, a sense of secrecy and guilt was even more prevalent. In some cases, husbands preferred to tell their family members that they had diarrhoea or TB rather than that it was HIV related infection.

- In the focused group discussions, adolescent boys said that there would be an adverse effect on the women, if HIV/AIDS spreads. They said that women will have to bear the entire financial burden of the family, and that they would be blamed by both the men and women in the family for the spread of the infection.

- Women were viewed as "Sati-Savitri", ever devoted and loving or were considered as the gateway to hell and expendable. Women experienced considerable shame. They also experienced despair and depression.

- Another area of discrimination is with respect to property rights. Many widows could not re-claim the dowry and jewellery, after their husbands had out of AIDS related infections.

- The experience of discrimination continues in widowhood as the community identifies her as a widow of an HIV positive man.

- Displacement from their homes and neighbourhood once sero positive status was known is common. In the case of men being HIV positive, the family often relocated to places where their status was unknown. Families also suffered when relatives did not visit them.

- Both men and women experienced discrimination frequently at the health service settings. A few respondents have experienced rejection when their status has been revealed by the doctors or family members, thus intensifying the feelings of rejection.

Concluding Observations

It may be noted that many of our findings are quite similar to ones coming out of other reports. The phenomenon of early sexual experience of young males, especially visits to sex workers that begin fairly early in life, and the taboo on matters relating to sex where young girls are concerned, are findings that come out as strong and clear from the *chawls* and settlements of Mumbai as they do from our sample[20]. The high degree of ignorance in the community about various aspects of HIV/AIDS in terms of visible symptoms, methods of transmission and requisite nature of care etc. is also similar.

Our study clearly indicates that the impact of HIV/AIDS on the individual and the family is highly gendered. Behind all such gendered manifestations of the corrosive impact of the epidemic is the strong and resilient hold of patriarchal values. A woman is either a Sati/Savitri, to be put on a pedestal and 'protected', or she is the 'gateway to hell' and totally expendable when the chips are down. She is never an equal. A woman afflicted by a deadly infection like AIDS is generally perceived to be totally expendable.

One aspect of this confused approach to sex is the high degree of secrecy that is cultivated around the infection. HIV-positive men would normally not divulge their positive status to their wives. Relatives and friends will be scrupulously kept in the dark, especially if there are marriageable daughters and sisters in the family. If a married woman is HIV-positive, her husband would try to hide the fact from all and sundry, for 'good women' are not supposed to get such '*dirty diseases*'.

[20] Bharat, 1996

One man interviewed by us was outraged that he got the 'disease' from his visits to sex workers, for he had been only visiting 'good girls'.

One obvious outcome of such secrecy from their partners, is the risk that the latter are being continuously exposed to. The need for secrecy completely overrides any sense of responsibility that may have existed.

Underlying the entire gamut of such behavioural response to HIV/AIDS, is the complex set of factors that shape the sexual mores and practices of the Indian male. On the one hand there is an enormous degree of shame and taboo regarding sexual matters. These are not talked about openly. There is also a considerable degree of guilt, shame and a sense of sinning attached to all matters sexual. On the other hand sexual prowess is equated with manliness and is an inalienable component of a macho image. The sexual needs of males are looked upon as an essential part of their being, and merit gratification, even if it means stepping beyond the accepted familial milieu. In this respect the differences from the Mumbai study where the recognition of the sexual needs of 'older women' who may be seeking out younger males in the neighbourhood in the absence of alcoholic or otherwise indifferent husbands, stands in sharp contrast to our findings in Delhi where no explicit references were made about such phenomena[21].

The absence of clearly defined, transparent, and socially accountable sexual mores and the prevalence of those that are fostered by myths and secrecy from the childhood, spells disaster when confronted by something like HIV/AIDS. The result is often an utterly confused mental state, the overt manifestations of which vary from person to person. One common response is a show of bravado, which is especially widespread among affected men who are economically well placed enough to spend on the expensive treatment, but are not very highly educated. Among the educated and affluent sections, the more common response is an all-consuming desire for secrecy. Underlying all such reactions is the pervasive sense of guilt and fear.

A rather extra-ordinary conclusion that our study findings appear to suggest, and one that could be a direct outcome of the warped and confused attitude to sex that is bred in our society from the

[21] Bharat 1996

childhood, is that mere awareness about HIV/AIDS does not necessarily lead to an altered behaviour pattern. All our interactions with affected families and with different sections of the community in Focus Group Discussions point to this rather startling finding.

Although such findings are not uncommon in Africa[22], to our knowledge no other study in the Indian context has highlighted this phenomenon. It appears that there is a huge gap between the exposure to knowledge on HIV/AIDS, and its internalisation and consequent behavioural change. If this indeed is representative of large segments of the population in India, it has obvious implications for policy which need to be spelt out.

The other conclusion that emerges from the study is that for a large majority of the affected families, especially those that are economically impoverished, the spectre of death, especially death that is not imminent, is accepted as a routine affair. Here again the similarities with the African experience are quite startling[23]. To what extent this is coloured by the attitude towards death in Indian society is an issue which needs to be probed further. In any case, the relative indifference to the possibility of death in the not-too-near a future is hardly surprising when the daily fight for bare survival is a way of life. Economists have always believed that the poor are more myopic. It is also not of much concern whether one dies of AIDS or some other disease like malaria or tuberculosis. The secrecy and stigma that is generally associated with the former goes down as one moves down the socio-economic spectrum. Similar findings have come out from some research on social consequences of HIV/AIDS in Africa. Once again, if this indeed is so on a larger scale, the policy implications of these findings need to be analysed carefully.

In conclusion, one rather encouraging feature that comes out from our findings is the nature of inter-generational changes that seem to be taking place in the area of gender sensitivity. Adolescent boys appear to be much more aware about the problems that girls and women face within the family and the community, and much more sympathetic to them than their adult counterparts are. We should refrain from

[22] Caldwell et.al.1999
[23] Caldwell et al. 1999

generalisations though, for such features could be the fall-out of NGO-presence in some of the study communities, resulting in greater intermingling of the sexes. Nevertheless this is an encouraging feature of the study sites that need to be investigated.

Recommendations

- The researchers found a severe lack of counselling services even for PLWH/A in hospitals. Counselling services should be introduced in all hospitals for PLWH/A and their families.
- Intervention programmes for reducing the spread of HIV/AIDS should address reproductive health and sexuality for both females and males.
- Gender sensitive sex education should be introduced and the needs of adolescents should be addressed.
- Tools used for information dissemination should be participatory and in tune with the culture of the region. Perhaps more culture-specific and participatory forms of communication such as street plays, folk theatre, puppet shows, FGDs, etc., would have been more effective means of generating awareness than billboards and posters.
- The medical fraternity should be educated and sensitised on the issue of HIV/AIDS.

Appendix I

Individual Interviews

[*These personal interviews were conducted in the hospital setting, except one (interview no. 16) which was conducted in the residence of the person. In almost all cases, the HIV positive persons were spoken to. In some cases, one or two family members were also interviewed. In two of the cases reported below, i.e., interview no.19 and 20, only members of the affected persons were spoken to.*]

Interview 1

The first person, who was met for the study was Ram, a 23 year old young man from Orissa. Ram is working with the ITBP (Indo-Tibetan Border Police). He seems to be a very shy and depressed individual and was accompanied by no one to the hospital. He came to meet the doctor with his blood report. We approached him and introduced ourselves and sat down on a bench in the lobby. It was explained to him that although we are not doctors, we would like to help him in any way we can in case he wanted it. Ram is a healthy young man. During the initial rapport formation period, he spoke about his childhood. Playing cricket is his hobby and joining the defence services was his long cherished dream, which was fulfilled when he joined the Indo-Tibetan Border Police two years back after he had finished his schooling.

He had come to know of his infection a few days prior to this meeting. Slowly he spoke about the infection and told us that he has decided not to convey his status to his family members. He said that he might have been infected on a visit to a sex worker once on the insistence of his friends. Ram said, "*There is no need to mention my HIV status at home. My mother is a widow and won't understand much about the infection. She may tell others. But, what's the use? Who'll help me? I have a very large*

family and the news of my status will spread like wild fire in the village and my family could be isolated, as the disease bears so much stigma...My family is putting pressure on me to get married but I have decided not to, and I will have to convince them somehow."

The doctor in his unit and two of his close friends know about his status. He had mentioned it to them. Their attitudes have not changed. Ram says that his friends are co-operative and helpful.

The second meeting was held two months later. Ram seemed to be very energised and cheerful. He had come to know of a few others in ITBP who were also receiving treatment. His CD4 count was above 500 and he said that he felt as if he had no infection at all.

He is being provided medical treatment by ITBP. His family lives in a village in Orissa. Ram's mother is economically and emotionally dependent on her son. Ram sends part of his salary to her. His brothers work in small industrial workshops in a nearby town.

Ram was not well informed about HIV and we had to explain to him about the modes of transmission, its consequences and kind of treatment available. He had never heard of HIV before. He says, "*I never knew such a virus is prevalent. I came to know only when I tested positive.*" Presently he has acquired the basic knowledge. He is mentally stable and had come out of his initial depression.

Interview 2

On our next visit to the hospital we met Deen Dayal, a 45 year old married man with 3 children. Deen Dayal comes from a middle-class background. He is from Delhi and is working as a senior technician in a Government hospital. He appeared calm and was very willing to speak to us.

He said his status was detected a few months prior to this interview and that he might have got the infection while

working in the Operation Theatre. A few of the senior doctors are supportive towards him and have counselled him on several occasions. Nobody else at his workplace knows about his HIV status. At present, he is getting opportunistic treatment for tuberculosis.

He says that his wife is supportive and taking care of his health. He says, "*Nothing has changed between us.*" He said that he is aware of use of condoms but since he came to know of his status he has stopped any kind of sexual activity with his spouse. This could not be verified though since we failed to meet his wife.

In his family, his wife and his elder brother who lives separately with family know about his status. He says, "*I just want to see my two daughters married*". One is 18 years and the other is 16 years. This is one of the reasons he has not told about his status to anyone else, if the word spreads around, his daughters would not be married and his family would have to face a lot of criticism. None in the neighbourhood or community knows about his status.

Deen Dayal had good knowledge of HIV before he came to know his status. He said that presently he has been suffering from skin blistering and excess of saliva secretion.

Deen Dayal appeared calm and talked to us smilingly. Still his worries and stress were clearly visible while he spoke to us. He lives in fear of an imminent death. He says, "*My only desire is to see my daughters married before anything happens to me.*"

Interview 3

Sanjeev is a 37 year unmarried male from a middle class family in U.P. His brother accompanied him to the hospital. Sanjeev looked extremely ill.

He seemed to be in severe mental depression and there was a lot of anger in him. His anger was directed towards the government for not bearing the expenses of the anti-retroviral treatment. It was his brother who spoke to us. Sanjeev did not show any interest in talking to us. He had a look of disgust on his face.

Everyone in the family knows about Sanjeev's HIV status, but it is not known to anyone outside the house. His clothing and utensils are kept separately and his mother provides him with all the care – washing his clothes, utensils etc. Nobody else touches his personal belongings.

It seemed to us that in spite of the fact that Sanjeev lived in the same house, he was isolated in the family. He did not seem to have much interaction with others in the family. It appeared that his family members treat him as if he is carrying a contagious infection, although this could not be verified from him as he refused to talk to us.

Sanjeev's brother told us that Sanjeev had been to Mumbai for a couple of years in the early Nineties. There he indulged in drugs and alcohol abuse. His peers initiated him into this. He became seriously ill and came back to his hometown. It appeared that he was still addicted to drugs and alcohol.

At present, Sanjeev runs a small shop in Kanpur. His brother, who was a businessman, helped him to set up the shop. Sanjeev seemed to be receiving all the support from his family. Presently he is suffering from tuberculosis, skin rashes and blisters.

We accompanied Sanjeev and his brother to a government hospital for a blood test. The laboratory staff refused Sanjeev, as he was late by few minutes. He was asked to come next day. Sanjeev talked to us for the first time. "*Look at these people, they are supposed to serve us, but they talk so rudely to us... We are also human beings... We have every right to live... You know anti-retroviral drugs come from foreign countries to be distributed freely, but they sell them in the market.*"

Interview 4

Dharmesh is a 29 year old married man from rural Delhi. He was willing to talk about himself but seemed in a hurry to meet the doctor first. He was told that the doctor's permission had been taken and he could speak to us and if he had any queries about the infection he could ask us.

Dharmesh owns his own PCO and a '*dhaba*' in Delhi. Basically he belongs to U.P. His parents and brothers live there. Dharmesh lives in Delhi with his wife and children.

He has all praise for his wife; "*She is like Lakshmi for me and very caring. I have told her about my infection.*" Dharmesh says that he uses condoms for sexual activities. He says "*I was aware of HIV before and knew the use of condoms but never thought of using them.*" His wife and three children had been sent to his wife's natal home in Allahabad, as he was ill and suffering from genital ulcers. Previously he has visited a lot of private doctors but that has brought no relief.

His family is in the village and is aware of his infection. They have given a lot of support except for one younger brother who has cut off relationship with him. His wife's family is not aware, he has told his wife not to mention it to them.

Neighbours in his village (not in Delhi) know about his status and their response is very discriminating. "*My wife has to bear sarcastic comments from various people*". None of his employees know about his status. He has saved a good amount of money by running his shop. Says in the past year he has spent around a lakh for his treatment with private doctors.

In a week's time we met Dharmesh again. He was very weak and was accompanied by a friend. The friend said that he still visits CSWs and does not use condoms. This friend was operating as a pimp in one of the communities. He spoke about various myths on the use of condom. Dharmesh's genital ulcers had become worse and he had been referred to the STD clinic of the hospital. He appeared more depressed than the previous meeting.

Interview 5

Manish is a well built 33 year old married male from Delhi. He is married and has two daughters. He has been making regular visits to the hospital for the past two years and was very approachable. He had finished his schooling before he started his

profession as a property dealer. Two years back Manish was advised to go for an HIV test after he started losing weight drastically.

Manish says that his wife has been found negative. According to him relationship has not changed with his wife, even after his HIV status was known to his wife. He says he practices safe sex. His wife is taking care of all household activities.

Manish does not have any siblings. Both his parents have expired. His wife is the only person who knows about his HIV status. Manish said that he has asked his wife not to tell her parental family.

No one in the community or neighbourhood knows about his positive status. He has in fact provided shelter to another positive person who has been thrown out of his home. He has even provided him with employment

He does not feel why he needs to mention it to anyone since people would just discriminate against him rather than support him.

He is a property dealer and has his own wrestling turf (akhada). He deals with disputed properties. His cousin brother is in the Police. He sold one of his properties for 20 lakhs and has kept it in the bank. He buys his medicines (anti-retroviral) by drawing the interest every month. His life style has not changed much. He is financially secure and is able to provide support for his wife and daughters.

Manish is mentally balanced and looks physically healthy although his CD4 count is down to 132. He says, "*at times I don't realise I am carrying the virus, I feel so healthy.*" He has enough knowledge of the virus and knows it does not spread by touch and takes the necessary precautions. Manish did not talk much about his family life. It seemed he wanted to avoid any conversation that centred on his family. Therefore we did not pursue it. Behind all his confidence, one could see his depressed state of mind.

Interview 6

Harilal is a 32-year old married man and comes from U.P. He did not show any hesitation to speak to us when we introduced ourselves. In fact he seemed relieved that he had found someone to speak to. He was accompanied by his brother and brother in-law (wife's brother).

He introduced himself as a lawyer employed as a legal adviser in an Indian company in Bangkok. He took leave from work after he complained of diarrhoea and started losing weight considerably. He returned to his hometown and was asked to get himself tested for HIV, which turned out to be HIV positive. For further treatment and consultations he had come to Delhi.

Harilal did not talk much about his Bangkok life. He told that he never done any '*galat kaam*'(immoral act).

Harilal hasn't yet conveyed his status to wife, since he has been staying away from her and hasn't yet got the chance to go to his village and speak to her. He plans to visit his village and tell his wife. He is sure his wife will understand the problems since she is educated and won't distance herself from him. Among family members only his brother-in-law has come to know of his status from the doctor. His own brother who also was accompanying him does not know. There was not enough time to speak to him as the doctor called him in.

The second meeting with Harilal took place exactly a month later. He hadn't been to his hometown and spoken to his family. He was very eager to know more about the virus and its effect on the body. This was explained to him. He said that he had saved money in the past few years and would be able to spend on anti-retrovirals for sometime but prolonged use would be difficult. He was very anxious about losing his job as he had been on leave for a long time. He is planning to return to Bangkok and continue with his work and save on more money for his treatment and his family but before that he wants to reveal his status to his wife. He was assured that he could return to his work and continue with life as any normal individual. He was asked to take care of his diet and was told to use of condom.

Interview 7

Ravi is a 30 year old married man from the ITBP. He stood in the far corner of the corridor and looked extremely depressed and dejected. He was carrying his HIV test report along with him. After introducing ourselves we sat together in a quieter place.

Ravi said he had come to know about his status very recently and has been unable to go back to his village and tell his wife. He has 4 children. He said his future seemed bleak and he felt absolutely uncertain and insecure. Ravi had to be assured that the virus was like any other virus that attacks a human body. He could lead a perfectly normal life if he took extra precautions. He needed to control his diet and do regular exercises. His CD4 count was 423 and he was assured that he had a relatively good count. He could continue with his duties, which would keep him active. Further details on the spread of the virus were given to him. He felt much relieved after having spoken to us.

Ravi has not spoken to any family members and was not sure whether he wants to tell them. He is a bit confused how to break the news to his wife. He said, "*If I don't tell my wife and start using condoms she might get suspicious as I have never used it before.*" We told him that he should tell his wife and take her into his confidence. This would provide him with psychosocial support.

He says "I have been discriminated in the work place and doctors have been threatening me that I would lose my job." He informed us that the government is providing the finances for his anti-retroviral treatment. Ravi says, "*I'm continuing with my job but if they throw me out it would be disastrous. I do not have land, no other source of income, above all I have a family to maintain*". He had to be reassured that that there were others too who were HIV positives and one could not be thrown out of job on these grounds.

He says "*I had never heard of HIV before, it was all new to me. If I knew I would have been more careful*" Even now he does not have enough knowledge. After the conversation Ravi felt much at

ease and relaxed. We told him that he could contact us if he had further queries.

Interview 8

Mohan is a 30 year old married man from rural Delhi. He had been working as a welder in Mumbai and had come to know of his status three months prior to this interview. His state of domicile is Bihar where his wife and two children stay.

He has come to Delhi for treatment. In Mumbai he is to frequently visit female sex workers. He has been unable to go back to his village in Bihar and tell his wife about his infection. He has no plans to reveal this to any of his family members because he would be discriminated. He had to be told that he had to inform some member in his family with whom he is close and will understand him. Mohan said that in Delhi he was staying with his friends who know of his status and they were helping him in whatever way they could. He says that his friends do not discriminate or make him feel guilty. They in fact want to help him and are looking around for some employment where he could feel involved.

He has left his job in Mumbai, and at present is jobless but is being helped by an NGO in the community to establish a small-scale business. He was being given counselling by the same organisation.

Mohan seems to have developed certain neurotic symptoms and complains of pain and irritation in his hands and legs. He complained repeatedly of these symptoms. His CD4 count has come down to 204. The doctors gave him prophylactic treatment. We told him that he needed to take care of his health and stop brooding. He was normal and could lead a very active life.

Interview 9

Sukhdev is a 55 year old married man. He had come with his wife Anita. The doctor had already briefed him about us and therefore it became easier for us to approach him.

Initially when we spoke to him his wife was around so he didn't speak much and asked us what kind of a research study we were looking into. Sometime later the doctor called Anita in his chamber, and the man started talking. He is a journalist by profession and has three children. His wife knows about his status and says he has good support from her. Although Sukhdev spoke very openly about his sexual life and his early indulgence in sexual activity it was difficult to ascertain whether Sukhdev still indulges in it. He enjoys watching blue movies/*masala* movies and reads erotic literature. He has been a regular client of call girls and says he went to the 'good' girls where he felt no need to use condoms. "*I did not visit cheap prostitutes who can be bought for Rs. 20/-. I have visited 'good' girls and I have paid them in thousands. Who would know that I could get the virus even then!*"

Sukhdev never mentioned of his wife's positive status. When we asked him about his wife's status, he said that Anita was negative. We came to know from the doctor that Anita is HIV positive too. Their son who is 18 years knows (overheard) about his father's infection and initially had questioned his dad "*are you having AIDS?*" He had then clarified that he was just HIV+ and had not yet got AIDS. His school going daughters (13 and 14 years) know nothing about their father's status. No one else in the family knows about his status.

In his social circle only one of his friends who is in USA knows about his status. This too has been mentioned to him so that he is kept updated with the latest research happening on HIV/AIDS. He receives support from his friend.

Sukhdev is a freelance journalist and has his own office. He continues with his writings and does not feel the need to mention it to anyone. He belongs to the affluent class. He visits many foreign countries. He says, "*there are no financial constraints and my children's future is secured. Last year I had taken my son to Europe, Canada, America and told him he could pursue his studies in any of these countries. I have enough money to spend on my children.*"

He says "*I have come to terms with my present status. I don't feel I need any kind of counselling. I read enough material on HIV and keep myself updated.*" The couple is on anti-retrovirals.

Interview 10

Raju is an unmarried man in his mid twenties from Delhi. When we met him he was extremely depressed with no place to go to.

He was living with his two brothers, mother and sister when he started frequently falling ill and had to leave his job. Earlier he was working as a construction labour. His brothers were irritated as a lot was being spent on his medicines. They felt he was getting to be a burden and was not contributing to household expenses.. They asked him to leave the house without knowing his HIV status. The only person who knew about his HIV status was his mother. His mother did not hesitate to throw him out. Raju says "*Mother knew about the stigma attached to AIDS and since I have a younger sister who will marry in future, she got scared that no one would come forward to marry her knowing that her brother has got AIDS.*" He said he had never expected his own family to take away all the support when he needed it most.

Once he was thrown out of his house he started staying at the railway station. Then he met one of the homeopath doctors who fixed his accommodation with another HIV positive person. He is provided food there and has also been employed by this other HIV positive person as a construction labourer. When we met Raju, he was very weak. He told us that he has lost weight. While talking to us, he also revealed that he even thought of committing suicide. Raju was suffering from tuberculosis. He was provided referral-counselling services and was asked to contact them.

Interview 11

Anwar is an unmarried 26-year-old. We saw him talking to a person in the lobby happily. He appeared to be very relaxed and lively. The doctor introduced him to us. He was very happy that he was doing so well and had no symptoms at all.

He has not spoken about his status to anyone at home or to his friends. He has a large and lower middle class family. He stays

with his widowed mother, 8 sisters and 3 brothers. "*I cannot speak about my disease to anyone, everybody knows how one can get this virus. I am scared of the stigma and the blame attached to the infection. I have five unmarried sisters and I am worried about their marriage. My family only knows that I am suffering from some minor health problems.*" He was also suffering from guilt complexes, he kept saying, "*I have done wrong and I'll have to suffer.*" We counselled him at this point and told him that there was not to feel guilty.

He runs his own small business of selling second hand clothes and has not mentioned his status to anyone. He said that he had been going to some private doctors too. We told him that once he started taking prescribed medicines from the hospital he must not go to the private doctors. We gave Anwar our contact number as he wanted to get in touch with us in the future. Presently he said he had no physical problems and he was happy he was feeling bright and active.

Interview 12

The next HIV positive person we met was Babu who is an unmarried 26-year young man from Andhra. He was very open to talking about his life and freely put across his views and opinions.

He said none of his family members in his village know about his status. He is not ready to reveal facts to anybody, as his family can't help him in any way. He says that "*If anyone in the village hears that I have visited a sex worker or have indulged in sexual activity before marriage, they will throw me out of my village and isolate my family members too. I have decided not to tell them, they will not be able to help me any ways.*" His family wants him to marry but he is undecided, "*I will marry once I become negative.*"

Babu has been in the BSF for 5 years when due to some infection his blood was tested and HIV status was found out. Later he was thrown out of BSF. He is presently in Delhi and staying with few of his ex-colleagues who he says are co-operative and helpful, but they do not know his status. At present he is

working in a private firm as a clerk. He has not mentioned his status to anyone.

Babu along with few other positive BSF jawans who were also thrown out wanted to fight a case against BSF in court but these friends were not willing to take all the trouble and said it would be too long a procedure. Babu is still in search of a good and sensitive lawyer who will give him a good hearing. He was furious with the way the BSF had treated them.

The company where he is working for pays him Rs. 2500 per month. He just about manages his monthly expenses but at times he has to face financial constraints. His family has landed property. But they do not even know that he has lost the job. They are asking him to get married soon. He is very much interested in marrying and says "*I would like to marry a positive girl, just for sake of companionship. But I feel I will be negative sometime and I can marry a negative girl too once I go back to my village.*"

Babu says he still visits sex workers and now he does not forget to use a condom. "*Though I knew about HIV/AIDS before but I was not aware of the importance of condoms.*" His CD4 count is above 300 and physically he is active. He also lives with the hope that he might become negative some day. He was given the names of other counselling centres in Delhi.

Babu used to repeatedly call us to gain confidence and support and to have someone speak out his feelings to. He gets into these depressive moods at times when he feels he doesn't have many friends to confide in. He also attends yoga classes and counselling sessions in one of the organisations actively working with people living with HIV/AIDS.

Interview 13

Rajesh is a 35 years old man from Bihar. He showed a lot of eagerness and interest to learn more about the infection. He didn't seem perturbed and appeared calm.

His family is in Bihar and he has informed no one there. He is married and has a 12-year-old daughter. He has not told his wife

about his infection. He stays mostly away from home and knows the use of condom and keeps it in mind whenever he visits his wife.

His cousin in Delhi knows and is helping him with treatment at AIIMS. His own brothers, mother, wife have been informed that he is suffering from TB and is on treatment. He says "*There is no point in telling my family about the infection, they will not understand much.*" He says that his cousin is supportive but his own brothers taunt him because he has not been able to send money to his family for sometime. He informed us that his daughter was being supported by a community-based organisation that was providing support for her education.

He had been working at a cloth mill in Gujarat for 10 years. In early 1998 when he fell ill he had to frequently remain absent from work. Once he came to Delhi for treatment, he had to leave his job.

Rajesh said that he had never heard of the infection before and came to know of its consequences once he was tested positive. He says, "*If I had known about this virus from before I would have been cautious.*" He was told to keep himself occupied in some work as he could lead a very active and normal life. Presently he has been suffering from loss of weight but he was told that since this was his first visit to the doctor it would take time for him to stable. If he regularly took the medicines and followed the prescribed diet he would feel absolutely normal.

Interview 14

Vivek is an unmarried young man of 24 years. He was accompanied by his sister and seemed very active. He was very eager to speak. His sister was extremely concerned and distressed and needed separate counselling.

Vivek's status was detected 5 years back. The family has a good business and in future will be able to provide anti retroviral treatment. His family (parents) had reacted very strongly when they heard about his status. They accused him. He had to bear lot of allegations from his family members and his parents revealed

his status to other relatives and friends. He went through major depression during this time and he started taking drugs. He got addicted to all kinds of drugs including IV. He even tried to commit suicide. Most of his family members know of his status, but his elder sister and her in-laws have not been informed. He says, "*If my parents had supported me from the beginning and hadn't overreacted to my status I wouldn't have taken to drugs.*" The only person giving him all the psychosocial support is his younger sister who wants to help him out. Presently, he says things have changed, he is leading a normal life with support from his family members who are now more co-operative.

When he was doing his 3rd year BDS, he was tested positive. The doctor who was treating him revealed the information to few of his other friends. He was soon isolated from his friend's circle and he faced a lot of discrimination from both teachers and students. Due to this severe ostracism he left his course half way. Presently he is busy in the family business of brick kiln.

"*I knew everything about HIV/AIDS. I had developed certain infections and I had this doubt that I might be positive. Then I read a lot of other material on it and got my test done.*" Vivek's CD4 count is above 300. He is on anti-retrovirals and is keeping himself busy by involving himself in the family business. The family has a good business and in future will be able to provide anti retroviral treatment. He said that he had started thinking very positively. He knew that he still had a long way to go and would try his best to lead a healthy and normal life.

Interview 15

Seema is a 33-year-old widow. She appeared very dejected and quiet. We had to sit with her and make her feel relaxed. She seemed lost and felt that life had ended for her.

Seema was married in 1989. She does not have any children. Her husband died in 1996 of AIDS and she was asked to get her HIV test done. A private doctor then assured her that she would be cured completely. After sometime she developed a fungal infection in her tongue, swelling and rashes on her face. She was then advised to consult the present doctor. She complained of

weakness and loss of appetite. Everyone in the family knows about her infection (both her maternal and matrimonial family). Her in-laws are providing her support. In Delhi she had been staying with her husband's brother's family. She does not have any complaints against her in-laws. No one outside the family knows about her status.

She is teaching in a school. She has not told her colleagues about her HIV status as there is stigma attached and she might be thrown out of job and she is frightened of being discriminated. Seema was feeling very low, she was repeatedly told that she was doing very well and it was good that she was still working. This would keep her occupied and in a better mental frame of mind.

Interview 16

We visited Meena at her home through an organisation providing support to PLWH/A. Meena is a 28 year old married woman with 3 children. A member of the organisation took us to her home. Her three children (8yrs, 6yrs and 5yrs) are receiving institutional support from the organisation. She comes from West Bengal. She was very welcoming and was happy to speak to us.

Meena spoke about her early years when she came to Delhi to work as a maid. After few years of working she married a man from Nepal. They have been married for 15 years.

Previously the couple was living in the settlement area of Moti Bagh. Later entire settlement was evacuated and all the settlement dwellers were shifted to Rohini. Meena's family got a single room accommodation from the government. They have a plan of extending it, if they are able to accumulate some money. She said that a lot of money had been spent on her treatment. Her husband is a daily wage construction labour. They have no relatives in Delhi. Her husband has no contact with his family for a number of years while Meena's family in West Bengal visits her once in a while. Her brothers occasionally visit in search of jobs but they have not been told about her HIV status. Her status has been strictly kept confidential between the two. No one in the neighbourhood knows her status.

Meena came to know of her status 3 years back. Her husband is HIV negative. The relationship between the two is strained and after a lot of counselling by the organisation both are staying together. She said she had never heard about HIV before and even now she had gaps in her knowledge.

She remains very low and depressed and has even stopped treatment saying they are unnecessary expenses. She was told that she should be visiting the hospital where she would get the right treatment, visiting private doctors would only create more problems. According to the organisation member Meena had been a CSW. She was being counselled by the organisation

Interview 17

We met Surinder at the hospital. He had come with his wife Rekha (36yrs) and their 9-year-old child, Rohit. The doctor had already mentioned to us that the three were HIV positive. Surinder is a truck driver and lives in a village near Gurgaon.

The family was visiting the hospital because the child was extremely ill. Rohit has been suffering since he was 6 months old and lately he was suffering from severe skin infections and loss of weight. He had dropped out from school sometime back and now stayed at home. He is unable to play and spends his time with his grandmother and his uncles. Even through the weakness he was experiencing, he managed to have a smile on his face. Their eldest child, who is 11 year old and the youngest one who is 6 years old are negative. The couple has been married for 12 years. The relationship between husband and wife hasn't changed. Surinder said that he had visited sex workers before marriage but never after marriage. Rekha says, "*I know my husband very well, he is a very good man and wouldn't have done anything wrong.*"

Surinder's parents and brothers live in the same house but they have their separate kitchen. They say that they face no discrimination in the family. Rekha participates in all the household activities and said that family members are co-operative and helpful. In the absence of her husband other senior family members accompany her and her son to the hospital.

According to Surinder everyone in the village knows about their status. He said there have been other HIV/AIDS cases in the village and recently a person had died of AIDS.

Surinder is continuing with his profession. Till now he says there hasn't been any financial constraints. They had not yet begun on anti-retrovirals. Surinder suffers from blisters on face and Rekha is suffering from persistent diarrhoea. Other than these opportunistic infections both seemed healthy and active. We gave them a diet chart, which they were asked to follow.

Interview 18

Nilima is a 30-year-old widow from Bihar. The first time we met her she appeared very scared, uncertain as to what had happened to her. She was accompanied by her brother in-law (husband's cousin).

Her husband had been ill for a long time and his positive status was known only a few months before his death when he was suffering from Kala Azaar. He had died a month prior to our first meeting with Nilima. She hadn't yet recovered from the shock. She herself keeps very weak and has been suffering from facial paralysis since her husband's death. She also has 2 children – a 10-year-old boy and the younger one is just 8 months old.

She is not receiving any financial support from anyone but she says the in-laws are supportive in terms of looking after her children and feeding them. Her husband's siblings have shunned her and are not supporting her in anyway. During the time her husband was ill and in the hospital her mother-in-law would take care of her husband since she had to be at home for her younger child who was just 6 months at that time.

In Delhi she is staying with her sister for the period she has come for treatment. But she realises she will not be supported forever.

In the second meeting her brother-in-law said the main concern was the financial constraint. No one will be able to help her financially. They are p! nning to sell her husband's share of the

landed property. She was given the name of an organisation that provides support to the children.

Nilima said that she didn't have any knowledge whatsoever about HIV/AIDS. She was scared that she would pass it on to her children. We told her about the modes of transmission and also the precautions she must take. Both her children have tested negative but the doctors have advised a repeat test for the younger child and have asked her to stop feeding him. After having spoken to her she seemed much relaxed and she was more aware of her condition.

Interview 19 (Affected family)

Usha is a 30-year old married lady and HIV positive. We never got a chance to speak to her as her condition had deteriorated considerably and she was in the terminal stages. When we saw her she was not in a position to even sit.

She was accompanied by her father-in-law, mother-in-law and brother-in-law (husband's sister's husband) in her first visit. Her husband is HIV negative. He does not work since he met with an accident 2 years back and became partially paralysed. He was not accompanying her to any of her trips to the hospital. In their first visit we could just hurriedly talk to them, as they had to return to their hometown in U.P. We spoke to her parents in-law who were concerned about her. They said that a few years back she had received blood transfusion after childbirth and were very sure that the blood had been infected. We explained to them the kind of home care she should get. They were well aware of the infection. In the second visit Usha's father-in-law was present. He said he knew about the consequences but felt that she is an "innocent victim" (got it through transfusion during childbirth). They feel it is their duty to take care of her. Her brother-in-law who lives in Delhi says he has no objection if she stays longer for her treatment. But he is aware of the stigma and has not informed the neighbours of the actual disease. The mother-in-law is providing all care at home, from changing her clothes, washing her and feeding her and they are taking the required precaution.

The father in-law said that both their family and Usha's parental family, come from a lower middle class background. Her father-in-law owns some agricultural land and is a retired primary school teacher. He says that he is willing to spend any amount for the treatment. He is even willing to sell off his land and house. The cost of medicine is coming around four thousand rupees per month. Usha has 2 daughters and the grandparents were concerned of their well being.

Interview 20 (Affected family)

Nirmala is a 32-year-old widow. She comes from U.P. A distant relative of Nirmala's was present at the hospital. We were unable to meet Nirmala as she had gone for her other check-ups. Her husband died of AIDS few months prior to this meeting. Nirmala's husband was sick for a long time. Treatments were being given for T.B, Diarrhoea and oral thrush. Nobody in the family knew that he was suffering from AIDS. Few days before his death it was known to his family members that he had AIDS. Immediately after his death Nirmala had to undergo the HIV test and she was found positive.

She has six children. Two of her eldest daughters are married and their in-laws came to know the cause of death of Nirmala's husband. Among other relatives all know of her husband's status but very few know about her. Neighbours do not know of her status as fear of discrimination and stigmatisation prevails.

She and her sons have inherited agricultural land, and a truck from her husband. She and her family are ready to spend for anti-retroviral treatment but prolonged use will not be economically feasible. Presently she is suffering from weakness and loss of weight.

Appendix 2

Case Studies

(These case studies are based on the information gathered from repeated visits to the households of PLWH/A, care home and the hospital. In most cases both the infected and the affected people of the households were spoken to. In two of these cases, i.e., Case 1 and Case 8, we could only speak to the affected family members because the infected had already succumbed to the infection.)

Case 1 (Affected Family)

Lata is a 38-year-old widow who is HIV negative with 3 children. We visited her home which is located in rural Delhi. An NGO worker accompanied us. She was very welcoming and received us with pleasure. The Delhi based NGO is providing home-based support to the children. On visiting we found that the economic condition of the household was very low, the size of the house was very small and there is no earning member in the household.

Lata is living with her children: two daughters and one son who are twelve years, ten years and three years respectively. Lata has three brothers and one sister. Her brothers have divided the property amongst them and are staying separately. In her in-laws' family she has two brothers-in-law who are staying nearby with their families. One of the brother- in-law is an inspector in the BSF.

Her husband was a truck driver. Previously he had been working as a DTC bus driver where his job was terminated due to his involvement in an accident. When her husband fell ill he was asked to get his test done by the doctors. His status was not revealed to the neighbours due to fear of stigma and shame but when he had AIDS he was admitted to the hospital and the neighbours learned about his infection from the doctors and nurses. Her family had to face rejection and

isolation. Even now she has to hear her neighbours saying, "*your husband was a bad and dirty man*". To avoid hearing these and to escape unnecessary fights she prefers staying indoors and has isolated herself in the neighbourhood. Due to this she remains depressed and low. She has to restrict much of her movement also because she is a widow. Her children do play with the other children but the neighbours have the fear that their house is infected and even they would catch it.

Among family members she is supported only by one of her brothers who visits her and provides her the monthly ration from the village and at times she even receives financial assistance from him. Her in-laws have severed all relations with her. During her husband's stay at the hospital she was managing the house with the help of her brother.

Fear of the infection is very high. She had no knowledge of HIV before her husband's status was known. Though she has been tested negative twice, one of the nurses from a reputed government hospital mentioned that even though she is HIV negative she would come to know if she has AIDS in ten years time.

There is no earning member in the household, only the two-room house is in her name. All the savings were utilised for her husband's treatment. Her children's education is being supported by one of the NGOs and she is receiving emotional support from them too. The future seems very uncertain, as her children are still very young. One does not know how long her brother will be supporting her. Lata was emotionally very disturbed when we met her. She has no one to talk to as she stays within the boundaries of the house for days. This is affecting her mental health to a large extent. We had to tell her not to keep herself restricted to the home. She had every right to move out and move around. We had to repeatedly tell her that she was perfectly healthy and must keep herself fit for her own self and for the sake of her children.

Case 2

Asha is a 32-year-old widow with 2 children. We met her in the hospital. We spoke to Asha, her mother in-law and brother in-law (husband's brother). Asha's husband, Sunil died one year back. After Sunil's death

she was asked to get herself tested, she was tested positive. Presently, she is suffering from loss of appetite and weakness.

Sunil comes from an extended joint family. His family trades in mustard oil but Sunil had his separate establishment of readymade garments. Asha has two children. Elder one is a son, studying in 6th and her daughter is in the 3rd. She said that after her husband's death she continued to stay with her in-laws and that she was being treated well by her in-laws and that they were taking better care of her than they had of their son. She felt that it might be due to the guilt factor that their son's wrong doings had brought her to this state. When her husband's status was known she had tried to gain more knowledge about the infection. She says, "*I did become suspicious of my husband's behaviour and I used to question him how did he get the virus but he would just weep and say I didn't do anything wrong. Then I thought that what's already happened cannot be brought back, but the suspicion remained with me. It's not possible for an ordinary Indian Woman to leave her husband. Even I had to take care of him.*"

During the interview she also mentioned she did not face any discrimination from neighbours and friends, who knew about her HIV status. They visit her frequently. All costs according to her were being borne by the in-laws and that she was receiving anti-retroviral treatment. Her mother in-law said that she remains mentally depressed and is unable to work. Her brother in-law said that their family is ready to bear the costs of anti-retroviral. He also said, "*We don't blame my sister in-law because she is 'innocent'. It is also the duty of the husband's family to take care of the daughter in-law.*" We spoke to Asha at length later and tried to counsel her to live and think positively.

Later we made a home visit to Asha's parental family where a number of other things came up which gave a slightly different picture from what was derived from the first interview. The household consists of Asha's mother, father, brother and sister in-law. Asha's mother and 'bhabi' were spoken to. Her mother she said that her son-in-law had been frequently falling ill with TB and high fever and he was finally asked to get himself tested for HIV. He was tested positive and while they were looking out for the right kind of treatment for him, a person claiming to have an ayurvedic cure for HIV/AIDS sold them products for Rs 40,000 and also took his photograph and got it signed by him. They made him write on it that he had been fully cured by the medicines. Sunil's garment shop was a rented one. When the owner learned about his status he was asked to close down his shop. He had managed to pay for this so called treatment from his savings. His condition worsened and his last 13 days he was at a government hospital in Delhi. The mother says, "*During his last days my son in-law was in the hospital, most expenses were borne by us. I used to carry food for him regularly. From his family only his younger brother and one of his uncle were with him, even his own parents refused to meet him when he was in his death bed.*" Asha's parents in-law visited only once when they were called for. After the death of Sunil, Asha was sent back by her in-laws, they didn't want to take up her responsibility and the fear of infection was very high. Her mother had a lot of discussion with the in-laws saying that, "*she got the infection from your son, it was no fault of hers, why won't you keep her with you.*" They accepted Asha and her children to stay with them. Asha's mother adds that she has noticed a sudden change in their attitude. Asha's in-laws are now extremely concerned about her health and they remain beside her even at her slightest discomfort. But during periods of long illnesses she stays at her mother's place. The mother says, "*She feels comfortable here but presently she is back at her in-laws since her sister in-law delivered a child and an extra helping hand was required at the in-laws place. After all she is staying with her in-laws she has to do some of the household work.*"

The neighbourhood around Asha's parental home has isolated them, mainly due to the fear of infection. They have stopped interacting and say that their house is infected. Few say, "*We want to visit your place but since your daughter has this deadly virus we feel scared.*" The community has isolated the family.

Asha's father and brother are into service. They were providing her with the anti-retroviral treatment, which had to be stopped due to severe side effects. Asha's parental family has had a severe setback after the death of their son in-law and the subsequent ill health of their daughter. Their concern centres around her and her two children. Though they have accepted the inevitable consequence of the infection they are still trying their best to provide her the comfort by giv-

ing her the right medicines and ensuring the quality of her life, but this again is being done at the expense of their physical and psychological health. The person's mother herself is a patient of severe asthma. Her daughter's condition has aggravated her health problems and her mind remains preoccupied about Asha's state. The family was very happy to have spoken to us and said that at times they just felt happy to have spoken to someone.

Case 3

Neetu is a 32-year-old widow with 2 children. She comes from Bihar. We met her at the hospital at three different visits. She comes from a lower middle class background and is a graduate. She is a teacher by profession.

In her first interview Neetu spoke about her HIV status. She came to know of it once her husband's status was known. Her husband expired in June 1999. According to Neetu, her husband was a frequent blood donor and she was very sure that he had got the virus during one of his donations. In the first meeting she was accompanied by her sister who resides in Delhi and her younger brother who stays in Patna. She informed that both of her parents in-law have expired. She told that her natal family was supporting her. She is working as a junior school teacher and has 2 children- 10 years and 5 years old. Both the children have been tested negative. She was not feeling too comfortable to share more information, so we left.

During the second meeting, the person was accompanied with her niece (sister's daughter). The niece who has recently got married seemed to be sensitive towards her aunt's condition and status. Neetu said that presently she was receiving both financial and psychological support from her own family- sisters and niece but none from her in-laws. She said that her husband has six uncles who are all settled in Bihar and before her husband's illness they were all staying together in a joint family. Her husband had been working as a contractor in Delhi for sometime but later they planned to return to Bihar where he got employed in his uncle's factory. Her husband was frequently falling ill and was tested positive when he developed TB. Her in-laws never learned about her husband's positive status but because he had TB, they were

asked to shift out and look for another accommodation. They weren't given any financial assistance by the uncles. During this period of crisis she was receiving financial assistance from her sisters in Delhi and to supplement this had to take up a job as a school teacher to support her family and to cover the medical expenses of her husband's illness. She adds, "*Having to look after my husband, his subsequent death and then having to work has drained me out both physically and psychologically.*" Presently she said that she has shifted back to her in-law's place where they have agreed to give her space to stay but no financial help. They still do not know of her status. The niece felt that her aunt is coping well but adds that she might be putting on a brave front but has a lot in her mind.

Neetu plans to return to Ranchi as her children have to continue with their schooling and she has to join work. Her mother stays in Patna but she does not plan to return there as she feels that education of her children would be hampered. She gets occasional help from her sister but she feels she can't ask for money directly. Its only when they give money she accepts. Recently she has received a sum of Rs 5,000 from one of her sisters. She was very happy and there was a sense of security even though it was temporary.

The problem faced during the interview was that all the 3 meetings took place at the hospital. It was difficult to get all the information in this setting. Few things needed to be studied in more detail: The support she is receiving from her sisters is it just restricted to financial help and given out of sympathy. During her stay in Delhi she was not staying with her sisters, one of her sister had let out a room at their office for Neetu, her mother and her younger son. The fear of infection and stigma seemed very high within the family. Not once did the researchers come across her brothers in-law (sisters' husbands). Neetu seemed to be very independent and wanted to manage things on her own. She didn't want to be a burden on any of her relatives and knew she could manage her life by continuing with her work.

Case 4

Bharati is a 22 year-old married woman with one son. We met her at a care home in Delhi. The care home provides palliative care to PLWH/

A. She has been staying here for past few months. Bharati was initially very hesitant to talk and refused to talk anything of her past. But she opened up gradually spoke very freely about her childhood, marriage and her present status. She came out to be a very independent woman and she is one of the responsible inmates at the care home.

Bharati spoke about her entire life. She was born in West Bengal but at a young age was sent to Delhi to her older sister who was working as a full time maid for a family. Her older sister brought her to Delhi at the age of ten and she too started working as an 'ayah' for a business family. Her job was to look after the employer's children. Her employers sent her to a nearby school where she studied for few years. She said that she was cared for very well and became part of the family and was never discriminated against. She was taken wherever the family went for their holidays, sometimes even to other countries.

She was 18 years when she fell in love with the employer's secretary and married him in the same year. Both had been attracted to each other for quite sometime, it was her employers who mediated between them and gave them the approval to marry. As she says, "*They after all meant more to me than my own parents who had only given birth to me.*" After her marriage she continued to work for the family and was provided with a small one-room accommodation at a distance from her place of work. She would be taking care of the employer's children throughout the week and during weekends went to her house. She soon had a son. After sometime she started becoming aware of her husband's unfaithfulness. The other servants working confirmed it. She was told by them that one woman used to regularly visit her husband at her own house. When she saw it with her own eyes she reported it to her employers. They went with her and confronted her husband. She made the decision that she would not allow her husband to have two women in his life and left him that very moment. She was fully supported by her employers. She says, "*after this episode I never met my husband and I didn't even bother to find where he was and what happened to him. I was happy to have my son with me.*" She learned from other sources that her husband would get these girls from G.B Road, which is a red light area. Her employers helped her to cope up and she visited her native place in West Bengal for sometime and left her son there with her mother.

In early 1999 Bharati fell ill with TB. Her employers took her to various doctors and got her tests done. They didn't tell her anything but she was kept separately in a room for one month. She was not allowed to come down and meet the children. From there she was sent to the NGOs care home where she received treatment and shelter. She says, "*I kept asking my madam what's wrong with me but she would not tell me, then they contacted this care home and sent me here saying that I needed proper care and treatment.*" She came to know about her status at the care home and it was entirely new for her. Her employer whom she calls 'madam' visits her frequently and pays for her care and medicines. She adds, "*Madam brings me everything I need though I don't make any demands. Madam would have kept me but she says that her in-laws don't want me to be at the house. She feels a lot for me and cries at times. She is very fond of me and I have been pampered enough by them.*"

The only other person who knows about her HIV status is her older sister who is now working for a family in Bhopal. She says, "There is no point telling it to my family in Bengal. I am not very attached to them and I don't know how sensitive they are going to be. This time when I visit them I'll get my son's HIV test done but I don't think he has the virus, he is a normal and healthy child."

She is presently looking out for a job because her stay at the care home is not long term one. She voices, "*Whatever I have done till now has been on my own. I have been very independent all my life and I'll be so till my end. I have seen people at the care home with full blown AIDS and how painful it is to die in this way. I won't be able to cope with it when I reach that stage. The moment I take to the bed, I might take too many sleeping pills and leave the world peacefully.*"

Case 5

Ritu is a 28 year old married woman. We met her too in the care home in Delhi. She and her husband, Ashok both were interviewed at a care home where the husband works as an accountant. Ritu is a regular drug user and Ashok at one time had been an alcoholic. Both had used the rehabilitation services of the NGO. Ashok was able to get over his addiction and was absorbed by the NGO and sent to Manipur to

handle one of their projects. He met Ritu there in Manipur. Presently both of them are staying at the care home premises in Delhi.

"*Ritu became pregnant before marriage*," Ashok says. He adds, "*I don't believe in abortions. I am a catholic and I thought a lot about it and asked myself what's wrong in marrying an HIV positive girl. I came to know of her positive status only after her pregnancy. My friends in the organisation told me that she had been tested positive and it had been kept a secret even from her. When I decided to marry her all of them discouraged me but I had made the decision. I wanted to support my child too.*"

Ritu has been a drug addict for a long time and has been unable to leave drugs even after visiting a number of rehabilitation centres. Relationship between the two is strained now because of her drug problem. The husband says, "*I am planning to send her back to Manipur, she is getting to be out of control. She even ill-treats her own child when she craves for it. I can't stand all this. At times I lose my temper and beat her too.*" Ritu said that she started with the drug problem at school and was brought into it by her friends. Her parents were very happy with her marriage. At her in-laws side no one has been told about her status or her drug problem. Her husband says, "*I didn't feel the need to tell my family, it wasn't necessary. We just visit them once in a while and if I tell them they might cut off all relations with us. My wife too is not comfortable with my family; she finds them a little dominating but that's fine because we don't have to live with them. Once when I had taken my wife and child on a holiday to their place, my wife complained of herpes. I could not mention it to anyone lest they should suspect. I was even anxious about getting a good doctor who would not ask unnecessary questions and wouldn't spread the word around. Fortunately I knew this doctor who was very helpful and treated her without asking any questions. Even if he had questions in his mind he didn't ask anything.*"

During the time of her pregnancy they were in Delhi and the couple thought that it would be best not to mention Ritu's status at the government hospital because of fear of discrimination. They had a feeling that medical staff should take precautions since they are at a risk of handling HIV cases anytime.

Everyone in the NGO knows about her status. The couple stays at the premises of the care home and she is constantly counselled to leave drugs. She manages to go to a nearby chemist's shop where she gets drugs without prescriptions and she injects high doses of it. She goes to any extent to get hold of them.

They have a 2-year-old daughter who has not been tested for HIV. They don't feel it is important as she is leading a normal healthy childhood. Even the doctor of the care home said it was not necessary to test her. She hadn't had any complications till date.

It was felt that the issue of Ritu's addiction to drugs was a matter of greater concern than her HIV positive status. Her positive status was accepted by everyone and since their place of stay, place of work and their circle of friends was all restricted to the NGO, there was enough support. One limitation faced was that we could not speak to Ritu at length. She was unable to comprehend much of what the researchers wanted to ask. In the second visit to the care home, the researchers learned that she had been sent to her parent's place as she had used drugs again and had distributed it to the other users in the care home.

Case 6

We met Puja at the care home. She is a 22 year old female and is staying at the care home with her 8 month old son. She was willing to talk and felt comfortable speaking of her past.

Puja is a Maharashtrian and her father was in the army. She was the only child of her parents. Her mother died when she was very young. Later her father married again. She never got along with her stepmother. During one of her father's postings, she met her to be husband. He was a Tamilian. Both families were happy with the alliance since both came from a similar background, both came from Christian families and both their fathers were in the army. She married in 1997 and within less than a year of her marriage her husband died of AIDS. She says, "*My husband was a very nice person and was very nice to me, he cared for me a lot. I wouldn't believe that he could have ever visited other women. He wasn't that kind of a person.*"

During her husband's illness and his stay at the hospital she would be the one taking care of him. Puja's in-laws were very harsh towards her. For her husband's treatment they took away all her jewellery and sold it. Her husband didn't know anything about it. She recalls, "*Once, when I went to visit him at the hospital he asked me why I wasn't wearing any jewellery. I told him that it didn't look good wearing it when he was in the hospital. He believed me and didn't ask me any further questions.*" When her husband died she was thrown out of her in-laws place. She feels if she had been HIV negative her in-laws would have considered her staying with them. Her own father and stepmother had already left the place without telling her where they were going. She was left alone with a few months old child. She managed to contact the care home through her husband's cousin who was part of the organisation working with HIV people.

During her stay at the care home she fell in love with an HIV positive drug addict who also works for the NGO. They have now married. She is happy with the fact that she has a support and the motivation to live. At the NGO she has learned stitching and knows crochet and once her training finishes she plans to take up a job outside. She is worried about her son who has been tested positive once and has to go in for a second test in few months. He has already developed skin infections and keeps falling ill. She is keen on working and wants to look for a crèche where she can keep her child but she is not confident as she feels her major limitation is her lack of basic education. She is also apprehensive about facing discrimination at her place of work because of her positive status. She was very uncertain of her future but said that the NGO was planning to employee her as a caregiver.

Case 7

Dr. Kumar is a 55 year old married doctor and his wife is 52 years. We met the couple at the hospital. Dr. Kumar has his private practice in a small town in U.P.

In the first meeting, the nephew of the couple was interviewed. There was a lot of initial hesitation from his side. He informed that he had come on behalf of his uncle who is HIV positive. Dr. Kumar was advised for an HIV test after he was suffering from TB. He has three children- two sons and a daughter. The daughter and elder son are

married. The nephew added at the end that his aunt was also found positive but she has not been informed about her and her husband's status so far. The main problem in informing the HIV status to other family members, as told by the informant is the stigma attached to this virus and they are scared of the reaction from the person to be informed. The nephew said, "*The poor lady (aunt) cannot help her husband, because it is an incurable disease and at the same time she has to bear extreme strains if she comes to know of it. Moreover she is not mentally strong.*"

Dr. Kumar has reduced his working hours drastically, as he has become weak; he has started with anti-retroviral treatment.

In the second meeting at the hospital, we met the couple. The nephew and the younger son accompanied them. The doctor deliberately informed the researchers that his wife is negative. Relationship between the two has not changed. Mrs. Kumar said that her husband remained very depressed and she seemed extremely concerned of his health not knowing that she herself is positive. But she suspects that her husband is hiding something from her and not openly telling her about his problem. From all that was said we could make out that none of the female members of the family had been told about the status of the couple. The nephew says, "*We didn't see why we need to inform them about it, they would unnecessarily worry and then there is the stigma attached to it. They might not react positively. My aunt has not been told about it because it won't help any of us, she will be under extreme strain and she would have to be explained about the infection which she might not have even heard of.*" Mrs. Kumar is being given opportunistic infections but she is not aware of it. She is suffering from some urinary tract problem and thinks the medicines are meant for it.

There was a lot of guilt and embarrassment among the male members in the family and it was difficult to get through the couple, Dr. Kumar refused to acknowledge his wife's status while the wife was left completely uninformed of her and her husband's status. We did try to tell her about the seriousness of the situation but could not go beyond it. Before leaving we told the nephew and the son that Mrs. Kumar should be told about the status and the family needed to

break the news gently to her. They were even given the names of few counselling centres in Delhi.

Case 8 (Affected family)

Rinku is 35 year old married woman who died of tuberculosis on the 5th of November, 1999 and her 36 year old husband, Amar is suffering from brain infection. We were unable to meet and speak to any of the two during the course of our study but we were able to speak to the affected family and made visits to Rinku's parental home.

The main informant during the first interview at the hospital was Amar's brother. He was eager to talk and was looking around for help. He informed that both his brother and sister in-law were positive. Four years back when his brother had gone to Mumbai he had contracted the virus and both had AIDS. The virus had affected his brother's brain and his sister in-law was suffering from tuberculosis. The couple has four children and the immediate concern was to rehabilitate them since financial conditions weren't good both sides. The informant said that once the sister in-law came to know of her husband's status she left her matrimonial house with her children and went to live with her natal family. Since she left they kept no contact with her and her family but lately relations had been somewhat renewed, as both the children needed support. Around the informant's home, the attitude of the neighbourhood and community was not positive. They had shown their dislike of having an HIV positive person staying in the community. Amar's brother's, and his family's concern was apparent but the fear of living with HIV was equally apparent. They are fearful of contracting the virus.

The second meeting was also at the hospital. This time Amar was present with his brother and his mother. He was in no position to talk. His brother informed that Rinku was admitted at a TB hospital and there was a slight improvement in her condition but Amar's condition was deteriorating by the day. The mother informed that all the care for her son was being provided by her and she was doing all his washing, was feeding him but their small accommodation was creating problems as he was defecating all around the house which might prove dangerous to others. They informed that the couple's children were being provided educational support by an NGO.

We made two visits to Rinku's parental family. The household has two unmarried brothers, her mother and her four children. They have three married brothers who stay separately. It was learned that Rinku's father had died in the 1984 riots. In the first visit we met her brothers. Her mother and her elder daughter were visiting her at the hospital. The brothers informed that they were finding it difficult to meet the household expenses. They were earning money on a daily basis by working on small electrical decorations and selling 'sunglasses' on the roadside. They informed that their sister came to know of her status a year back when she started falling ill frequently and got herself tested. Her condition soon became serious and she was taken to the TB hospital. They informed that Rinku's mother and her eldest daughter who is 12 years old are providing with all the care and were visiting the hospital every alternate day to wash and change her clothing as none of the hospital staff wanted to do it. The brother informed that there is no contact from her in-laws and relations were very strained.

There is a lot of economic and psychological strain on the family. The fear of the household members of contracting the infection is evident. They felt anyone would contract it if they spent enough time with the infected person. We explained the virus and its modes of transmission to them.

In the second visit to the same household the researchers learned about Rinku's death. We met her children and one of the female relatives. The eldest daughter informed that their mother was very sick and she had been discharged from the TB hospital since nothing much could be done. The couple was then made to stay together in a rented room nearby. The husband was alive at the last visit but he had lost his sense of coherence and orientation since the virus had affected his brain. Except for the eldest daughter who is 12 years old who used to take food for her parents and wash their clothes none of the children were allowed to meet their parents. The eldest daughter had to leave school because of her parents' illness. She says, "*I had to leave school because when my parents fell ill, there was so much at home, who will do it. My grandmother says that I am her daughter now. I have to look after my younger siblings and have to see them grow.*" She adds, "*We received absolutely no support from my father's family. Once I met my father and*

went with him to his house, my 'dadi' did not allow me to enter and asked me to leave. She said that I had come to beg."

The burden of caring for the couple had come on Rinku's parental family. It was difficult to ascertain whether the neighbourhood around the family knew about the status of the couple. They might only know that they are suffering from TB. There was a lot of ignorance among the family members on how HIV/AIDS is transmitted.

While talking to the children it was evident that all the strain and crisis at home had made them mature. The eldest daughter spoke as if she understood the responsibilities and that she had to look after her siblings as if they were her own children. This early realization has made them psychologically stronger and they were coping up with the loss of their parents in a very matured manner.

It was not possible to revisit the house as the members were in mourning. We were unable to meet Rinku's mother who might have given a clearer picture and a more detailed understanding of the psychosocial dynamics within the family.

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