

CHAPTER VII

SOCIAL IMPACT OF HIV INFECTION

7.1 INTRODUCTION

Illness, disability and death related to HIV related illness affect population at multiple levels and multiple ways. HIV infection poses serious health problem with disastrous social implications. Social implications of HIV infection are related to the widely prevalent stigma and discrimination against people living with HIV within the family, neighbourhood, community and society as a whole. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. On a national level, the stigma associated with HIV can deter governments from taking fast and effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care. In this chapter, various issues and dimensions of stigma and discrimination related to HIV infection are explored. Instances of discrimination at various levels are identified *viz.* personal, household, neighbourhood, workplace and health facilities. Qualitative data also support the instances of discrimination against PLHIV at various setups. A Probit regression analysis is used to identify the determinants of the probability of PLHIV being accepted in the family.

7.2 STIGMA AND DISCRIMINATION AGAINST PLHIV AND SOCIAL IMPACT OF HIV INFECTION

“Responding to AIDS with blame or abuse towards people living with AIDS simply forces the epidemic underground, creating the ideal conditions for HIV to spread.”

PETER PIOT, WHO

Originally, the word *stigma* means a visible mark, such as a brand or tattoo, which was used to disgrace, shame, condemn, or ostracize a person. Now, stigma is used to mean a quality or condition that reduces a person who has it, from a valued, respected person, to a tainted, discounted one. In some cultures, being female or black is considered stigmatizing. Many cultures, which do not understand the biological origins of mental illness, stigmatize the mentally ill. Stigma is not new to public

health. Stigma and discrimination are important negative effects frequently experienced by those with communicable disease (Busza 2001). For example lepers were excluded from the society and leprosy was viewed as divine punishment for moral misconduct in past centuries (Veldiserri 1987, Herek G M, 1998). The response to those living with HIV, has in many respects been similar.

UNAIDS characterizes HIV related stigma as a process of devaluation of those living or associated with the pandemic and it defines the discrimination that may follow as the unfair and unjust treatment of an individual based on real or perceived HIV status. HIV/AIDS is one of the most stigmatizing medical conditions in modern history (Kalichman, 2004). Many communities direct unfavorable attitudes, beliefs and policies towards people, who have or who are associated with HIV/AIDS, including their loved ones, family members, close associates, and social groups (Brimlow, Cook, & Seaton, 2003). Some communities are less prejudiced toward people with HIV/AIDS than others. Erving Goffman was a sociologist who originally developed the idea of social stigma (Goffman, 1963). In his work, he identified six dimensions that influence whether a personal quality or condition is stigmatizing. These are summarized in the chart 7.1.

Chart 7.1: Dimensions of HIV/AIDS-Related Stigma

Dimensions	Dimensions of Stigma (<i>Goffman, 1963</i>)	Dimensions of HIV Related Stigma (<i>Herek, 1990</i>)
Conceal Ability	Can the condition be hidden from others? The less concealable a condition, the more stigmatizing it is	Although concealable early in its course, later stages of HIV disease are rarely hidden from others.
Disruptiveness	Does the condition interfere with social interactions and relationships?	HIV/AIDS disrupts social relationships.
Aesthetics	Do others react to the condition's appearance with dislike or disgust?	HIV/AIDS physically disables and disfigures (fragile, lean) people, and is therefore aesthetically displeasing.
Origin	Is the person responsible for having this condition in the first place?	The origin of HIV/AIDS is often, although not always, blamed on personal behaviors and choices.
Course	What is the course of this condition? Can the outcome be altered?	The course of HIV/AIDS is degenerative, and the final outcome is not alterable.
Peril	Can the person with the condition physically, socially, or morally contaminate others?	HIV is a high-peril condition, in that it poses physical risks to others.

Chart 7.1 depicts that dimensions characterized by Goffman in 1963 regarding stigma were found to be more or less equally suitable in characterizing the dimensions of stigma related to HIV infection by Herek in 1990.

Because HIV/AIDS is a stigmatizing condition, and people do not want to be discriminated against, many people are hesitant to find out their serostatus or to seek treatment for HIV infection and other infections. People living with HIV are hesitant to disclose their HIV positive status to their family or community or neighbourhood in general, to avoid stigma and discrimination. This curtails their rights to avail public health services at large. PLHIV are less likely to face adverse consequences of stigma and discrimination attached to HIV related diseases if others do not know about their HIV status.

This chapter analyses the stigma and discrimination experienced by PLHIV respondents on four different settings, namely family, community/neighbourhood, workplace and healthcare facilities. Discrimination faced by HIV households at the time of death related to AIDS in the household was also discussed. Though the stigma and discrimination prevails at a larger platform in the society against people living with HIV, in the scope of this thesis, we have tried to analyze the stigma and discrimination at family level. We had postulated that the stigma and discrimination against PLHIV in the family, lead to their rejection in the family. On the basis of this argument we had tried to analyze the probability of PLHIV being accepted by the family and its determinants.

Because of the stigma attached to HIV infection PLHIV experience discomfort, mental trauma, have been deserted by spouses and families, rejected by communities and workplace, refused medical treatment and had been denied last rites. This is the main obstacle to prevent further infection and to access care and support and treatment services that allow PLHIV, to lead a happy productive life. Details about their HIV status and related issues are presented before discussing the stigma and discrimination experienced by the PLHIV.

Table 7.1: Distribution of Respondents by the Way of Discovering Their HIV Status

Characteristics	Male Respondents		Female Respondents	
	Number	Percent	Number	Percent
Diagnosing HIV Status				
Voluntary testing	69	43.95	134	54.92
After prolonged illness	77	49.04	62	25.41
While donating blood	2	1.27
During pregnancy	40	16.39
During surgery	3	1.91	3	1.23
Any other specify	6	3.82	5	2.05
Time Since HIV Diagnosis				
Less than or equal to one year	44	28.03	51	20.90
One to three years	50	31.85	60	24.59
Three to five years	34	21.66	67	27.46
Five and more years	29	18.47	66	27.05
Place of HIV Testing				
Government hospital	46	29.30	134	54.92
VCTC/STD clinic	24	15.29	20	8.20
Private hospital	72	45.86	71	29.10
Blood donation camp	1	0.64
Any other specify	14	8.92	19	7.79
N	157	100.00	244	100.00

Source: Author's Own estimates, based on primary data

From table 7.1 it is seen that while nearly 50 percent of the men who had tested HIV positive had gone in for the test after prolonged illness, this percentage was nearly half in the case of women (25.41%). However a high percentage of women (54.92%) had gone in for the voluntary testing and comparatively the percentage of men is low. Survey respondents consist of mostly of those who had tested HIV positive in the last five years. Comparatively high percentage of women (54.92%) had got the test done in government hospitals than men (29.30%). We probe more in detail about the respondents who had gone for the voluntary testing. Voluntary testing for HIV provides an insight about the sexual behaviour of an individual.

Table 7.2: Reasons Going For Voluntary HIV Testing

Characteristics	Male Respondents		Female Respondents	
	Number	Percent	Number	Percent
Reasons				
Sickness	11	15.94	4	2.99
Health provider's suggestion	12	17.39	11	8.21
Knew other with HIV	3	2.24
Partner infected	10	14.49	113	84.33
Due to risky behaviour	35	50.72	1	0.75
Any other specify	1	1.45	2	1.49
TOTAL	69	100.00	134	100.00

Source: Author's Own estimates, based on primary data

A high percent of female respondents (84.33%) who had gone in for the voluntary testing, because of their partners were diagnosed with HIV. On the contrary, half of the men who responded for going in for voluntary testing for HIV, admitted to risky behaviour. This depicts that most of the women respondents might have got HIV infection through their sexual partner, who might be having a highly risky sexual behaviour.

7.3 DISCLOSURE OF HIV STATUS

Disclosure of HIV status, by an individual, depends upon the kind of reaction that the individual expects from others. HIV infection status of PLHIV was almost universally known by the families of PLHIV. About 7 percent of PLHIV survey respondents have not disclosed their HIV status to anyone.

Table 7.3: Distribution of Survey Respondents by Disclosure of HIV Status

Characteristics	Male Respondents		Female Respondents	
	Number	Percent	Number	Percent
Percent of Respondents Who Have Disclosed their HIV status to any one	146	92.99	228	93.44
Person To Whom HIV Status Disclosed*				
Spouse	105	71.90	52	22.90
Parents	48	32.90	131	57.70
Brother/Sister	58	39.70	98	43.20
Close Friends	15	10.30	7	3.10
Co-Workers	3	2.10	2	0.90
Children	15	10.30	26	11.00
Other Relatives	4	2.70	4	1.80
In-Laws	3	2.10	138	60.80
Any Other Specify	2	1.40	8	3.50
Percent of Respondents Who Have Not Disclosed Their HIV Status To Any One	11	7.01	16	6.56
Reasons For Non-Disclosure**				
Stigma and Discrimination	3	...	13	...
Rejection and Social boycott	4	...	11	...
Any Other Specify	6	...	1	...
Disclosed The HIV Status				
Immediately after diagnosis	119	81.51	200	87.72
Less than or equal to one year	20	13.70	17	7.46
More than one year	7	4.79	11	4.82

*, ** Multiple responses percent may not equal to 100

Source: Author's Own estimates, based on primary data

It is evident from Table 7.3 that most of the respondents have informed someone or other about their HIV status immediately after diagnosis. This may be reasoned because of self perceived notion of trust and other reason.

7.4 STIGMA AND DISCRIMINATION FACED BY PLHIV

Respondents were asked questions to reveal the extent of stigma and discrimination, which they had suffered. An attempt was also made to collect information regarding the incidents of discrimination against other members of household in which PLHIV live, but there were no significant visible incidents as such. We had attempted to collect information about the incident of stigma and discrimination against PLHIV in four different settings namely, family, community/neighbourhood, workplace and health facilities.

7.5 STIGMA AND DISCRIMINATION IN FAMILY SET UP

From table 7.3 it is visible that most of the PLHIV respondents have disclosed their HIV status to one or other member of their family or in relation. Though PLHIV have disclosed HIV status to other members of their family because of their self perceived notion of trust and support, they were asked how the other person behaved, when they disclosed their HIV status to him/her. PLHIV were asked the reaction of their family member, at the time of disclosure of their HIV status to them and now how they are treated in family.

Table 7.4: Distribution of PLHIV by Reaction to Their HIV Status

Characteristics	Male Respondents		Female Respondents	
	Number	Percent	Number	Percent
Initial reaction of person to whom HIV status disclosed*				
Shocked	84	57.5	84	36.6
Denied/Disappointed	76	52.1	77	33.9
Angry	25	17.1	39	17.2
Embarrassed	8	5.5	9	4
Non-Supportive	5	3.4	44	19.4
Sympathetic	26	17.8	54	23.3
Any Other Specify	8	5.5	12	5.3
Current Attitude*				
Neglected/Avoided/Isolated	14	9.6	80	35.1
Verbally/Physically Teased	3	2.1	25	11.1
Deprived of use of basic amenities	3	2.1	10	4.4
Denied of property share	1	0.7	25	11.1
Asked to leave home	2	1.4	18	8
All are supportive	95	65.1	122	53.3
Family is not but spouse is supportive	3	2.1	0	0
Initial hesitation but then supportive	37	25.3	17	7.6

*multiple responses

Source: Author's Own estimates, based on primary data

Initial reactions of family member or relatives were varied. As it is to be expected, a considerable percentage of families were shocked and disappointed. However, surprisingly, it is seen that in a larger percentage of cases the family sympathized with the female PLHIV (23.3%), in all probability the family support may imply the support from the natal family. As expected, in the patriarchal society like India, 19.4 percent of females responded for initial non support from the family in comparison with 3.4 percent of men PLHIV.

Although generally, one expects that family members of PLHIV would be shocked when they first come to know about the HIV status of the individual, what is more relevant is their reactions after news settles in. The current attitude of family members towards the PLHIV depicts the gender gap in the percentage receiving support from the family. Gender gap is more noticeable in the negative attitude towards the PLHIV. It is seen that in context of ‘relationship’, women experience more agony than men. Discrimination like neglect, isolation, verbal teasing was reported by a higher percentage of women (Bharat *et al*, 2001.).

7.6 STIGMA AND DISCRIMINATION IN THE COMMUNITY / NEIGHBOURHOOD

Community’s perceptions and notions about the HIV infection also influence the family’s response to the HIV infected individual. Though it is seen that majority of PLHIV have disclosed their status to one or other member of family, it is not evident from the survey, whether PLHIV are more acquainted with the community/neighbourhood. Majority of PLHIV have not disclosed their HIV status in the community/neighbourhood.

Table 7.5: Stigma and Discrimination Faced By PLHIV in the Community / Neighbourhood

Characteristics	Male Respondents	Female Respondents
Absolute number of respondents who have disclosed their status in neighbourhood	9	19
Absolute number of respondents who have disclosed and faced stigma and discrimination in neighbourhood	7	17
Verbally teased	7	13
Name calling and labeling	5	5
Poor access to facilities	1	6
Other relatives and children are avoided	...	2
Any other	...	1

*multiple responses

Source: Author’s Own estimates, based on primary data

It is evident from Table 7.5 that merely 7 percent of survey respondents have disclosed their HIV status. This is because of the perceived stigma and discrimination against PLHIV in the society. Table 7.5 also highlights that those who have disclosed their HIV status were stigmatized or discriminated at community level by one or other way, mostly in form of verbal teasing, name calling or labeling. Hence most of the PLHIV had maintained silence about their HIV status as a coping mechanism against perceived stigma and discrimination.

7.7 STIGMA AND DISCRIMINATION AT WORK PLACE

In the workplace, stigma and discrimination against PLHIV can manifest through discriminatory hiring, promotion practices, work allocation, establishment of unfair benefit packages, and negative attitude of employers and co-workers. We had probed in detail about the incidences of stigma and discrimination against PLHIV at work place.

Table 7.6: Disclosure of HIV Status in Workplace

(In percent)

Characteristics	Male	Female
Percent of respondents those who are currently working	73.25	63.11
Percent of respondents who have not disclosed their status at workplace	89.57	82.47
Reason For Not Disclosing HIV Status*		
Social discrimination and isolation	43.80	43.60
Lowered prestige	31.50	23.90
Fear of job loss	75.30	84.60
Any other specify	8.20	0.90
Percent of respondents those who are currently working and disclosed their status	10.43	17.53
Percent of respondents who are facing discrimination	33.33	11.11
Type of Discrimination by Employer (<i>absolute numbers</i>)		
Forced to take up voluntary retirement	1	...
Being forced to resign	1	...
Poor access to shared facilities	1	2
Not applicable	1	1
Attitude of Co-Workers		
Neglected avoided isolated	3	3
Verbally abused teased	1	...
Number Facing Discrimination	4	3

*multiple responses

Source: Author's Own estimates, based on primary data

Table 7.6 highlights that most of the PLHIV are reluctant to disclose their HIV status at the work place. Percentage was higher in categories, males as well as females (89.57 and 82.47% respectively), those who have not disclosed their status at workplace. Fear of loss of job is the main reason highlighted not to disclose the HIV

status. Of those who have disclosed their HIV status, discrimination is faced by four men and three women. Number of respondent, who are facing discrimination as such is low and it was found that those who had disclosed their status are primarily working with the NGOs, working for the welfare of people living with HIV. However, at the other workplace, instances of discrimination have been shown in the table.

7.8 DISCRIMINATION AT HEALTH FACILITIES

PLHIV are prone to many opportunistic infections (OI). They have to go to hospital often. While one expects that they would be treated with care and consideration, the health care settings have emerged as the most frequently encountered place of discrimination. The discrimination at health care settings ranged from not agreeing to treat HIV-positive individual to ill treating them, not touching them, informing others about the patient's HIV positive status, charging additional fees from them, etc.

Table 7.7: Discrimination at Health Facilities

(Absolute number)		
Characteristics	Male	Female
PLHIV reporting discrimination at health facilities (%)	11.46	14.34
Place of Discrimination		
PHC/CHC	1	...
Government hospital	6	19
Private doctor	6	3
Private hospital	5	13
Type of Discrimination*		
Neglected /isolated	4	14
Verbally abused/teased	7	9
Refused medical treatment	3	7
Referred to other health facility	4	4
Poor access to sharing amenities	4	6
Doctor, nurse didn't touch	6	12
Excuse given for non admission	2	4
Any other	1	4
Attitude of other Patients		
Isolated/avoided	5	5
Verbally abused, teased	1	3
Status not known to others	12	25
Not discriminated	...	2
Absolute Number of PLHIV who were Discriminated at Health Facilities	18	35

*multiple response

Source: Author's Own estimates, based on primary data

Findings from Table 7.7 are also corroborated by the existing literature in the field. In a study conducted in Mumbai and Bangalore, many healthcare providers and facilities were found to deny care and treat patients' poorly and stipulated conditions for agreeing to treat HIV patients (Bharat et al, 2001). Doctors often refuse to aid the delivery of a pregnant woman, despite minimal risk of contracting the infection (ILO, 2003).

Indian courts have started exhibiting sensitivity towards PLHIV. In November 2002, the Delhi High Court issued notice to both the Union Government and the Delhi Government seeking their replies on the refusal of several city hospitals to treat an HIV positive person.

“In a shocking development, a pregnant woman delivered the baby outside the gates of the hospital as the doctors at Government district hospital Uttar Pradesh India, allegedly denied her treatment. The medical staff denied treating her as she was HIV positive, and asked the family to take her to some other hospital in the region.....” (07/02/2009 ToI)

Several instances had been seen in the recent past, where it is visibly marked that most of the PLHIV are discriminated at public health care facilities. These findings clearly illustrate the likely impact of HIV infection on the social capital of the HIV infected individual. Individual Social capital contributes to social relationships, which an individual shares with his/her family, friends, relatives, neighbourhood, community and society as a whole. PLHIV live in the disturbed harmonious relationships, as stigma and discrimination attached to HIV infection loosen the social bondage. On the other hand, society's general perception towards PLHIV, threaten individual social capital.

In the scope of this thesis, social impact of HIV at individual level, relationship between HIV infection, stigma and discrimination faced by PLHIV in the light of their acceptance in the family is examined, thus leading to a distinct mark on individual social status.

7.9 ACCEPTANCE OF PLHIV IN FAMILY- ECONOMETRIC MODEL AND RESULTS

It is observed that PLHIV are discriminated and stigmatized at various places in the society. Perceived stigma and discrimination, leads to discouragement to PLHIV to disclose their HIV status. This hampers their right to access public health care.

Though stigma and discrimination against PLHIV prevails at different levels in the society, discouragement at family level, perils most because it is ultimately the family setup which is expected to support PLHIV. It has been observed that gender is an important predictor of perceived acceptance of PLHIV in family. Male PLHIV are more likely to be accepted in family than female. Socio-economic indicators significantly influence the acceptance of PLHIV in the family. Age of PLHIV is expected to be significantly influencing the acceptance of PLHIV in the family setup. It is observed that denial of PLHIV in the family is significantly negatively associated with socio-economic status of HH, as well as the employability of PLHIV. AIDS related death in the family turns into an insensitive attitude towards other PLHIV members in the family. Similarly, migration status (migrant or native) and family status (nuclear or joint) are expected to influence the acceptance of PLHIV in the family. This expected relationship is investigated through a probit regression analysis. Dependent variable constitutes the probability of PLHIV being accepted in the family. Given the dependent variable is binary, *i.e.* either the PLHIV individual is accepted in the family or not, standard Probit model specification was employed. Probit model follows a normal cumulative distribution function (CDF). The model assumes a latent or unobserved variable y^* , which is generated from a familiar looking model.

$$y^* = \beta x + e$$

Where β is a K-vector of parameters, x is a vector of explanatory variables and $e \sim N(0, 1)$ is a random shock. We observe $y = 1$ if $y^* > 0$ and $y = 0$ otherwise. Qualitatively, logit and probit models give similar results, however, the chief difference between the two is that logistic has a slightly flatter tail; the normal or probit curve approaches the axis more quickly than logistic and as Greene (1997, p. 875) concludes his discussion of the issue (choice of link function- inverse normal cumulative distribution function or logit transformation), with the summary “in most applications, it seems not to make much difference,” choice of link function is largely a matter of taste. Explanatory variables included in the model are summarized in the table 7.8.

Table 7.8: Explanatory Variables Used In the Model of PLHIV Acceptance

Explanatory Variable	Measure
Gender	1 = Male 0 = Female
Age	In complete years
Wealth	Wealth Index (PCA)
AIDS related Death	1 = Yes 0 = No
Family Status	1 = Nuclear Family
Migration Status	1 = Migrants
Occupation Status	1 = Currently employed

Out of 401 PLHIV respondents, 374 PLHIV respondents have disclosed their HIV positive status to one or other member of family. Results of Probit regression analysis are shown in table 7.9.

Table 7.9: Probit Model of PLHIV Acceptance in Family

Variables	Marginal Probability	Coefficient	Std.Error ^a	Z	p> z
Gender	0.1411	0.4858	0.2408	2.02	0.044**
Age	0.0062	0.0206	0.0116	1.78	0.076*
Wealth Index	0.0450	0.1482	0.0796	1.86	0.062*
AIDS related Death	-0.2123	-0.6826	0.1865	-3.66	0.000***
Family Status	0.0080	0.0261	0.1663	0.16	0.875
Migration Status	-0.0241	-0.0808	0.2432	-0.33	0.740
Occupation Status	0.0131	0.0429	0.1663	0.26	0.797
Constant	0.1695	0.4735	0.36	0.720
Pseudo R2 = 0.1566					

*weakly significant at p<0.1; ** significant at p<0.05; *** significant at p<0.01

^a reported std. error is that of coefficient, not for marginal probabilities

Source: Author's Own estimates, based on primary data

Wealth index, as a measure of socio-economic status is also found to be a statistically significant coefficient (0.1482), Std.Error (0.0796), z value (1.86), which is higher than the critical value at 90% confidence interval p (0.062). Gender, age, AIDS related death found to be statistically significant variables, defining the probability of a PLHIV member to be accepted in the family. Change of gender from female to male, significantly increases the probability of PLHIV member to be accepted in the family (Marginal Probability = 0.1411, p = 0.044). Likewise, death of any member in the family due to HIV related illness significantly decreases the probability of PLHIV to be accepted in the family (Marginal Probability = -0.2123, p<0.001). Age and wealth index score is found to be weakly significantly increasing the probability of PLHIV being accepted in the family. This shows that dismissal of PLHIV is found to be more at the lower section of society.

Hence, denial is more prevalent in case of female PLHIV members of the household. PLHIV Women are often cursed to bring misfortune in the family and after the death of their husband, they are mal treated in their in-laws' house. Denial is more frequent in in-laws' house than parental house of PLHIV women. HIV illness related death in the family, significantly leads to denial of current PLHIV member of the family. Myths and ignorance about the correct knowledge about HIV infection significantly contribute to the denial of PLHIV member in the family. However, that analysis is beyond the scope of this study. In this study more emphasis is on people living with HIV and their own status of HIV information.

It is presumed that lack of correct information about HIV infection has led the current PLHIV to HIV infection. Two concepts here are of great importance, ignorance and behaviour. Hence, it is proposed that if an individual is ignorant about the modes of transmission of HIV infection, he/she would be at a greater risk of HIV. Ignorance about HIV infection is characterized by various socio-economic factors.

In this section we are exploring the links between ignorance about HIV infection in the past and associated factors, which led to current HIV status. We had asked question to PLHIV respondents if they had heard about HIV/ AIDS in past before they were diagnosed HIV positive. This is just about hearing about HIV/ AIDS. It is quite possible that they did not have complete or accurate knowledge about HIV transmission or due to lack of accurate knowledge they had not considered themselves at risk of HIV. Table 7.10 shows the distribution of PLHIV respondents.

Table 7.10: Distribution of PLHIV Respondents and knowledge of HIV/ AIDS in the Past

Characteristics	Gender of PLHIV Respondents							
	Male				Female			
	Yes	Something	Not at all	Total	Yes	Something	Not at all	Total
Marital Status								
Married	53.6	11.6	34.8	112	36.1	14.8	49.2	61
Separated/Divorced	50.0	25.0	25.0	8	29.4	17.6	52.9	17
Abandoned	100.0	0.0	0.0	1	0.0	0.0	100.0	2
Widowed	35.7	21.4	42.9	14	26.1	7.5	66.5	161
Living together	0.0	0.0	0.0	0	50.0	0.0	50.0	2
Unmarried/ No live-in Relation	50.0	18.2	31.8	22	100.0	0.0	0.0	1

Contd...

Table 7.10: Distribution of PLHIV Respondents and knowledge of HIV/ AIDS in the Past

Characteristics	Gender of PLHIV Respondents							
	Male				Female			
	Yes	Something	Not at all	Total	Yes	Something	Not at all	Total
Age Group								
15-19	100.0	0.0	0.0	1	50.0	50.0	0.0	2
20-24	80.0	20.0	0.0	5	31.6	10.5	57.9	19
25-29	61.1	22.2	16.7	18	28.8	6.8	64.4	73
30-34	65.8	10.5	23.7	38	23.6	12.5	63.9	72
35-39	55.3	10.6	34.0	47	31.9	6.4	61.7	47
40-44	28.0	16.0	56.0	25	27.8	22.2	50.0	18
45+	30.4	17.4	52.2	23	46.2	0.0	53.8	13
Educational Status								
Illiterate	28.0	8.0	64.0	25	13.8	6.2	80.0	65
Primary	54.5	9.1	36.4	33	28.2	10.3	61.5	39
Secondary	50.7	21.7	27.5	69	31.3	10.7	58.0	112
Senior secondary	43.8	12.5	43.8	16	58.8	17.6	23.5	17
Sen sec plus	100.0	0.0	0.0	14	54.5	9.1	36.4	11
Total	51.6	14.0	34.4	100.0	29.1	9.8	61.1	100.0
N	81	22	54	157	71	24	149	244

Source: Author's Own estimates, based on primary data

Female PLHIV respondents (61.1%) were more ignorant about HIV/ AIDS in the past. However, around 2/3 of male PLHIV respondents may have known about HIV and AIDS. That HIV knowledge could be vague or it is quite possible they would not have realized the gravity of HIV in the past. Though this study didn't explore the mode of transmission, if national state reports are to be believed, majority of cases of HIV transmission (85%) occur due to unprotected sexual intercourse. Hence, we are assuming here, that because of easy access to cheap commercial sex in the brothels of city, the risky behaviour had driven to HIV infection. Because of inadequate knowledge of HIV, it is quite possible that PLHIV respondents could not have identified the potential threat of HIV due to their risky behaviour.

7.10 QUALITATIVE ASSESSMENT

Stigma and discrimination against PLHIV hinders response to HIV. In Indian society, cultural and social taboos restrict people to talk on issues related to sexual matters and sexuality in public. Lack of awareness and correct knowledge about HIV transmission, heartens the HIV epidemic to grow and curtails the human rights of PLHIV in particular. In an attempt to recollect the instances of social stigma against PLHIV, three case studies were conducted based on the characteristics of PLHIV respondents. These case studies emphasize the need to examine some sensitive issues

like women social status, child abuse, homosexuality, domestic violence and sexual assault of woman in marriage.

Case I Widow living with HIV

BOX 7.1

She is forty four and was married to a widower. Her parents married her to a widower due to her pounding age. Her husband had a child from his first marriage. Her husband was falling sick often after marriage. Meanwhile, she became pregnant. During her pregnancy, her husband died due to HIV related illness. Unfortunately, she was not administered Nevirepine; hence the child born to her is also HIV positive.

Key statistics

Age	44
Gender	Female
Marital Status	Widow
Education Status	10 th
Occupation Status	Housewife
Household Size	2
Symptomatic	Yes
On ART	Yes

After the death of her husband, she was criticized and verbally abused by her in laws, who often cursed her for bringing misfortune to the family. They denied her a share in her husband's property and asked her to leave the house.

Her parents are too old to take care of her and due to societal discrimination, they could not help her. Her relatives tease and scold her for bringing misfortune to her parental family. She is residing in a rented house alone with her child, who is studying in third standard, maintaining a silence about her status in the neighborhood. She is continuously ill and suffering from opportunistic infections since last one year, but no one is there to take care of her and her child. She is maintaining herself and her child on a mere saving which she had in the past. Nutritional support from local NGO, although is a great help for her immediate requirements but she is in acute need to have job, so that she can live a comfortable life with dignity and pride.

Voluntarily, she works for HIV awareness and dissemination of information to people living with HIV.

Discussion

This case study reflects the conditions of HIV positive widows and problems faced by them. They are innocent and in spite of no fault of their own; they are often cursed for the misfortune and are ill treated in their in-laws' home after the death of their husbands. This case study advocates some social security schemes for HIV positive

widows, as life for HIV positive widows, who are often dragged out from in-laws' home is much more difficult than HIV positive men counterparts.

Case II Higher Risk Behaviour Group and Vulnerability to HIV Exposure (Case of Male Having Sex with Male MSM)

BOX 7.2

He comes from an upper middle class family setup. This case is different from the other cases as being indulgence in high risk behaviour since his childhood days. He is thirty-four now, educated and residing with his parents. He is MSM (male having sex with male). When he was seven, he was abused by one of his relative. Since then, he was inclined towards males sexually. In the early 80's awareness regarding the safer sexual practices and about HIV was very low.

Key statistics

Age	34
Gender	Male
Marital Status	Unmarried
Education Status	Graduate
Occupation Status	Working
Symptomatic	Yes
On ART	Yes
HRG	MSM

He had multiple sex partners by the age twenty-one. Sometimes to seek sexual pleasure or some times to get some extra money, whatever is the case, he was indulging in high risk behaviour. In 1995, while donating blood in a blood donation camp, he got to know about his HIV status. He maintained silence for long time and didn't disclose his HIV status to anyone. Meanwhile, he kept changing jobs. In 2002, when his condition deteriorated more, his family got to know about his HIV status from the family doctor. Response from the family was not good. He was scolded and cursed for bringing bad name to the family. He faced a lot of discrimination. His family kept his utensils aside. He felt like committing suicide many times. Gradually, as the years passed by, there was change in the attitude of his family.

Since last two years, he is working with some local NGO in Pune city and earning a handsome salary to live a healthy and positive life. He hopes for a positive life and when he got to know about his own HIV status, he shifted to safer sexual practices.

Discussion

This particular study exhibits the hidden crimes in the society like child sexual abuse, which can lead to negative psychological impact on child and may lead to change his sexual orientation. This has been empirically proved in many studies earlier.

This study raises two very sensitive issues in the society:

- Child sexual assault
- Homosexuality.

Child abuse increases the vulnerability of children to HIV infection and homosexuality is considered as criminal offence as per section 377 of Indian Penal Code (IPC), thus leading to risky behaviour many times.

This study depicts children's vulnerability to HIV infection. Sexual assault of any child threatens the exposure to HIV infection. Hence this study advocates a minimal level of sex education compulsory to school children, so that they are aware of basic norms.

Case III Domestic Violence and Sexual Assault in Marriage

BOX 7.3

She is twenty eight, married and living with her parents now. Eight years back she got married to a man who was more than ten years older than her. She was pressurized to get married from the family at early age itself, though she wanted to continue her education.

After the marriage, she was staying in a joint family in a low locality of Pune city.

After marriage her in-laws went on pinpointing her on trifles, off and on. Sometimes, she was forced to bring money from her parental home. Often she was physically abused and sexually assaulted by her husband. Meanwhile, she gave birth to a girl child. Her husband often used to go out to other women and indulged in high risk behaviour. She was sexually assaulted by him many times. Two years back, she became pregnant again and was informed by the health provider that she is HIV

Key statistics

Age	28
Gender	Female
Marital Status	Separated
Education Status	Graduate
Occupation Status	Working
Symptomatic	No
On ART	No

positive. She had gone for abortion this time. In spite of all this there was no change in the behaviour of her husband.

She was left with no other choice except to leave him. Now she is separated, and living with her parents since last two years.

Last year she was under utter tension and often thought of committing suicide, but to educate her daughter, she had continued her fighting against HIV infection. Now she is working with a non-governmental organization in Pune and earning a sound income to educate her daughter and maintain herself. She wants to see her daughter as a doctor.

Discussion

This case study depicts economic dependence of women and deprivation of their human rights. They have no say in matters of family and have no sexual freedom. In marriage they are expected to treat their husbands, unconditionally. In the Indian family set up, they cannot insist with their husband for safer sexual practices because this will only bring disgust for them.

On the contrary, this study highlights the physical abuse against women in marriage, which causes mental trauma and sometimes even to take drastic steps like suicide as well.

7.11 OBSERVATIONS

Stigma and discrimination against PLHIV is a great impediment in HIV diagnosis and at the same time, it hinders HIV prevention and care programmes. In a society like India, where cultural and social norms are conservative, sexual issues are culturally taboo and HIV infection is considered as someone else's disease- a disease particularly attached to risky sexual behaviour³⁸ of an individual; PLHIV are not well accepted in the societal setup. Perceived stigma and discrimination against PLHIV in society at large, curtails human rights of PLHIV to live life with dignity. It is evident from the discussions in the chapter that most of the PLHIV experienced negative attitude of the person to whom they disclosed their HIV status at the first instance. However, during the course of time, male PLHIV were more or less accepted by the family, it is female PLHIV who are more discriminated. This raises the issue of the

³⁸ Here risky sexual behaviour means polygamous relationships, multiple sex partners, involvement in commercial sex, same sexual intimacy and other sexual behaviour which increases the probability of exposure to HIV.

prevailing gender gap in a sensitive issue like HIV. Alarming gender gap points towards proper intervention strategies against HIV infection. From the analysis of data it is observed that most of PLHIV have not disclosed their HIV status in their neighbourhood. This is primarily because of perceived stigma and discrimination against PLHIV, as those who had disclosed their HIV status in their community/ neighbourhood, had faced instances of stigma and discrimination one or other way. This highlights the inadequate and misinformed knowledge about HIV infection, modes of HIV infection in society at large. NGOs, government or other agencies working in the field of awareness regarding HIV can be a helping hand to disseminate the correct information and knowledge about HIV.

PLHIV, who are working, have not disclosed their HIV status in the work place because of fear of losing job. Those who had disclosed their HIV status are primarily working in NGO sector hence were well treated at the work place. This calls for an immediate intervention policies regarding work place. Health care settings emerged as frequently encountered place of discrimination against PLHIV. Government / public health care settings emerged as the most frequently encountered place among health care settings. WLHIV are more discriminated in health care settings than male counterpart. Perceived stigma and discrimination against PLHIV in a health care setting curtails their rights to basic health care facilities, as most PLHIV maintain silence because of stigma and discrimination and do not avail health facilities.

This chapter examines the determining factors associated with the probability of a PLHIV being accepted in the family. It is observed that denial of PLHIV is more associated with lower socio-economic status of family, female gender and death due to HIV related illness.

These empirical arguments are substantiated by the qualitative findings of case studies incorporated in the chapter.

Lastly;

“Let us resolve to replace stigma with support, fear with hope and silence with solidarity. Let us act on the understanding that this work begins with each and every one of us”

*Kofi Annan
(Former secretary UN)
On World AIDS Day,
December 1st 2002*

