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Formative Research Report

Stigma and Discrimination Faced by Women Living with HIV/AIDS

A REPORT FOR **BREAKTHROUGH** BY **PRASTUT CONSULTING** SUPPORTED BY **DFID AND NOVIB**

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Acronyms and Abbreviations

PLHA:	Persons living with HIV/AIDS
WLHA:	Women living with HIV/AIDS
MLHA:	Men living with HIV/AIDS
SEC:	Socio-Economic Classes
UT:	Union Territory
STI:	Sexually Transmitted Infections

Executive Summary

The Rationale

Discrimination against women in India is most evident in the declining sex ratio: from 972 females per 1000 males in 1901 to 933 females per 1000 males in 2001. The girl child is deprived of proper nutrition, healthcare and education, given her lower social status in society. Unequal treatment and increased vulnerability make women hapless victims of HIV/AIDS. Nearly 40 percent of HIV-positive people in India are women, according to UNDP. The UNDP states that nearly 80 percent of HIV infections among women in 2005 were the outcome of women contracting the disease from their husbands.

Interplay between Gender and HIV Positive State

Gender plays a key role in the nexus between HIV-related stigma, moral judgement, shame, and blame. Given women's lower standing in the social hierarchy, this study has developed some basic hypotheses in a bid to understand the dynamics of gender in HIV-related stigma and discrimination. The hypotheses emerge from the central theme that "women are more likely to be stigmatised in India where women's powerlessness is glorified in a pativrata (dedication to the husband) image". Key among these hypotheses are: the family plays the biggest role in women's discrimination, a woman's economic status determines her access to support from the family, women are blamed for their spouses' infection, HIV-positive women are stigmatised as being loose characters. Ultimately, lack of family support, ridicule and stigmatising behaviour of the community, denial to financial independence and a means of livelihood are factors that give rise to internal stigma. Internal or self-stigma is also exacerbated by the Indian belief in 'karma' and destiny.

Objectives of the Research

The research addresses the stigma felt by Indian women in different socio-cultural contexts within the country and identifies indicators to measure the stigma.

1) Understanding of awareness, attitude and behaviour of community towards HIV/AIDS and towards PLHA

2) Examine the forms in which HIV/AIDS-related Discrimination and Stigma is experienced and manifested at the levels of individuals, families, and institutions (community) towards the WLHA

3) Investigate the role of gender in the causes and consequences of stigma.

4) Identifying the stigma and discrimination faced by MLHA (Men living with HIV AIDS) and WLHA (Women living with HIV AIDS) in the community and evaluate whether differences exist between attitude and behaviour towards MLHA and WLHA

5) Identification of relevant stigma and Mapping of stigma indicators with rights of women

Research Methodology

A formative research has been conducted using qualitative research methodology. The research has been undertaken in two stages:

Stage One: To understand the need states of WLHA and identify Community, family and WLHA related stigma and their Indicators.

Stage Two: Validation of indicators through qualitative focus group discussions.

Research Locations

Three states – Maharashtra, Karnataka and Uttar Pradesh where Breakthrough is already operational through intervention programs were considered as appropriate for the research so that Breakthrough activities in these states would receive further focus. Within each of the three states districts were chosen based on the following criteria: Industry, Migrants, Non CSW belt and ANC Prevalence rate. Based on these criteria, urban towns in the districts of Aurangabad in Maharashtra; Udupi in Karnataka and Kanpur in Uttar Pradesh have been selected as the research locations.

Tools Used for Qualitative Research

1. **Transect Walks:** HIV/AIDS is a sensitive and stigmatized subject and the attitude towards it is likely to be influenced by general attitude towards health, hygiene, education, social interactions between different communities, etc. It was considered appropriate to conduct observation on these aspects in areas identified for the community interviews at each location.

2. **Qualitative in depths:** The research was aimed at identifying the complete spectrum of emotions, experiences and stigma experienced by the WLHA to reach up to the level of her need states. A free flowing discussion providing the WLHA and her family to express them selves was required with sensitive handling by the interviewers. Qualitative in depth interviews with community members in different occupations (MLHA, WLHA and family of WLHA- both in laws and natal family) were undertaken.

3. **Focus Group:** FGDs were considered an appropriate tool to probe the community about their knowledge, attitude and practices about HIV AIDS. FGDs with WLHAs were held in one location out of three where the topic of HIV AIDS was not such a taboo topic and discussed freely (Udupi)

Discussion guidelines were prepared to cover the probe areas.

Sample Size Used

Community interviews were undertaken across the SECs is all the three locations Altogether 151 respondents were met from the community. 30 WLHAs, 28 Family Members, 6 MLHAs and 9 Women from the general population were met with in addition to the meetings held with workers and staff at the positive networks.

SEC Category	Transact Walk Number of interviews in three locations each	FGDs Number of interviews in three locations each	Total
SEC-A	4	None	4
SEC-B	2	45	46
SEC-C	11	44	55
SEC-D	None	46	46
TOTAL	**17**	**135**	**151**

Training of Research Team for Use of Tools

The research team was sensitized towards the topic of HIV AIDS at a workshop conducted by Breakthrough. The team was trained to work on the discussion guidelines prepared and recruitment and selection of the respondents. Mock interviews and exercises were undertaken as part of this training.

Data Collection Process

Access to HIV+ women was done only through Positive Women Networks. Given the sensitivity of the discussions required with the women it was considered appropriate if the network member made the first contact with the respondent to clarify the purpose and method of research, the process and type of support sought from the respondent. MLHA respondents were also arranged through the positive networks.

The networks also arranged for the families of the positive women to come to their centre for the interviews. Families who do not support the WLHA were not possible to be contacted either through the network or directly – in case we had visited them they could have caused some harm to the respondent. Views of the family were sought from supportive families only but as we moved into discussion with these families in some cases we realized that the support was more on a surface level. Either the WLHA was earning or the family was attracted by the incentives provided by the research to agree to the interview. Areas of non support to the respondent became evident as we started speaking with the families.

Respondents from the community were recruited directly by the Prastut Team.

The Community:

Awareness

Most people have a high awareness of HIV/AIDS due to the media blitz. However, there are differences in their awareness levels and need for more awareness based on their socio economic class.

Respondents in the higher SECs were not only able to state the routes of infection but were also able to describe the symptoms, the stage at which HIV turns into AIDS, and were also conjecturing upon how long a person can survive after being infected. In the middle SECs the community was able to describe the routes of infection and were also able to mention that it reduces the immunity of the body and wounds take longer to heal. In case of the lower SECs unsafe sex emerged as the most associated with the disease. Community in the lower SECs viewed itself most prone to the disease and felt the need for detailed information on prevention and available treatment. In all the three research locations across the lower SECs in each group someone recounted a close relative, friend or a neighbour having suffered and died from this disease.

Source of Awareness

In Kanpur awareness among higher SECs has been generated through serials like Jasoos Vijay and mainstream ads depicting celebrities – though an ad depicting an elder brother explaining the younger brother has been liked more. In Udupi community has been receptive to awareness programs by the youth and in schools. In Aurangabad it has mainly been the ads in the TV, newspapers and hoardings which brought awareness. Community is more open to getting needful information from family like situations shown in serials and ads and also one to one meetings in Udupi. Awareness among the middle SECs not only comes from mass media but also through cases in their vicinity when a person dies or through frequently held health meetings in their neighbourhood, medical camps organized by companies or during hospital visits. In case of the lower SECs it is not only TV and newspapers but close actual experiences are a source of awareness.

Fear about the Infection

There is fear about the infection but for different reasons in each of the three research locations. In Aurangabad, casual physical contact with HIV-positive persons is feared the most. Hence, it is perceived that segregation is the only way of preventing the spread of the disease. In Kanpur, fear has fuelled doubts in the minds of people. They were uncertain as to whether one could contract the disease if one ate food cooked by an infected person, if he/she happened to cut his/her finger while preparing the meal, whether the infection could be passed on by a HIV-infected child who bites another while playing, or if a HIV-person sneezed in the vicinity of a non-infected person. Many expressed the view that even talking to an infected person could lead to transmission of the virus. Udupi demonstrated the highest awareness and the people are not fearful of PLHAs and are willing to accept them as part of their households, though they would like to practise prevention by keeping utensils and clothes separate.

In the higher SEC too they all held the view that the infected person must be made to stay separately – even if he is allowed to stay together as in the case of Udupi, and touching and talking can happen, they would still be treated as separate as a matter of prevention. In case of the middle SECs more fear persists even in an open society like Udupi. Except for touching and talking communities in all three research locations had reservations about

eating from the same plate as they feared spread through saliva, using toilet, eating food prepared by infected person, or allowing children to play. The lowest SECs were more scared about the condition of the AIDS person – he becomes thin – which is a sign of too much indulgence in sex which actually repel them. The sight of the HIV person itself is a fear indicator. The lower SECs are tolerant in terms of touching, eating and staying together and even eating food prepared by them but would not like to stay with them.

Shame and Blame towards the PLHA

The community in Aurangabad felt the infected person was responsible for his misdeeds, in Kanpur the community had a fatalistic attitude saying perceiving the virus to be the result of one's bad deeds. In Udupi there were no negative emotions of blame towards the infected persons. The overwhelming association with 'shame' was apparent in Aurangabad where the community felt that HIV-positive people are immoral and there is no sympathy for them. They prescribe that such people should be isolated and not allowed to participate in community functions.

The correlation between shame and judgement is a very strong one. Consequently, in Aurangabad the general view was that infected persons are 'dirty' and should be kept apart. In Kanpur too the general view is that the virus happens only to bad people. Udupi, in contrast, displayed a more mature behaviour – most felt that infected people need the care and support of their families though they also felt that disclosure of HIV status by the infected person is important so that he can avail of proper treatment and so that others can take necessary prevention measures.

In all the three research locations among the higher SECs the cause of the disease being emphasized was multiple sex partners and unsafe sex results in the infected person being looked down upon. Since multiple partners are not an accepted norm in the Indian society, particularly among the upper middle class and middle class, any person who indulges in this practice is considered to be immoral – whether or not he has contracted AIDS. In the lower middle SEC different views were prevalent for men and women; women are not considered to be immoral as it is assumed that they would have contracted it from their husbands. A man on the other hand, is always assumed to have got it from prostitutes. However at the lower SEC level they are more accepting of his immoral character – they can also forgive him for his deeds and keep him with them observing all the precautions. The lower SEC has brought out fact very categorically – whether a person suffers from AIDS or any other disease, he would be shunned anyway unless he is an earning member of the house in which case his presence would be tolerated.

An underlying blame which can be discerned is the belief that women as sex workers are to be blamed for the spread of infection to men. There is a definite school of thought in the community that men going to prostitutes are not abnormal but it is the existence of these kinds of women and increase in their numbers which is really responsible for the spread of the disease. The source of the disease is therefore being attributed to women. Using the same analogy, even when women in the general population are infected by their husbands, community would have a tendency to believe vice versa and may suspect the woman to be a loose character equating her to a sex worker.

Community also holds the view that ideally if a person is aware that he is infected he does not have the right to pass it on to his spouse and infect her. However this does not seem to be practiced – even when a man is diagnosed with the infection and by the time since his spouse has also got infected the blame squarely falls on her rather than the man himself. Community also held the view that a woman has no life of her own– as long as he is alive she needs to look after him and serve him even if it means getting herself infected.

Enacted Stigma

It has been mentioned across all the three research locations even among the higher SECs that they are aware of cases wherein the AIDS infected persons have been separated from their family and even their spouse in some cases. The lower middle SEC is aware of cases of separation and abandonment also but they have also mentioned about cases of sympathy from the family and community which is a tiny ray of hope. The AIDS victims themselves isolate from the family and community fearing abuse and ridicule. The SEC C are optimistic however about bringing about a change; the family is the unit which can bring about this transformation. In Udupi they feared that if the family does not lend support the person may even commit suicide. In the lower SEC since it is the economic condition which drives most emotions, though there are case of indifference and abuse there are also cases when the person continues to fulfil his responsibility towards the family and is accepted within the family.

Community also chose to highlight cases where the wife had abandoned or divorced her husband and he was left alone to cope with the disease. They also glorified cases when a man abstained from sex with his wife after knowing he is infected. The woman does not seem to have the right to leave him and if she is spared by her husband it is not because that is her right but because he is an understanding kind hearted person who is making a supreme sacrifice.

Women have been denied staying with their children, blamed for their husband's condition and worse of all local channels seem to popularize separate ashrams for her .which reinforces that she has no right to shelter in her in laws or natal home once her husband dies

Message Suggested

Community was not very certain about what messages they would like to hear. Some of them said using spiritual persons to spread the message that AIDS is not dirty would be impactful. Interviews with HIV positive people and their description about the normal lives which they lead should be done to reduce the perception among the normal masses that it happens to only immoral and dirty people. The message which the middle SEC would like to see is that of family support informing that they need care and support and AIDS is not communicable like other diseases. SEC D is not influenced by celebrities – they need constant messaging through regular discourses on TV by spiritual leaders, at health centres, small meetings and through clubs. They would like the message to provide information about the symptoms and also not to isolate the AIDS patients from their families or be shunned by society. They feel that the elder member of the family needs to be educated through such messages.

The Family:

The family is an important social institution in India. Though the joint family system is disintegrating in urban India, the emotional ties with the extended family and its members continue to be as strong as ever. In many instances, approval/disapproval of the extended family – even if they are not in the vicinity – is an ever-present issue for individuals. This strong emotional connect with the family is even more palpable in the case of persons who have been infected with HIV.

We could speak with only family members of WLHAs who were supportive of them. This is a limitation for the present research as getting views of families who do not provide support to the WLHA would have been a critical piece of information.

Family comes face to face with the disease only when it is disclosed to them. Fear is all-pervasive among family members. In most cases, even if a HIV-positive relative is living with them, they try to maintain barriers by raising a wall or not allowing children to play with the children of PLHAs. WLHA is often reduced to an object of sympathy at her natal home – she is made to realize that she is a burden and of no use. If she is able and economically of some use she is exploited and her children are deprived of a normal playful childhood. If her parents are old she prefers to battle it alone she cannot even access their emotional support lest she ends up disturbing them.

As it is widely believed that only immoral people can get the infection, the WLHA bear the brunt of the blame. If she has been a dutiful daughter-in-law, she may not be blamed for infecting her spouse. But in instances where the woman's relations with her in-laws have been less than cordial – and or have been vitiated due to dowry demands – she is likely to be blamed and also thrown out of the house.

From the family's point of view, having a HIV-positive member in the family is a matter of shame. The family keeps this fact a closely guarded secret for fear of losing social status and incurring social ostracism. This seems to be the practice in all three locations, which only results in isolating the WLHA even more. A key fear is that the family will be shunned and their sons and daughters will not find good matrimonial matches.

Disclosure of status often leads to ridicule and judgement among the larger extended family and therefore WLHAs only tell their immediate family members about their status – and sometimes they do not reveal their status to their own parents or brothers. On the flip side, it has been observed that economically independent WLHAs find acceptance among their family members, particularly if they contribute to the family income. Whatever their reasons may be for supporting a HIV-positive female member of the family, WLHAs feel grateful for whatever little support they get.

Favouring the MLHA

There is no sense of fear when it comes to their own brethren or son. It is only the WLHA who finds herself without any takers in the in law family and natal family with fear being attributed as the cause. The son on the other hand is not blamed for being immoral as long as he is earning the daily bread for the family. Even when the son is not earning he is cared for as mothers have a soft spot for the son. But when there are no parents, elder brothers may or may not support the MLHA even if he is earning well but friends do not desert them so they do have someone whom they can depend upon.

Women are already suffering from domestic violence for dowry, childlessness and other discriminations. She is also already tolerating a wayward husband and has to willingly embrace the HIV from her husband. The HIV condition coupled with already existing domestic violence overflows her cup of woes - it gives a good opportunity for the in laws to throw her out of the house and deny her property rights. There are cases where she is not blamed but the son is – either because she is required to look after the positive son or when she is an earning member. Ultimately she is chained to her fate. She cannot disclose it to her natal family also if there are other brothers or sister in the husband's family to be married off – she has to bear the ill treatment and discrimination silently. There is no medical care initiated for her though the son can always get his treatment by going outside into another town too, but she is confined to the house and made to do the household work despite her need for medical care.

Poor economic condition in most homes makes the task for the natal family difficult – some of them support her willingly while some do it grudgingly while some do not do it at

all leaving her to her fate. She is not the priority for anyone. If the family has the means they may offer her support – else they are not really bound to do it.

The WLHA:

WLHAs were recruited by the positive networks whom the research team had contacted at the three locations. They were cooperative and eager to tell their side of the story. Discussions with each WLHA were held separately in a closed room. Permission to audio tape the interviews was sought from her before hand.

It is only when women or their husbands test positive for HIV that they find out about the infection and its causes. Positive women today who have been carrying the virus even for as recent as last two years were totally unaware of what HIV was when they were diagnosed with it. On finding out about their HIV-positive status, the tendency is to hide this fact from their family and neighbours. Disclosure is a real problem with most women. Fear of social ostracism forces many to hide their HIV status from family members in their natal as well as marital homes.

In most cases women find themselves shelter less after the death of their husband. If they move out and stay in their parents' house they do not want to be burden on their brother's family or cause any harm to them. They feel that separate utensils, separate food, and washing clothes are a small price they have to pay in return for the roof above their head.

Even when they stay separately with their child, though they know that contact alone cannot lead to transmission of the disease in the case of their children they feel 'scared' and therefore make it a point of not sharing their bed, food and clothes with their children. However, they are hurt most if their child is taken away from them- they are denied being a mother to their child and want to keep their child with them at any cost.

Even if women are infected by their husbands, there is a reluctance to blame him for her woes. Men visiting sex workers are generally accepted as normal. As one woman in Aurangabad said, she doesn't get angry when her husband visits sex workers. Often the wife who has only had sex with her husband is blamed for her and as well her husband's condition.

But worse is the constant barrage against her character – even if she is working hard for her livelihood to support herself and her child she is rebuked by her own family who accuses her of being of loose character and cursed for being alive.

The issues which hurt WLHA most are denial of their right to live, denial of any rights in parents and in laws house (after husband's death) and pointing fingers at her character.

The stigma attached to the infection consequently gives rise to shame, a feeling of self-disgust and hatred. Not only is the WLHA a victim of social ostracism at the community level, but often she is discriminated against by her immediate family. A few can expect some support and shelter from their natal homes but there is little else apart from that. This leads to WLHAs isolating themselves more and more and trying to cut themselves off from social events, outings and other normal activities.

The self hatred turns their life into a mere existence for the sake of their children. But she feels that eventually the future of her children may also get bleak because of her own positive status.

In most cases WLHAs are discriminated against by their marital home family members and neglected by their natal homes. While bad treatment from in-laws is accepted by most as being a fact of life, the ill treatment by their birth home family members causes pain. WLHAs are not looking at financial support but more emotional support and a few words of kindness from their marital home family members.

Conclusion

We have seen in our interactions with the community, family and the WLHA herself – at the core of the entire stigma and discrimination towards the WLHA is a simple fact that she is a woman! She is destined to bear the brunt of the sins of her husband and she can be thrown in and out of houses, can be robbed of all her possessions and left in a state of destitution for all the family or community cares. She has come to face the wrath of HIV at a very young age when she is entering a new married life full of dreams – but soon her dreams are shattered when she finds herself positive. She then is cursed for bringing bad luck to the family though the positive son may be well cared for. She nurses her husband till his last days and is happy that she could discharge her responsibilities as a wife. Yet she does not want to get married all over again probably to an HIV person for the sake of companion ship and she recoils even at the mention – she cannot bring herself to nurse another person once more. She would rather embrace loneliness than seek companionship.

And there lies the crux – she is now a loner – being HIV positive - all because she was an innocent victim to her husband's misdeeds, she has been blamed, rebuked, denied property, jewellery and even basic human rights like food and shelter and also motherhood in some cases. However good she may be, she is only good till such time as the husband and the family need her. She is made to pay a heavy price for her husbands philandering ways – and for that too she is blamed. Like one woman in Kanpur said probably she has been a demanding wife troubling her husband for getting her things and he in his frustration had to visit the prostitute to take his mind off so ultimately she has failed in her duty as a wife and deserves to be thrown out anyways.

Stigma Indicators

Community Interventions at the community, family and WLHA level can be monitored and evaluated if there is a change towards the attitude towards WLHA. Indicators identified from the qualitative research would have to be measured using appropriate scales at the base line and end line levels. A summary list of indicators which have been identified is available in the last chapter of the report.

Section

1

Background

SECTION 1.1: VULNERABILITY OF WOMEN IN INDIA

"At its heart, this is a crisis of gender inequality, with women less able than men to exercise control over their bodies and lives….Violence, poverty, inequality, and the lack of basic rights all need to be addressed if HIV/AIDS is to be brought under control."

Women and HIV/AIDS: Confronting the Crisis,

UNAIDS/UNFPA/UNIFEM report

The foremost indicator of discrimination against women in India is the declining sex ratio – from 972 females per 1000 males in 1901 the sex ratio declined to 933 females per 1000 males in 2001. Significantly, the sex ratio in the 0-6 year's group has dropped sharply from 945 in 1991 to 927 in 2001. Discrimination against females is manifested through a variety of discriminatory practices from childhood to adulthood. For example, girl children are breast-fed less often than male children. According to a study by NCAER (1990) girls in India are less likely than boys to receive medical care and often go without medical attention until the illness reaches a critical stage and becomes life threatening. The inequity against women continues even when the girl becomes a mother. India has the dubious distinction of having the second-highest maternal mortality rate in the world, estimated at 385-487 per 100,000 live births. However neglect during child birth is not the only reason for a woman's death, as she is denied medical attention in totality. Tuberculosis – and not childbirth – is the leading cause of death among women in the reproductive age group, followed by burns and suicides.

Women's empowerment needs to be taken up by other social interest groups because by and large she has no voice and is unable to take decisions about her own well being. Though formal education of women in India began more than a hundred years ago – the Indian Constitution guarantees to all women the right to education through Article 10. Yet literacy among women continues to be abysmally low. The disparity between male and female literacy has constantly been at 25 per cent between 1961 and 1991. According to the Census 2001, though 54.16 percent of women can now read and write, an overwhelming 245 million women are still illiterate, making this the largest group of unlettered women in the world. More than 50 percent of girls drop out of school by the time they reach middle school.

There is a growing trend of feminization of poverty. As employment opportunities in rural areas decline, men migrate to the urban areas in search of work leaving women to care of children and elders. Increasingly, women are beginning to dominate the informal sector and their activities are limited to a narrow range with the lowest returns. Her vulnerable state is compounded by atrocities committed against her which are on the rise. Between 1990 and 1996, crimes against women grew 56 percent. Cruelty to wives comprised 28 percent of all crimes in 1996. Dowry deaths have emerged as a major killer of women in urban as well as rural areas. According to one estimate, nearly 6,000 dowry murders are committed every year.

Increased Vulnerability of Women towards HIV AIDS

Unequal treatment and increased vulnerability make women hapless victims of HIV/AIDS. As a majority of women continue to be financially dependent on, and socially inferior to, men, they find themselves unable to refuse sex or insist on condom use. In many instances, the threat of violence and physical abuse undermine women's ability to guard against the disease. The result has taken shape into a feminization of HIV/AIDS. Her very existence and right to live is challenged as she finds herself being subjected to yet another weapon to discriminate her with.

While there have been studies identifying the discrimination faced by PLHAs and also by women, the nature and extent of discrimination varies with the social and cultural context.

SECTION 1.2: FEMINISATION OF HIV IN INDIA, THE GROUND REALITY

HIV Prevalence in India

In 1986 the first case of HIV infection was detected in India. Today, NACO1 estimates – based on the annual sentinel surveillance – that there are 5.134 million HIV-positive people in India (UNAIDS puts this figure at 5.7 million).

Table 1: The spread of HIV in India 1998 – 2004

Estimated population infected with HIV/AIDS (millions)						
1998	1999	2000	2001	2002	2003	2004
3.5	3.7	3.86	3.97	4.58	5.106	5.134

Source: NACP India

According to the surveillance data, six states – Andhra Pradesh, Karnataka, Nagaland, Manipur, Maharashtra, and Tamil Nadu – are high prevalence states, with 70 percent of all HIV infections. The HIV prevalence rate among women attending antenatal clinics in these states is 1 percent and above. The moderate prevalence states are Gujarat, Pondichery and Goa. Based on the 1998-2004 data, states have been re-classified into four broad categories:

1) High prevalence states (exceeds 5% among HRG and 1% among ANC),

2) Moderate prevalence states (exceeds 5% in HRG and less than 1% among ANC),

[1] A National AIDS Control Programme (NACP) was launched in 1987 with the program activities covering surveillance, screening blood and blood products, and health education. In 1992 the National AIDS Control Organization (NACO) was established.[5] NACO carries out India's National AIDS Programme, which includes the formulation of policy, prevention and control programmes.

The same year that NACO was established, the Government launched a Strategic Plan for HIV/AIDS prevention under the National AIDS Control Project. The Project established the administrative and technical basis for programme management and also set up State AIDS bodies in 25 states and 7 union territories. The Project was able to make a number of important improvements in HIV prevention such as improving blood safety.

3) Low Prevalence but High vulnerable states (migration, illiteracy, weak health infrastructure)

4) Low Prevalence and low Vulnerable (rest of the states and UTs).

Table 2: Distribution of HIV infection in States according to prevalence.

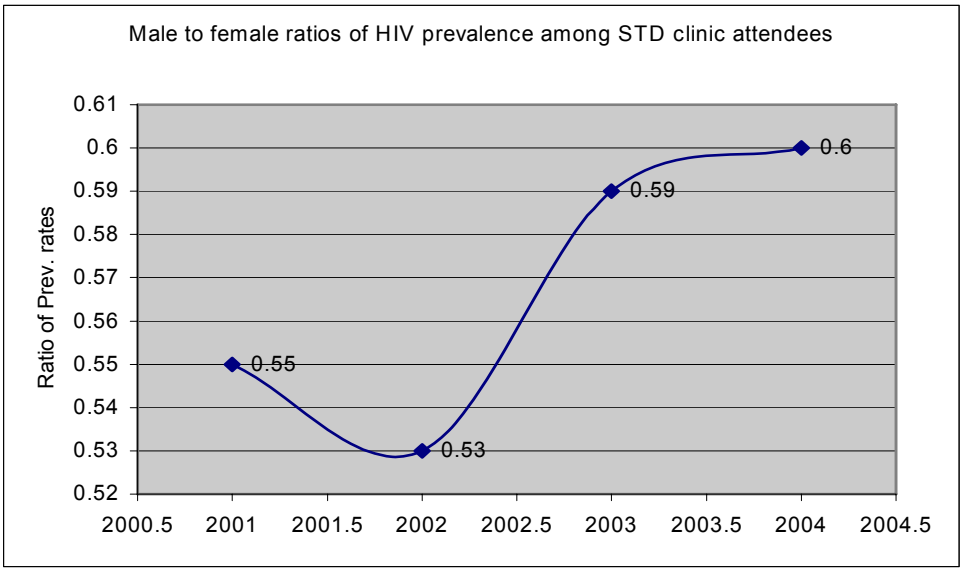
Epidemic Stage	Infected Population ('000)	Per cent
High Prevalence	3,562	69.38
Moderate Prevalence	105	2.05
Low Prevalence	1,467	28.57
Total	5,134	100.00

Source: NACP

Feminisation of the Infection

Nearly 40 percent of HIV-positive people in India are women, according to UNDP. Due to biological reasons, women are at a greater risk of contracting HIV through unprotected sex. The UNDP states that nearly 80 percent of HIV infections among women in 2005 were the outcome of women contracting the disease from their husbands. Second, lack of awareness also puts them at greater risk. As a large proportion of women are already marginalised – due to gender discrimination, poverty, lack of education and trafficking – this has serious implications in the light of the rapid spread of HIV in India. The most significant reason for the rising incidence of HIV infections among Indian women is their lower status in the social hierarchy.

The NACP III Framework acknowledges that "empowering women is basic to reducing their vulnerability to HIV/AIDS and sexually transmitted infections (STI)." Women and children are particularly vulnerable. Literacy and awareness levels of women lead to further vulnerability



SECTION 1.3: SPREAD OF HIV AMONG WOMEN IN GENERAL POPULATION

Though HIV/AIDS is still largely concentrated among at-risk groups – including sex workers, injecting drug users, and truck drivers – the surveillance data suggests that the epidemic is beginning to spread beyond these groups into the general population. The NACP points out that "an increasing number of women in monogamous relationships are getting the infection from their spouses".

- In 2004, the proportion of housewives with a single partner who were infected with HIV rose to 22 percent of all HIV cases in India.
- The increasing HIV prevalence among women also signifies an increase of mother to child transmission of HIV and paediatric HIV cases.

Increasingly, there is recognition of the fact that women are particularly vulnerable to HIV infection given the combination of discrimination, poverty and their social standing.

SECTION 1.4: CAUSES ATTRIBUTED FOR THE SPREAD

Cause One: Control over Sexuality and Sexual Relationships

Most husband-wife relationships in Indian marriages are unequal. Consequently, the woman has little control over her sexuality and her sexual relationship with her husband. Discussions about sexual health are rare and in most cases, the woman is denied the right to insist on condom usage. According to a UNIFEM-community based research in India, the primary reasons for the increased vulnerability of married women are low condom usage and inability to negotiate sexual matters within marriage. Besides women who insisted on condom use were suspected of infidelity.

Cause Two: Economic Situation

As women are financially dependent on men, it becomes impossible for them to refuse sex or even to insist on condom use.

Cause Three: Violence and HIV/AIDS

Domestic violence is a fact of life in many middle class and lower middle class homes in India. 2 The wife is subject to the brutal treatment for insubstantial reasons such as neglecting the home (40 percent), going out without permission (37 percent), disrespect to in-laws (34 percent), being unfaithful (33 percent), bad cooking (25 percent) and lack of money (7 percent).

According to a recent study women who are beaten or dominated by their partners are much more likely to become infected by HIV than women who live in non-violent homes.3

[2] The National Family Health Survey (1998-99), which surveyed 90,000 women in the 15-49 years age group, found that nearly 23 per cent of rural women and 17 per cent of urban women had been beaten at some point in their lives by their husbands. It also revealed that nearly 56 per cent of the women surveyed justified wife-beating. Sixty per cent women in rural India justified beating while 47 per cent urban women did so. The percentage of uneducated women who justified wife beating was higher (62 per cent) compared to those who had been to high school (32 per cent).

[3] Women and HIV/AIDS: Confronting the Crisis

Moreover, condoms are irrelevant when a woman is being beaten or raped. WHO states that during "forced vaginal penetration, abrasions and cuts commonly occur, thus facilitating the entry of the virus – when it is present – through the vaginal mucosa". Marital rape, often a common occurrence though such incidents are not talked about, thus exposes women to the risk of HIV infections.

Cause Four: Mother to Child Transmissions

The main reason for marriage is to have children. In a society where a woman's social status depends on her fertility and her ability to have a male child, there is a high risk of mother-to-child transmission of the virus. Even when a woman may know about her partner's HIV-positive status she may still risk a pregnancy because of the significance attached to motherhood in Indian society.

Cause Five: Reproductive and Sexual Health

Neglect and lack of awareness of reproductive and sexual health also leads to greater risk of HIV infection among women. According to a study of 400 women at a health clinic in Pune, 93 per cent of whom were married, 25 percent had sexually transmitted infections (STIs) and 14 percent were HIV-positive. 91 percent of these women had never had sex with anyone but their husbands.

Cause Six: Women as Caregivers

Women have low access to healthcare and their nutrition and health needs go largely unmet due to the bias towards males in Indian society. Family resources are almost entirely allocated for meeting healthcare needs of men. Even in cases where women have been infected by their husbands, they are the main caregivers. They are expected to care for their HIV-positive husbands while their treatment is only partially taken care of or completely neglected.

SECTION 1.5: STIGMA AND DISCRIMINATION TOWARDS HIV/AIDS IN INDIA

In a study of social reactions to people with AIDS in India, 36 percent respondents felt it would be better if infected individuals killed themselves and the same percentage believed that infected people deserved their fate. Nearly 34 percent said they would not associate with people with AIDS and about a fifth stated that AIDS was a punishment from God (Ambati, Ambati and Rao, 1997).

The invisibility of the disease in India is also due to the fact that HIV positive people maintain secrecy about their status for fear of ostracism within the community. While this invisibility may suggest that there are relatively fewer instances of community-based discriminatory responses, Bharat says that the degree of stigmatisation differs from case to case. For instance, stigmatisation and discrimination may arise when an individual identified as HIV-positive is seen as a source of infection to others, or when the physical appearance of someone with AIDS produces revulsion or fear. On the other hand, someone who is known to have HIV but whose behaviour or appearance is "non-threatening" is sometimes tolerated and may even be supported in the community.

Stigma doesn't end with death either. While in life, HIV-positive people end up maintaining secrecy, in death, their plastic-covered bodies are a dead giveaway of their AIDS status.

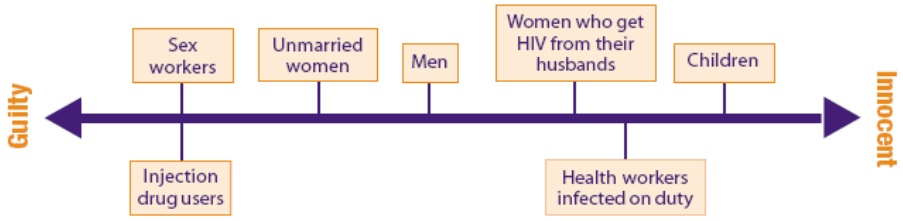
The plastic sheet is seen as a 'symbol of shame and stigma associated with AIDS'. Many people who die of AIDS are even denied the last cremation/burial rites by their family because of the fear of social ostracism.

SECTION 1.6: INCREASE IN STIGMA AND DISCRIMINATION AGAINST WOMEN DUE TO HIV AIDS

Stigma and discrimination in the HIV/AIDS context is much stronger when a woman contracts HIV. Women risk violence, abandonment, neglect of health and material needs, destitution and community ostracism. Gender plays a key role in the nexus between HIV-related stigma, moral judgment, shame, and blame.

The extent to which a woman is considered guilty depends on her marital status and whether she is a CSW (Commercial Sex Worker). If a woman is a CSW she is perceived to be guilty however women who are infected by their husbands are perceived as less guilty even in this situation. If such a woman has not had cordial relations with her neighbours, or if the community wants to throw her out for other reasons, then there is always a tendency to question her moral integrity. It's more likely that she will be considered to be guilty rather than innocent. These innocence-to-guilt schemes are represented in the figure above.4

Box 3: Schematic of "Innocence-to-Guilt" Continuum



Source: 2005 International Center for Research on Women

1.6.1 Hypotheses towards Increased Vulnerability of Women due to HIV AIDS

"Women are more likely to be stigmatised in India where women's powerlessness is glorified in a pativrata (dedication to the husband) image."

Hypotheses One: Family plays the largest role in discrimination

According to an ILO study conducted in 2002 in Maharashtra, Manipur and Tamil Nadu, it is the family of the infected person that discriminates the most compared to other sections of society. The women feel betrayed by the lack of understanding from family members despite the fact that they were the prime caregivers and continued to do all the household chores uncomplainingly.

[4] ICRW, 2005

Hypotheses Two: HIV women are not cared for by their families while males receive support

Another Indian study (Bharat, 1996) found that HIV positive men were more likely to receive care and support from their families than women who were infected. Shalini Bharat writes: "Daughters, wives and daughters-in-law experienced greater levels of stigma & discrimination than sons, husbands and sons-in-laws." The relationship most strained by HIV status was that between parents-in-law and daughters-in-law, followed by the spousal relationship. Discrimination against daughters-in-law was blatant even when sons received good familial care. Discrimination against HIV positive women included:

- Being thrown out of the house - In most cases, after the death of the son, parents refused to take responsibility for the well being of their daughter-in-law and asked her to leave. She either had to return to her birth family or was forced to support herself. Some women who were thrown out of their marital homes were not welcome in their birth homes either. Being HIV-positive therefore translated as being homeless.
- Being denied a share of the family property
- Being denied access to care and treatment
- Being blamed for the husband's HIV-positive status, especially when the diagnosis was made soon after marriage. Quality of the infected individual's relationship with his family also determined whether he/she would receive support.

Hypotheses Three: Economic status determines whether she would receive support

Economic status, age and educational status are factors that determine whether the HIV positive woman would receive support from the family. If a woman is the bread winner of the family or contributes to the family income, she is less likely to face discrimination.

Hypotheses Four: HIV positive women are stigmatized as having loose character

Women were stigmatised as being of "loose character" and a potential source of infection to their husbands, at the same time as they were expected to provide care. When she becomes HIV-positive, she is more likely to be blamed, even if she has been infected by her husband and has never had sex with any other man. "As a result of this blame-the-victim stigma, many women who are offered HIV tests refuse such testing because of the difficulties they would face were they to test positive for HIV," wrote authors Arvind Singhal and Everett M. Rogers in their book Combating AIDS – Communication Strategies in Action.

Hypotheses Five: HIV positive women are blamed for their husband's status

In many instances, the wife was blamed for not keeping her husband "under control" when it was discovered that the husband had contracted the disease by visiting sex workers. The rejection of the wife was on the grounds that she had failed in her role as a wife.

Hypotheses Six: Separation from children

One of the common forms of discrimination against HIV-positive women, found Bharat, was forced physical separation from their children. Some were forced to give up their children because they were too weak to look after them.

SECTION 1.7: IMPACT OF STIGMA – VIOLATION OF HUMAN RIGHTS

Ultimately, stigma acts as a violation of the basic fundamental rights of the person living with HIV/AIDS. There are six significant concerns, which have been identified for placing HIV-related stigma within a rights discourse.

1) Equality issues involving the right to freedom from inhuman/degrading treatment and punishment, including physical violence, exclusion from social functions, etc.

2) Issues relating to right to individual liberty and security. These could include denial to property or inheritance within their natal and marital homes, loss of financial support, or denial to form a family or significant relationships.

3) Education and Self determination issues involving the right to education and to become members of societies and clubs.

4) Livelihood opportunities which impact the right to employment.

5) Privacy issues including mandatory testing without consent or abortion without adequate counselling and access to reproductive rights.

6) Healthcare and treatment issues including access to reproductive rights and denial of information on ARV treatment.

1.7.1 Stigma and Denial of Healthcare and Treatment

The most common forms of stigmatised behaviour in a healthcare setting, as listed by Bharat, are as follows:

- Delays in treatment and slow service (e.g. made to wait in queues, asked to come again)
- Excuses or explanations given for non-admission (but admission not directly refused)
- Shunting patient between wards/doctors/hospitals.
- Keeping patient under observation without any treatment plan.
- Unnecessarily repeated HIV tests.

- Conditional treatment (e.g. only on the condition that the patient will come for follow-up or join a drug trial programme).

Landmark Judgements – Right To Healthcare

The Supreme Court of India in Mr. X Vs Hospital Z, states that people living with HIV/AIDS, *"deserve fully sympathy and are untitled to all respect as human beings. Their society cannot, and should not be avoided, which otherwise would have bad psychological impact upon them. They have to have their avocation and government jobs or services can not be denied to them."*

Article 21 of the Constitution of India imposes an obligation on the State to safeguard the Right to Life of every person. Preservation of human life is thus of paramount importance. Government hospitals run by the state and the medical officers employed there in are duty bound to extend medical assistance for preserving human life. Failure on the part of a Government Hospital to provide timely medical treatment to a person in need of such treatment results in violation of his Right to Life guaranteed under **Article 21. – Supreme Court judgment in Pashchim Bangal Khet Mazdoor Samiti Vs State of West Bengal**.

1.7.2 Stigma and the Right to Privacy and Reproduction

With more and more women contracting HIV from their husbands, there is a heated debate about whether there should be a law for mandatory testing for all couples before they get married. A public interest litigation (PIL) was filed in the Bombay High Court demanding these tests on the grounds that by concealing their HIV-positive status, many grooms-to-be often put their brides-to-be at risk. However, this proposal is being vehemently opposed by human rights groups as it amounts to a violation of privacy and personal freedom. Currently, as per the NACO guidelines, no individual should be made to undergo a mandatory HIV test as a precondition for employment or healthcare services. Besides the fear is that if pre-marital HIV testing is made mandatory it may lead to even more stigmatisation. As it is, testing negative does not rule out the possibility of unsafe sex practices in future.

Further, in the case of mother-to-child transmissions (MTCT), there is a need to ensure that there is informed consent to testing during pregnancy and to the intervention and to termination/continuing with the pregnancy. Other issues that need to be addressed include provision of adequate pre-test counselling, infant feed counselling and contraceptive advice; protection of confidentiality; provision of family planning services; potential adverse effects of taking anti-retroviral (ARV) especially in repeat pregnancies of HIV-infected women, and access to care and treatment from the MTCT intervention.

Behaviour with HIV-Positive Pregnant Woman from a Low-Income Group

"When a young woman who is first time pregnant is found to be HIV-positive, we ask her to call her mother-in-law. We explain the report to the mother-in-law. These patients who come here are from low income groups and if the girls are newly married, they are really dumb and don't understand anything, so the mother-in-law is called to explain." – Gynecologist in a Mumbai hospital as quoted in Bharat's study.

Given the animosity between daughter and mothers-in-law this form of disclosure is only likely to cause more stigma for the young woman. The need for counseling as well as

maintaining confidentiality is not felt because the woman is from a 'low income' group and therefore further adds to the burden of stigma that the HIV-positive stigma has to face.

1.7.3 Stigma and the Right to Liberty and Security of Individuals

The impact of HIV on a woman's economic condition is enormous. In India women are not expected to earn a living. This means that when she contracts HIV through her spouse, she is rendered virtually homeless and without the financial means to support her children and herself. Often women whose husbands have died of AIDS are thrown out of their marital homes and denied a share of the property. Many of them do not even find shelter in their natal homes. States the UNIFEM report*: "One of the most serious economic effects of HIV for women has been the loss of property. According to the Positive Women's Network of South India, widows generally have the lowest status in the household under normal conditions and rarely inherit the property they shared with their husband during the marriage….Adding to the picture HIV/AIDS robs women of any remaining status or rights they may have in a household."*

While there is a law, dating back to 1956, that allows women to inherit property from their fathers, the reality is that very few women actually inherit any property and most of them are unaware of their rights. Says the UNIFEM report: *"International human rights instruments can give structure and direction to activists' efforts. For instance, the CEDAW Committee has called on governments to go beyond simply passing laws and implement measures that can eliminate the bias that makes it difficult for women to act on their rights. In cases where poor women from rural areas do not have access to legal representation, governments are expected to find ways to provide subsidised or free legal advice even in isolated areas."*

1.7.4 Stigma and the Right to Employment and Livelihood Opportunities

"Women's vulnerability (to HIV/AIDS) is due to two main reasons – one, the lack of adequate awareness among the community and second, their husbands. Last year (2005) around 80 percent of the women infected were through their husbands," said Denis Broun, country coordinator, UNAIDS (Joint United Nations Program on HIV/AIDS).5 What makes a woman's situation even worse is that having been diagnosed with HIV, the stigma attached to the disease makes it virtually impossible for her to pursue livelihood opportunities that can enable her to support her family and herself.

Instances of stigma in the workplace need to be addressed as they directly impact the right to livelihood and employment of HIV-positive persons. A study by ILO among 500 employees of the Singareni coal mines operated by SCCL Ltd in Andhra Pradesh revealed that though a majority of the respondents (72 percent) would like their infected colleagues to continue working, 26 percent would prefer them to retire from work. Twenty five percent of the respondents mentioned that the community will not allow HIV-positive persons to stay in the village/locality. And 22 percent felt that an infected person would not be accepted by their families. Nearly 42 per cent felt such persons should not be treated along side general patients. Twenty six percent of respondents were not in favour of sharing their work tools with their infected colleagues and 29 percent were not comfortable shaking hands with an HIV positive person.[6]

[5] 40 percent of India's AIDS patients are women, IANS
[6] Study Report on Economic Impact of HIV/AIDS on Singareni Collieries Company Ltd, November 2005

1.7.5 Stigma & the Right to Freedom from Inhuman and Degrading Treatment

Women also have to face domestic violence7, which can undermine her fundamental rights. Women often have to face the double whammy of domestic violence as well as the HIV infection, which puts them at greater risk of losing not only their rights but also their homes, property, children and recourse to any legal redress.

Today, HIV-related stigma is almost akin to the stigma that people of lower-caste communities faced not so long ago. As one outreach worker who works among HIV- and AIDS-affected people commented: "Untouchability has always existed in our society and will always exist. Then how can one even hope and say that all this will change? Positive people are seen as untouchables. To change the attitude of people towards them is next to impossible."

1.7.6 Self Stigma: An Outcome of Violation of Rights in the HIV Context

Lack of family support, ridicule and stigmatising behaviour from the community, denial to financial independence and a means of livelihood are factors that give rise to internal stigma. As USAIDS points out: "Internal stigma can lead to a person's unwillingness to seek help or access resources." Moreover, members of already marginalised groups – such as sex workers, widows, disowned single and/or divorced women, unmarried women with children, and members of lower castes – who become infected with HIV are likely to experience greater stigma, thus perpetuating self/internal stigma as well. Bharat writes: "Shame and stigma seem to have been internalised by many HIV-positive respondents and they have a tendency to feel guilty and to tolerate the judgmental behaviour of others.

Internal or self stigma is also exacerbated by the Indian belief in 'karma' and destiny. This is particularly true of a majority of Indian women who have been raised to believe that their fate lies in the hands of their husbands and that they have no option but to silently suffer whatever destiny has in store for them."

Clearly then, as Bharat points out, "it's not enough to raise awareness about HIV/AIDS, its transmission routes, or even about legal rights. What is urgently needed is anti-discrimination policy supported by a law that will ensure the protection of HIV-positive people's rights."

SECTION 1.8: THE WAY FORWARD

There is sufficient evidence to suggest that women with HIV AIDS suffer from stigma and discrimination at the hands of the community and the family. They are also a victim of self stigma. The nature of stigma is deeply rooted in the socio cultural set up of the Indian society. Though stigma in a general context is available from numerous studies conducted earlier specific studies directed at the HIV positive Indian women have yet not been attempted.

The HIV/AIDS Act, 2005

The HIV/AIDS Act is proposed to be enacted and is expected to be tabled in Parliament in the monsoon session of 2006. The Bill seeks to *"provide, keeping in view the social,*

[7] The Government of India has introduced a Bill on domestic violence in the Lok Sabha titled, The Protection from Domestic Violence Bill 2001. The Bill has come under fire from women's activist groups as it is felt that if the Bill is passed, it might have dangerous implications for women facing domestic violence.

economic and debilitating effects of the HIV epidemic in India, for the prevention and control of the HIV epidemic in India, the protection and promotion of human rights in relation to HIV/AIDS, for the establishment of National, State, Union Territory and District authorities to promote such rights and promote prevention, awareness, care, support and treatment programmes to control the spread of HIV, and for matters connected therewith or incidental thereto." The Act prohibits discrimination by the state or any person in relation to any sphere of public activity; hate and discriminatory propaganda; and victimisation.

Under the Chapter 'Special Provisions' of the Bill, an effort has been made to recognise the special needs of women. Some of the special provisions include:

1) Right to Residence

2) HIV-related IEC before marriage

3) Counseling and information to be made available to pregnant HIV-positive women

4) Sexual Assault protocols for survivors of sexual assault with regard to HIV-related counseling, prevention, and treatment.

On the issue of discrimination, the Act states the respondent must prove on the facts before the court, that the discrimination did not take place as alleged; or the respondent must prove that the conduct is not based on one or more of the prohibited grounds."

SECTION 1.9: THE BREAKTHROUGH INTERVENTION PROGRAM

Breakthrough was established in 1999 to raise awareness about human rights using education and popular culture. Since then, Breakthrough has built expertise in effective IEC interventions through mainstream media products and interpersonal training activities. Breakthrough uses education and popular culture to promote public awareness and dialogue about human rights and social justice. Breakthrough works across five program areas, including women's rights, sexuality, caste equality, religion and peace and racial and ethnic justice.

The organization encourages individuals and communities to get involved in promoting social harmony and building a culture of human rights through four avenues:

- Public education in partnership with the creative world to produce radio, music, art, television and theatre for social change
- Our interactive website, www.breakthrough.tv, which is an educational and entertaining forum packed with ideas for action.
- Forums and workshops that involve diverse communities.
- Multi-media educational materials for schools, colleges, neighbourhood groups and other relevant institutions.

Breakthrough's integrated strategy combines the mass media's potential to shape public dialogue with interpersonal reinforcement, skill building and social mobilization to influence knowledge, attitudes and social norms from a rights-based, gender sensitive perspective. This combination of strategies will lead to an increase in individual and collective responsibility in promoting women's human rights with a focus on violence against women and women's vulnerability to HIV/AIDS. Strategy components include:

- Effective, gender-sensitive and culturally relevant media products.
- Educational and advocacy materials for multiple users.
- Workshops, trainings and forums for dialogue and awareness.
- Interactive and widely used website.
- Alliances with civil society groups, government agencies, educators, media outlets and the entertainment industry.

Breakthrough's first effort at mainstreaming the voices of marginalized communities by placing their issues squarely in popular media was Mann ke Manjeeré (Women's dream) a music album and two music videos. This effort brought the usually taboo issue of domestic violence into mainstream popular culture.

Over the last decade another challenge has been added to the struggle for women's rights in India: the increasing threat of HIV infection. Recent trends of HIV infection in India indicate that gender inequality and lack of public dialogue about sexuality and health are significant factors in increasing women's vulnerability to the infection.

Women in India still face significant human rights violations on a daily basis. These violations take many forms including sex-selection feticide, female infanticide, domestic violence, forced prostitution, sexual assault, inability to prevent sexually transmitted infections, marital rape and violence against widows. Discriminatory social practices and unequal laws ensure that women have limited access to resources of their own, whether land, housing or money, with the result that both private and public spaces, including the natal and marital home, can become sites of violence.

HIV positive women experience further violations as a result of their husband's positive status. In most instances, women are expected to nurse their husbands through their illness, but are then expelled from the marital home once their spouse dies. It is not uncommon for the husband's family to demand that the wife's family pay for her husband's treatment. Because of patriarchal values and the stigma associated with HIV/AIDS, positive women often face limited access to care and treatment, homelessness, job loss and often have their children taken away.

Breakthrough's understanding of how violence against women and their increased vulnerability to HIV/AIDS are connected to women's economic and social rights, resulted in a yearlong campaign to reduce women's vulnerability to HIV/AIDS, What Kind of Man Are You? This multi-media campaign on HIV Prevention among married couples (2005) was created by McCann Erickson. The multi-media campaign (music video featured on MTV; TV spots; internet; radio; outdoor; SMS line) promoted male responsibility for condom use to prevent the spread of HIV. Launched in 7 languages, it encourages dialogue within marriage to address gender inequalities that make it difficult for women to negotiate safe sex. Even married women in monogamous relationships are placed at risk for infection when their husbands and sexual partners engage in high-risk sexual activity outside the marriage. Women are often not in a social or economic position to insist on fidelity in marriage and relationships, demand condom use, or refuse sex to a partner who may pose a risk to their sexual health. This problem is further exacerbated by the extremely low levels of condom use at a mere 3% of all methods of family planning.

Along with the multi media campaign Breakthrough took up Trainings of Trainers (TOT's) and Peer Education to address the issue holistically. Breakthrough has trained over 600 educators, community based organizations, and networks of positive people through intensive workshops and follow-up interventions, enabling them to incorporate gender and

rights frameworks in their work and train their constituents (with emphasis on young people) on women's rights, violence and HIV/AIDS. It has reached over 2500 school/college students all over India in 2004-5 alone. In 2005, supported by Levi Strauss Foundation, in partnership with Naz foundation, it has launched a 1-year peer education programme for students to disseminate HIV/AIDS information on campus.

Breakthrough's approach to programming draws from our understanding of human rights as universal, indivisible and intersectional. Thus we believe that gender-based violence and women's vulnerability to HIV/AIDS are necessarily linked and must be dealt with holistically to effect significant positive change in attitudes and behaviour in this area. The two planned projects will complement each other and allow for a comprehensive education program on women's human rights and sexuality.

The proposed multi-media and Peer Education programmes targeted at the stigma and discrimination faced by HIV positive women will support Breakthrough's mandate of using media and education to promote human rights. Breakthrough's previous experience with women's rights and HIV has made them uniquely situated to tackle stigma against WLHA. Breakthrough will build on the issue expertise in gender, human rights and HIV and its experience with media and peer education to create an integrated programme that combines the extensive reach of mass media with the critical reinforcement of ground level outreach. The feminization of the HIV/AIDS epidemic is resulting in increased vulnerability of women and girls. This vulnerability includes the effects of HIV/AIDS-related stigma and discrimination, which are particularly devastating for women. The impact assessment of "What Kind of Man Are You?" (The first phase of the campaign launched in 2005) conducted by ORG-Neilson, demonstrated that misconceptions about the connection between HIV and 'deviant' behaviour is leading to PLHA being ostracized. NACP III also recognizes the need to address stigma to increase care and support. The Breakthrough campaign aims to involve families and communities in upholding the rights of WLHA, thus reducing stigma and increasing access to care and support. The campaign plans to utilize a 360- degree communication approach, encompassing mass media activities as well as the ground level outreach necessary to reinforce these messages.

Section 2

The Formative Research

In order to design intervention programmes or communication directed at the stigma it is necessary to identify the indicators which define stigma for the HIV positive Indian women. Measurement of these indicators over time would serve to suggest the extent to which a program has been successful.

SECTION 2.1: OBJECTIVES OF FORMATIVE RESEARCH

- Understanding of awareness, attitude and behaviour of community towards HIV/AIDS and towards PLHA
- Examine the forms in which HIV/AIDS-related Discrimination and Stigma is experienced and manifested at the levels of individuals, families, and institutions (community) towards the WLHA
- Investigate the role of gender in the causes and consequences of stigma.
- Identifying the stigma and discrimination faced by MLHA (Men living with HIV AIDS) and WLHA (Women living with HIV AIDS) in the community and evaluate whether there exists differences between attitude and behaviour towards MLHA and WLHA
- Identification of relevant stigma and Mapping of stigma indicators with rights of women

SECTION 2.2: RESEARCH OBJECTIVES AND METHODOLOGY

Scope of Research

A formative research with a focus on identifying the stigma, indicators and need states of HIV positive women in India has been designed. The scope of this research is to identify the stigma and discrimination faced by WLHA in India and the current levels of different kinds of stigma prevailing against WLHA in India.

Existing stigma indicators have been evaluated for their suitability in the context of the HIV positive Indian women. New set of indicators also have been identified from the interplay of HIV/AIDS and the socio cultural context of Indian women which serve as a base line for making an assessment of stigma. These indicators would be used for an end line research to measure the impact of the intervention.

SECTION 2.3: RESEARCH METHODOLOGY

The formative research has been conducted using qualitative research methodology since behaviour patterns in the different socio cultural contexts would have to be compared and similar and dissimilar stigma would need to be identified. This has been undertaken in two stages:

Stage One: To understand the need states of WLHA and identify Community, family and WLHA related stigma and their Indicators.

Stage Two: Validations of indicators through qualitative focus group discussions.

SECTION 2.4: RESEARCH LOCATION

Three states – Maharashtra, Karnataka and UttarPradesh where Breakthrough is already operational through intervention programs were considered as appropriate for the research so that Breakthrough activities in these states would receive a further focus.

2.4.1 Prevalence of HIV in Three States

Based on the surveillance data six states in the country have been categorized as high prevalence states consisting of about 70% of the total infection.

High Prevalence States: Andhra Pradesh, Karnataka, Nagaland, Manipur, Maharashtra and Tamilnadu. The HIV prevalence rates among women attending antenatal clinics in these states is 1 percent and above.

Moderate Prevalence States: Gujarat, Pondichery and Goa

High Vulnerable States: Migration, illiteracy, weak health infrastructure Vulnerable states with poor health indicators need special attention. These states, which have large populations, lack the infrastructure to detect the epidemic early and to respond effectively. Unless they receive extra support they could see a full-blown epidemic with no early warning signs.

Vulnerable States: All other states and UTs

S. No	Name of State /UT	Number of sites in 2004	HIV Prev. 1998 (%) (180 sites)	HIV Prev. 1999 (%) (180 sites)	HIV Prev. 2000 (%) (232 sites)	HIV Prev. 2001 (%) (320 sites)	HIV Prev. 2002 (%) (384 sites)	HIV Prev. 2003 (%) (455 sites)	HIV Prev. 2004 (%) (670 sites)
High Prevalence States (Observed HIV Prevalence levels State wise: 1998 - 2004, NACO)									
1	Andhra Pradesh	STD 8	24.9	29.5	30	26.6	30.4	19.6	16.4
		ANC 23	2.25	2.6	2	1.5	1.25	1.25	2.25
2	Karnataka	STD 7	16.7	15.5	12.8	16.4	13.6	10.4	12
		ANC 27	1.75	1	1.68	1.13	1.75	1.25	1.25
		IDU 1	-	1.3	4.23	2	2.26	2.8	0
3	Maharashtra	STD 9	16	20	18.4	9.2	7.6	10	10.4
		ANC 35	2	2.1	1.12	1.38	1.25	1.25	1.25
4	Manipur	IDU 3	70.7	48.8	64.34	56.26	39.06	24.4	22
		STD 2	4.15	12	11.6	10.5	9.6	13	7.2
		ANC 10	0.75	2.3	0.75	1.75	1.12	1.25	1.5
5	Tamil Nadu	STD 11	16.3	10.4	16.8	12.6	14.7	9.2	8.4
		ANC 30	1	1	1	1.13	0.88	0.75	0.5
		IDU 1			26.7	24.56	33.8	63.8	39.9
		MSM 2			4	2.4	2.4	4.4	6.8
6	Nagaland	IDU 3	13.2	7.6	7.03	5.5	10.28	13.86	4.49
		STD1	11.1	4.4	6.9	7.4	2.42	0.9	1.7
		ANC8	0.7	1.3	1.35	1.25	1.25	1.25	1.43
Medium Prevalence States									
7	Goa	STD 2	19.4	13.5	12.02	15	11.29	14.3	15.77
		ANC 2	1.2	0.8	1.17	0.5	1.38	0.5	1.13
		MSM 1			53.2	50.79	24	30.1	1.7
8	Gujarat	STD 8	2.5	6.7	4.65	4.14	6.17	4.5	3.6
		ANC 8	0	0.4	0.5	0.5	0.38	0.4	0.13
9	Pondichery	STD 3	7.2	5.8	4.1	2	2.02	2.6	4.8
		ANC2	0.5	0.9	0.25	0.25	0.25	0.13	0.25

Both Karnataka and Maharashtra are high prevalence states whereas UP is a low prevalence high vulnerable state.

SECTION 2.5: CRITERIA FOR SELECTING LOCATION IN THE STATES

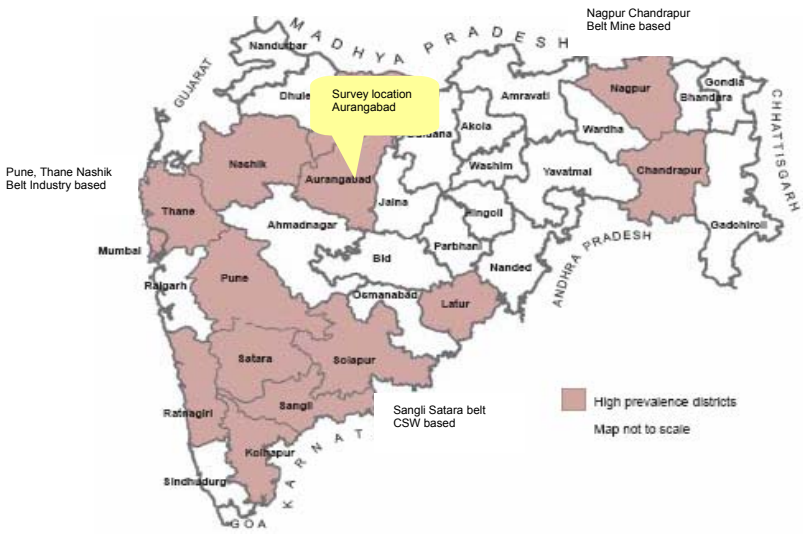
Within each of the three states districts were chosen based on the following criteria: Industrial, Migrant, Non CSW belt and ANC Prevalence rate.

2.5.1 Selected Districts

State	Location	Characteristic
Maharashtra	Aurangabad	Industrial, Migrant, Non CSW
UP	Kanpur	Industrial and Migrant
Karnataka	Udupi	High Incidence amongst low risk group, Medium ANC rates

2.5.2 Selection of Aurangabad in Maharashtra

Maharashtra is the second most populous state in India and the prime commercial and industrial centre and has a high HIV prevalence, both historically and currently. As the hub of commercial and industrial activities, Maharashtra has a sizeable migrant population, which is mainly male. A high concentration of people has turned the state into an overcrowded and polluted place with several million homeless people. It also has a significant problem with illicit drugs and a large sex industry. The epidemic began among groups with a high risk of infection, such as sex workers and their clients. But it has now spread to the general population.



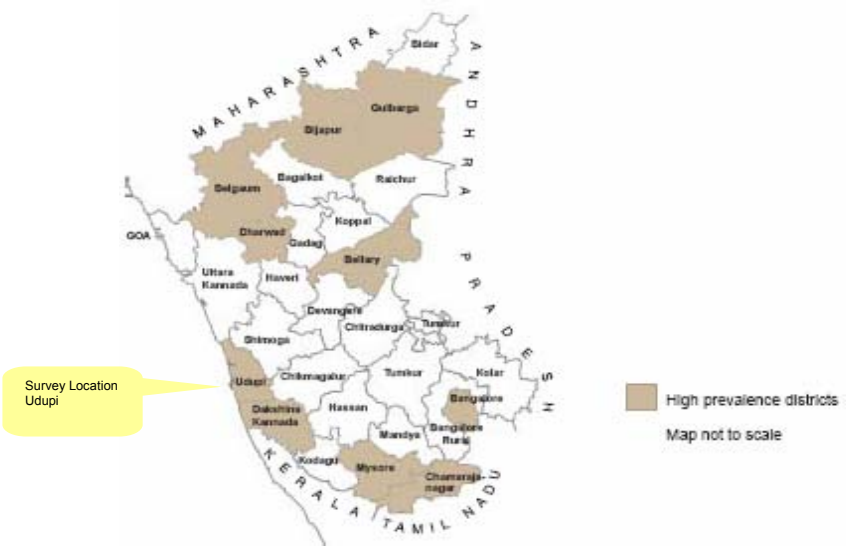
The spread of HIV in Maharashtra is as shown in the picture:

The focus of the research is women in the general population. Areas where CSW activity is high – Sangli, Satara belt and the Mumbai, Thane belt has therefore not been considered. The other

area of high incidence is Nagpur-Chandrapur belt which is largely the mining belt. Again since the objective was to represent the situation nationally a region with industrial and migrant population and not very high incidence of CSW activity was considered to be more suitable. The Aurangabad belt towards the north of Maharashtra was a good choice given the above mentioned criteria. It has small and large industries and large industrial area with a migrant population. Aurangabad also has a tourism industry, good media penetration, average literacy rate and predominance of Muslim community which would enable the religion angle to be explored also.

2.5.3 Selection of Udupi in Karnataka

Karnataka is now one of the states of India most seriously affected by the HIV/AIDS epidemic. The proportion of women in antenatal clinics who test positive for HIV infection is high. This is a sign that the epidemic is spreading into the general population and is no longer confined to high-risk groups.



HIV in the General Population: Percent of Pregnant Women at Antenatal Clinics Who Tested Positive for HIV, 2004

According to the BSS 2004 the incidence of HIV AIDS is 1.5% in Karnataka. HIV rates are 1% or higher among low risk group of women testing positive at anatenatal clinics. This figure varies across districts – from 3.8 in Belguam and Mysore districts to 0.3 in Kodagu. Udupi district lies in between the two extremes – it has reported 1% incidence among the low risk group – women testing positive at ante natal clinics. Udupi due to its proximity to the coastal region, high service class prevalence was considered an appropriate choice as it is representative of the non industrial belt and low CSW belt in Karnataka.

District	District Hospital	First Referral Unit	Total
Belgaum	3.8	4.8	4.3
Koppal	1.8	4.3	3.0
Dhawad	1.8	4.0	2.9
Bagalkot	2.8	2.5	2.6
Bangalore (rural)	2.8	2.3	2.5
Mysore	3.8	1.0	2.4
Gulbarga	2.0	2.5	2.3
Davangere	1.0	3.3	2.1
Tumkur	1.3	1.8	1.5
Bijapur	2.0	0.8	1.4
Uttar Kannada	1.3	1.5	1.4
Dakshin Kannada	2.5	0.3	1.4
Bellary	1.0	1.3	1.1
Raichur	1.3	1.0	1.1
Mandya	1.3	1.0	1.1
Gadag	1.5	0.8	1.1
Udupi	1.5	0.5	1.0
Hassan	0.8	1.3	1.0
Chanmarajnagar	0.8	1.3	1.0
Chikamagalur	0.5	1.5	1.0
Bidar	0.8	1.0	0.9
Chitradurga	0.8	0.8	0.8
Kodagu	0.3	1.3	0.8
Kolar	1.3	0.3	0.8
Bangalore (Urban)	1.3	0.0	0.6
Haveri	0.8	0.5	0.6
Shimoga	0.5	0.5	0.5

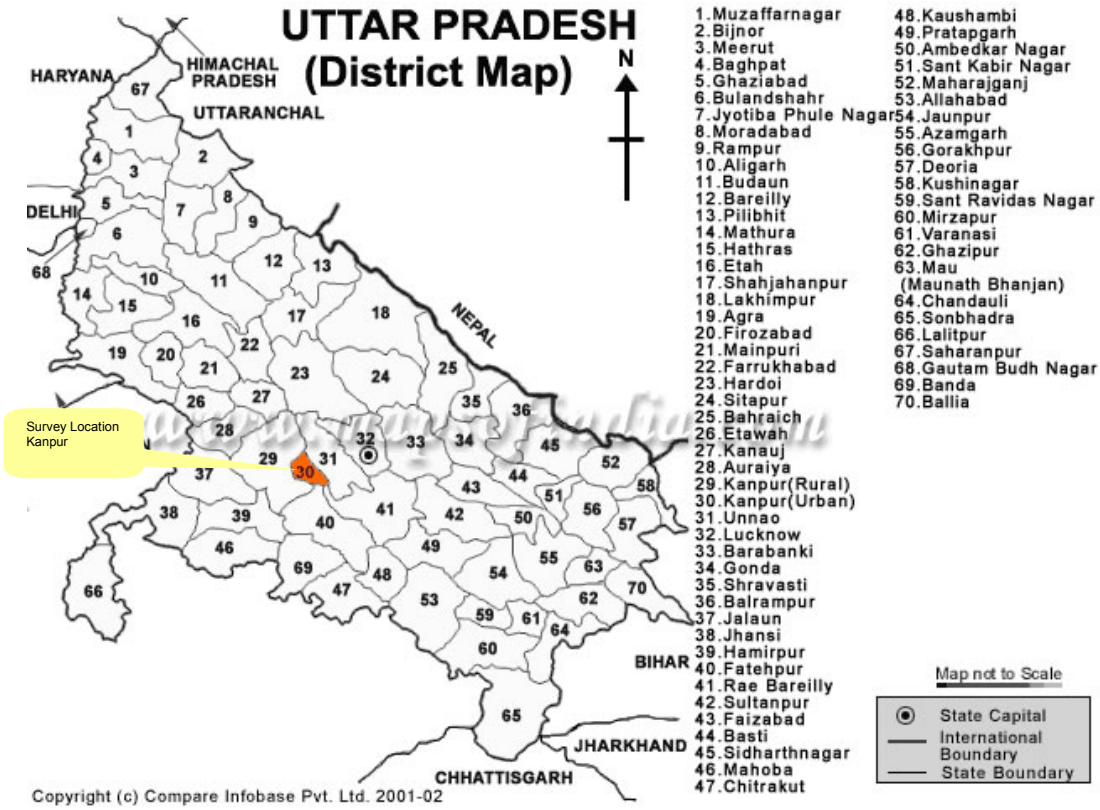
2.5.4 Selection of Kanpur in Uttar Pradesh

An industrial centre was considered as an appropriate choice for the research location. UP is largely agriculture centric and with large concentration of rural areas. Since the research was focused on urban areas, Kanpur in Uttar Pradesh which is one of north India's major industrial centres was considered as an appropriate choice. It is the biggest city of the most populous state of India. Women's vulnerability has seen an increase because of the large influx of single male migrants and involvement of women in commercial sex work

due to poverty. Further, alcoholism among men, gender based violence and the lack of decision making powers women have even within marriage increases her vulnerability.

Kanpur is also a Centre of peer education Group Intervention of Breakthrough.

Kanpur was an appropriate choice for the research location in UP due to its industrial and migrant character.



2.6 Demographics of State and Districts Selected

Maharashtra

Indicator	Maharashtra	Aurangabad
Population	96752247	2920548
Sex Ratio	922	919
Literacy	77.27	73.63
Life expectancy (Female)	67 Yrs	
HDI	(0.523) Rank 4	
Health infrastructure		
No. of Govt. Hospitals in District	405	6
No. of CHCs	295	
No. of PHCs	1,695	

Karnataka

Indicator	Karnataka	Udupi
Population	52733958	1109494
Sex Ratio	964	1127
Literacy	67.04	79.87
Life expectancy (Female)	65.4 Yrs	
HDI	(0.478) Rank 7	
Health infrastructure		
No. of Govt. Hospitals in District	337	
No. of CHCs	224	
No. of PHCs	1,459	

Uttar Pradesh

Indicator	Uttar Pradesh	Kanpur District
Population	166052859	4137489
Sex Ratio	898	868
Literacy	57.36	77.63
Life expectancy (Female)	56.4 Yrs	
HDI	(0.388) Rank 13	
Health infrastructure		
No. of Govt. Hospitals in District	65	7
No. of CHCs	262	
No. of PHCs	3,761	
No. of VCTCs	70	

Source Census 2001 & National Human Development Report 2001

Section

3

Research Process

SECTION 3.1 TOOLS USED FOR QUALITATIVE RESEARCH

HIV/AIDS is a sensitive and stigmatized subject and the attitude towards it is likely to be influenced by general attitude towards health, hygiene, education, social interactions between different communities etc. It was considered appropriate to conduct observation on these aspects in areas identified for the community interviews at each location.

Transect walks were used for the purpose of observation.

3.1.1 Transect Walks

Transect Walks are walks through a community or location to identify different places, people and activities regarding HIV AIDS and the community. For the area chosen for transect, walks observation was done on:

I. Key locations in the area – market, health services, schools, places of worship etc. were observed for availability and access to women. (VCTC facilities)

II. Identification of what people do and where they do it- for example places where people meet, work and relax.

III. Observation of the environment – cleanliness, food sold in open, drainage system, power shortage, water shortage, public hygiene, availability of medicines, condoms etc.

IV. Observe whether there are groups of Street children, unemployed youth gatherings, people playing cards etc.

V. Community organizations and their activities – what good acts have they promoted in the community? Types of non-governmental organisations or religious organisations in the community.

VI. Observe how people interact with each other at different places. Interactions between men and women - observe whether restricted or free/with respect.

3.1.2 Qualitative in-depths

The research was aimed at identifying the complete spectrum of emotions, experiences and stigma experienced by the WLHA to reach to the level of her need states. A free flowing discussion providing the WLHA and her family to express themselves was required with sensitive handling by the interviewers. Qualitative in depth interviews with community members in different occupations, MLHA, WLHA and family of WLHA (both in laws and natal family) were undertaken. Discussion guidelines were prepared to cover the probe areas.

3.1.3 Focus Group Discussions

Qualitative data derived from focus groups are extremely valuable when vivid and rich descriptions are needed. The conversations in focus groups give a sense of what is going on in people's minds and lives. Listening as people share and compare their different points of view provides a wealth of information—not just about what they think, but why they think the way they do.

FGDs were considered an appropriate tool to probe the community about their knowledge, attitude and practices about HIV AIDS.

FGDs with WLHAs were held in one location out of three where the topic of HIV AIDS was not such a taboo and discussed freely (in this case, Udupi) – the WLHAs were also more accepting of their problem and facing it normally hence they were able to provide objective views and also describe their experiences in more detail.

(Details of information and probe areas are described for each segment in the Annexure)

SECTION 3.2 SAMPLE SIZE

Community interviews were undertaken across the SECs is all the three locations Altogether 151 respondents were met from the community.

SEC Category	Transact Walk Number of interviews in three locations each	FGDs Number of interviews in three locations each	Total
SEC-A	4	None	4
SEC-B	2	45	46
SEC-C	11	44	55
SEC-D	None	46	46
TOTAL	**17**	**135**	**151**

30 WLHAs, 28 Family Members, 6 MLHAs and 9 Women from the general population were met with in addition to the meetings held with workers and staff at the positive networks.

SECTION 3.3: CRITERIA OF SELECTING THE RESPONDENTS

The research was focused towards gaining an understanding from five stakeholders - Community and Key Informants, Women in General Population, Men living with HIV AIDS, Women living with HIV AIDS and Family of Woman living with HIV AIDS.

The WLHA formed the main criteria around which all the other stakeholders were selected. Positive networks at the three locations - Aurangabad, Kanpur and Udupi were approached to contact the WLHA. The networks also helped in selecting the locations for the transect walks (areas from where they generally get the PLHA).

SECTION 3.4: METHOD OF RESPONDENT CONTACT

Access to HIV+ women was done only through Positive women networks. Given the sensitivity of the discussions required with the women it was considered appropriate if the network member made the first contact with the respondent to clarify the purpose and method of research, the process and type of support sought from the respondent. The positive networks on their end were trying their best to enrol as many members as possible by visiting blood banks, testing centres and providing information about the support they can receive from the positive networks.

The main challenge for measuring stigma among PLHA is sample selectivity. The only way to ethically contact PLHA for a survey is with a request for participation through networks of PLHA, service organizations, and health care providers, which precludes the possibility of obtaining a random sample of all people living with HIV. As a result, any data collected from PLHA may present biased results, as the data will be from a very select group of PLHA. PLHA participating in any study will: (a) have to know they are HIV-positive; and (b) belong to an association or be in search of social or health services from selected organizations that necessitate some level of public disclosure of HIV status. Those who fear or have experienced the most HIV stigma may be the least likely to have been tested or, if tested and positive, to participate in a group or seek services. Because this study also recruited PLHA respondents via networks of PLHA, it too suffers from this limitation.[8]

The networks also arranged for the families of the positive women to come to their centre for the interviews. Families who do not support the WLHA were not possible to be contacted either though the network or directly – in case we had visited them they could have caused some harm to the respondent. Views of the family were sought from supportive families only but as we moved into discussion with these families too in some cases we realized that the support was more on a surface level – either the WLHA was earning or the family was attracted by the incentives provided by the research to agree for the interview. Areas of non support to the respondent became evident as we started speaking with them.

In some cases particularly in Udupi the respondents and their relative's houses were also visited. However, in Aurangabad and Kanpur the research team had been advised not to visit the homes of the respondents as it would create a negative environment for the respondent from neighbours and family.

Local areas in the urban limits from where the network had registered maximum number of members were used for selection of the community sample.

MLHA were also arranged through the positive networks.

SECTION 3.5: PROCESS OF SELECTING THE RESPONDENTS

The networks were informed in advance about the respondent profile desired for the interviews. The main consideration was that the WLHA should not be from High Risk groups like CSW or partner of truck drivers etc. They should preferably be wives of industrial workers, supervisors or service class people. We were targeting to sample

[8] USAID study

respondents from the middle to lower socio economic classes to cover the complete spectrum of the spread of the infection and stigma associated therein. In Aurangabad and Udupi we were able to access respondents in the middle income group but in Kanpur access was limited to lower socio economic groups only.

SECTION 3.6: TRAINING OF RESEARCH TEAM

The research team was sensitized towards the topic of HIV AIDS at a workshop conducted by Breakthrough. The team was trained to work on the discussion guidelines prepared and recruitment and selection of the respondents. Mock interviews and exercises were undertaken.

Ethical Norms Guiding The Research Process

The Prastut team was sensitized to the interaction process with the HIV infected participants through a day long workshop. The workshop enumerated and provided training on the following aspects:

Understanding HIV+ - What is HIV? What is AIDS? How quickly do people infected with HIV develop AIDS? How many people are affected by AIDS? How is HIV transmitted? And how is HIV not transmitted?

Discussion about Human Rights

Role Playing between an interviewer and HIV positive person to sensitise the interviewer on

- Making the respondent comfortable
- Maintaining the confidentiality of participants
- Ensure that no harm comes to the participants during the research process
- Maintain the rights and dignity of the participants
- Respect the privacy of the individual
- Ask relevant questions on economic and social profile
- Resist from usage of words like fatal disease
- Making respondent aware of the purpose of the research

SECTION 3.7: THE RESEARCH PROCESS

The exploratory research was planned for three days per location. The Prastut team comprising of 4 researchers (2 familiar with the local language) visited the locations. Separate male and female researcher teams were used for interviewing the male and female respondents and family members respectively.

The conclusive research was conducted over a span of 2 days at each location – 3 FGDs per day. In case of Udupi it was conducted for 3 days.

SECTION 3.8: DATA COLLECTION PROCESS

The networks in Aurangabad and Udupi were found to be very active and cooperated with the Prastut team in arranging for respondents at their centre and making both the research team as well as the respondents comfortable. In case of Kanpur however, the situation which the research team came across was different – there was only one positive network centre in Kanpur located in far outskirts of the city. The centre had not more than 10-12 members out of which most of them belonged to high risk groups like sex workers. The network was finding it difficult to reach out to HIV positive persons in Kanpur as the disease was largely underground in Kanpur. Blood banks and Government hospitals also did not report whereabouts of the HIV infected persons who often left wrong addresses. HIV AIDS suffered from a social taboo in Kanpur. Discussion about the issue and getting the community or even the PLHA to respond was an uphill task in Kanpur.

3.8.1 Data Collection

The interviews were recorded on audio tape after taking the consent of the respondents and their families. Interviewers in regional language were used to make the respondent comfortable. The interviews were conducted in the premises of the positive network offices to provide a safe and familiar environment to the respondent.

Recorded interviews and FGDs were then transcribed for the purpose of content analysis.

3.8.2 Findings from Research

The findings from the research have been analysed in the framework discussed above and presented in the following chapters: Chapter Three – Community Transect Walks and Qualitative In-depths; Chapter Four – Community Focus Groups; Chapter Five – Family In-Depths; Chapter Six – WLHA In-depths and Focus Group.

Section 4

Perception of Stigma & Discrimination: The Community View

4.1 PERCEPTION OF STIGMA AND DISCRIMINATION – THE COMMUNITY VIEW

The three research locations – Aurangabad, Udupi and Kanpur have been assessed for their awareness and perception about HIV/AIDS and their attitude towards those infected with HIV/AIDS. The stigma and discrimination on account of the community has been identified to lead to stigma indicators which would be relevant in measuring the stigma and discrimination at the community level. These indicators would set the tone for further qualitative research to test their necessity and sufficiency towards measurement of community based stigma.

SECTION 4.2: Transect Walks

Transect walks were conducted in the three locations in areas suggested by the positive networks in the respective cities.

4.2.1 Aurangabad City – Areas of High HIV Prevalence

The areas of high prevalence in Aurangabad as reported by the Aurangabad Positive People's Network are Mukundwadi , Areas near Bus and Railway station, CIDCO, Waluj, Bayajipura (industrial areas), Vaijapur city and villages and Kannad.

Transect walks were planned for a day each in two industrial areas – Mukundwadi and Waluj.

4.2.1.1 Transect Walk Findings - Mukundwadi Area

The Mukundwadi area has a population of 25000 to 30000 people out of which approximately 20% are Muslims, 60% are Marathas and 20% are other communities. It is a predominantly a trader and business community area. There are 10 private hospitals and 1 Government hospital in the area. There are 4-5 high schools. There are 2 temples and 2 mosques. There are no parks or recreation facilities. There are market places for fruits, vegetables and other items. Chemist shops were also observed. The area was clean - having a proper drainage system. Food was being sold in the open by hawkers.

The area had problems of load shedding and scarcity of water supply. Unemployed youth were observed on the streets however there were no street children. The area was peaceful in nature it had not witnessed any communal riots though a mix of different communities were staying together in the same neighbourhood.

The people in the area had a friendly and helping nature. It was observed that women are treated respectfully. A maternity home was also visited wherein it was observed that HIV tests are advised. TV penetration is high.

4.2.1.2 Transect Walk Findings - Waluj Industrial Area

The estimated population of Waluj is 20000 out of which 30% are Muslims, 70% are Maratha, Jain Samaj and converted Christians. There are 8 private hospitals and only one Government Hospital. There are 5 primary and secondary schools and 1 College of Arts and Commerce. The place also has temples, mosques as well as a church. There are 2 playgrounds but no parks for recreation.

The place is not clean, not many hawkers were observed but food stuff was being sold in open. There is no proper drainage system and a heavy load shedding in the area. The youth and others find employment in industries in the area. There is adequate TV penetration in the area. Some social groups are also active and have taken on the role of AIDS awareness in nearby villages for the last 4 years.

Women were observed as being treated with respect.

4.2.2 Kanpur City – Areas of High HIV Prevalence

It was extremely difficult to trace a network of positive people functioning in Kanpur. Through references from the Aurangabad network and Udupi networks a small network run by Mr. Khan was identified. The network office was located in the outskirts of the city. Despite repeated requests and meetings with the network head to arrange for the respondents and their families at the centre response received was of disinterest. We had no information about the respondents or their place of residence. We therefore selected two most populated commercial hubs of the city Transport Nagar and Rail Bazaar as a representative of the community views in Kanpur.

4.2.2.1 Transect Walk Findings - Transport Nagar

It is a densely populated area having a population of nearly 50,000. The area is crowded by transport carriers, packers & movers, transport companies and agencies. People are employed in transport related professions like driver, cleaner, mechanic and small shop-keeper undertaking re-treading & repairs, tyre maintenance, welding and fabrication. These persons live and work in Transport Nagar. The other residents of Transport Nagar are involved in various occupations related to food and vegetables, wood craft, leather processing etc. There is a mix of religions in the community - Hindus, Muslims and Sikhs.

Cleanliness is not upto the mark and there is no proper drainage system. There are power shortages throughout the year - TV watching takes place in the evening when there is power. We observed very few clinics and there was no good hospital. The basic education in Transport Nagar is good but women were not even seen outside on the streets as they were mainly confined to their homes.

4.2.2.2 Transect Walk Findings - Rail Bazaar

The area has different kinds of shops ranging from grocery, spices, soaps and detergents, pan bidi shops to courier agencies. It also has few small hotels and medicine shops. It is a busy commercial area of the city. The area is very crowded due to rickshaws and narrow roads. It is not clean and unhygienic food was sold openly. There is a problem of load shedding.

There were no health facilities except for few private nursing homes. Education level is high with large number of graduates manning the shops.

During casual conversation with people on the streets they mentioned that they do not believe in gender discrimination and consider women to be equal to them but there were no women seen in the market place.

4.2.3 Udupi Town – Areas of High HIV Prevalence

The areas chosen for transect walks in Udupi are Kundapura and Shankarpura – Kundapura is in the central part of the town representing the commercial area whereas Shankarpura is on the outskirts which is representative of the locations. Some of the positive persons who are members of the network come from these places.

4.2.3.1 Transect Walk Findings - Kundapura

There is a central market place near the bus stop; all kinds of shops are available in the market. There are two government hospitals with all facilities like casualty services, post mortem, cardiac etc. There are six private hospitals and nursing homes. Kundapura has around 10 schools providing education till secondary medium and one college (Mahatma Gandhi Memorial College) for graduate and post graduate studies.

The area has 4-5 temples, 2 churches and 2 Mosques. People like to visit these places in the evenings and on holidays. Two to three playgrounds are also available apart from the college and school playgrounds. The main profession of the people of Kundapura is farming of rice, coconuts, and flowers, and processing of all these things. People do not prefer to go outside to large cities for work; instead they are engaged in farming and allied activities with in 35-40 km from the town. It is a small town so everybody knows each other and prefers to meet in their homes, parks or on street.

Drainage systems exist, creating a clean environment, less power problems and no water problems in the area. Hawkers generally cover food items by glass or cloth, therefore cleanliness is maintained while selling food items. There are many shops available for medicine. Apart from farming the people who are less educated work as labourers, Bus conductors/drivers, Rickshaw and taxi drivers. Unemployment is low.

4.2.3.2 Transect Walk Findings - Shankarpura

Shankarpur is also a small town; only one main market exists, where all kind of shops are available, including grocery, footwear, medical and barber's shop, etc. There is one government hospital with all facilities like a pathology lab, ICU and casualty ward. There are 5 private hospitals and nursing homes. There are 2 schools with secondary education. College education is available in Udupi or Kundapura. No mosque is observed in this area, although two temples and two churches are available for worship.

There is no play ground available for the community; children usually play in front of their house or in their schools. The main occupation of people is farming and business of Jasmine flower, which is transported to all over India. The community is engaged in farming or transportation of Jasmine flowers.

People meet each other at temples or at churches over weekends. People are more religious and God fearing. People also believe in plantations which is the most important reason for keeping this place green in every season.

Not many hawkers are observed in this area. Food items are kept in glass cup-boards, No dry or wet garbage was observed. Power and water supply is now better than before. There are two medical shops. Informal gathering of people is not observed in this area. Some people told us that they do gather for playing cards but very rarely. Instead are busy in doing their individual work.

One organisation named JAYCEE, regularly organises blood donation camps, free eye treatment, AIDS awareness campaign etc. in this area. Recently one more organisation named ICYM (Indian Catholic Youth Movement) has also come in to picture and does all above mentioned activities.

SECTION 4.3: COMMUNITY INTERVIEWS UNDERTAKEN

Community Interviews were undertaken in different SEC categories. The areas chosen were predominantly SEC C or lower therefore more interviews have been conducted with the SEC C.

SEC Category	Number of Interviews in three locations
A	4
B	2
C	11
Total	17

Table: Details of Age and Occupation of the Respondents

Respondent Occupation	Age (Years)	Socio Economic Class (Based on Education and Occupation)	Location of Research
Gynaecologist	34	A1	Waluj
Students from Rajeshree Shahu College (3)	21	A2	Waluj
Vice President Youth Congress	44	A2	Mukundwadi
Students (3)	21	A2	Transport Nagar
Civic Authority	35	B1	Shankarpura
College Students (3)	21	B2	Kundapura
Barber	36	C2	Waluj
Vegetable Vendor	51	C2	Mukundwadi
Pan Bidi Shop	26	C2	Mukundwadi
Dhobi	32	C2	Transport Nagar
Vegetable Vendor	28	C2	Transport Nagar
Transport Company Employee	31	C2	Transport Nagar
Barber	36	C2	Rail Bazaar
Owner of pan bidi shop	34	C2	Rail Bazaar
Vegetable Vendor	36	C2	Kundapura
Barber	20	C2	Kundapura
Pan Bidi Vendor	32	C2	Shankarpura

SECTION 4.4: COMMUNITY INTERVIEWS – INFORMATION AREAS

The respondents were approached by the researcher and requested to provide some time for discussion regarding some community problems. They were probed on their awareness, perception (fear, blame, shame, judgement) and enacted stigma towards HIV/AIDS. They were also asked whether they personally knew of someone with the infection.

SECTION 4.5: FINDINGS - AWARENESS OF CAUSE

Most Dominant Source Mentioned is Unsafe Sex With Multiple Partners Outside Marriage..

[This infection] Happens through unsafe sex with different women, ***Owner of pan bidi shop, Aurangabad, SEC C***

It happens by frequently visiting other women, ***Pan Bidi Vendor, Udupi, SEC C***

Occurs due to unsafe sex with several women, transmitted through sex only, ***Vegetable Vendor, Aurangabad, SEC C***

HIV happens 90% due to sex and only 10% due to other reasons, ***Barber, Udupi, SEC C***

Occurs due to prostitution mainly "Our profession is the most affected by it. Because due to nature of our work we do not get married easily, and go to prostitutes whenever we are travelling. "Earlier 5 years ago very few people were using condoms and because of this behaviour it has spread" ***Transport Company Employee, Kanpur, SEC C***

It is a harmful and incurable disease [which] occurs through prostitution only, ***Youth Congress President, Aurangabad, SEC A***

HIV can happen to anyone through blood transfusion and sex, Prostitutes are responsible for the spread of this disease, ***Students, Udupi, SEC A***

HIV happens through sex but it can be protected by using condom, AIDS is a disease like cancer, the way cancer can happen to anyone even AIDS can happen to anyone, ***Civic Authority, Udupi***

Transmitted by Blood is the next highest mentioned source..

HIV is caused through blood transfusion, syringe etc. ***Vegetable Vendor, Udupi, SEC C***

I am aware of HIV that it happens and transmitted through sex and blood and Blades, Vendor Syringe etc. ***Vegetable Vendor, Kanpur, SEC C***

Incurable disease transmitted through blood, person dies early, ***Barber, Aurangabad, SEC C***

Also Drugs have been mentioned …

It is a "mahamari" which comes from Sex or blood and whoever takes drugs. ***Dhobi, Kanpur, SEC C***

Students have also mentioned mother to child as a source …

It happens through unsafe sex, injection syringe or through HIV + mothers, ***Group of 3 Students from Rajeshree Shahu College, Aurangabad, SEC A***

We are aware of HIV and also know about the routes of infection. We are also aware about the precautions to be taken – condom usage, ***Students, Kanpur, SEC A***

Visits by truckers also results in spread of disease..

Only 10% of pregnant women come for regular check ups, they are advised to have HIV checks. No one interested in HIV awareness programs, Number of HIV cases increasing due to truckers visiting this industrial area, ***Gynaecologist, Aurangabad, SEC A***

The majority of the lower SEC class was aware of only spread of disease through unsafe sex. Local petty traders like pan bidi shop owners and vegetable vendors are aware about the routes of the infection as unsafe sex and through blood. The barber was aware of the transmission through blood. Due to the nature of his job, the barber is more conscious of the route being transmission through blood. He is very scared of the infected person as he thinks it has a direct link with his profession as he is touching the patient.

In case of the middle SEC classes more routes of transmission were known.

The gynaecologist explained that pregnant women are not interested to know much about HIV awareness. This implies that the general population considers themselves to be safe from the disease – it is considered to infect those who are immoral and indulge in bad practices.

The community finds it easy to talk about HIV/AIDS as the awareness generation about HIV/AIDS has been taken up by mass media and also local media channels extensively. Community is aware about the causes of the infection but sensitization regarding the infection happening to them or their families and their role has never occurred to them. They feel that HIV/AIDS is something which can happen only to those who are in the company of sex workers.

Community in Udupi was however sensitive towards its prevention. They have a normal view about the infection and believe that it can happen to anybody and there is nothing very abnormal about acquiring this disease.

The Awareness level indicator about modes of transmission of HIV AIDS (% of people in community aware) is relevant and should be measured for all the three locations.

SECTION 4.6: FEAR

Fear of Staying in Same locality……HIV + people should not be allowed to stay in the community…Fear of even talking and touching…..They should make their positive condition public so that they can be avoided..

They should be kept outside the village; they should not be allowed to keep the disease private. I do not know of any such person nor would I like to support any one who has this disease, ***Owner of pan bidi shop, Aurangabad, SEC C***

Person infected should be kept away to prevent spread of disease, they should not be allowed to use the common facility of the community, Can work with them but would not like to be with the person constantly, ***Vegetable Vendor, Aurangabad, SEC C***

Am afraid of such person spreading the disease, everyone in the society should know about him so that he can be avoided. If anyone comes to know of such a person in our community we will definitely alert everyone about him. Even if my best childhood friend has this disease and I come to know of it I will break my friendship with him and not even talk to him. I will even go near such a person leave alone eating food with him, ***Barber, Aurangabad, SEC C***

I have seen on TV that it is not communicable disease by talking, or hand shake. ***Dhobi, Kanpur, SEC C***

We should be careful not to be infected by them but they need not be thrown out, PLHA themselves should stay away from common places, I will not keep the person at my house but will arrange to admit him or her to a hospital, ***Youth Congress President, Aurangabad, SEC A***

They should take care not to spread the disease, the infected person generally visits the doctor who then informs the relative who inform everyone else and that is how the information about a person becomes known. We however are not aware of any such person. Names of PLHAs should be published so that other people can avoid them but they can be allowed to stay in the society, we will support them, ***Group of 3 Students, Aurangabad, SEC A***

Fear of spread through sources not yet known….

I feel sorry for them but I am not ready to accept HIV+ people in my daily and normal life due to fear "I know how it spreads, but we humans have not discovered many things about HIV, We do not have a cure till date, and also we do not know many ways how it can be communicated?" "What will happen if a HIV positive person, while cutting vegetables cut his hand too?" Will it not be a way to communicate the disease whoever will eat that food?" What will happen if any HIV positive child while playing with our child bites in anger?" "We can not trust the precautions told by TV, they tell us very few precautions it only shows that there are other ways too?" ***Owner of pan bidi shop, Kanpur, SEC C***

Fear of using same utensils and washing clothes together….

I think that their utensils should be kept separate, ***Pan Bidi Vendor, Udupi, SEC C***

If it happens to my relative, I will take care of him but keep their utensils and clothes separate. ***Pan Bidi Vendor, Udupi, SEC C***

Fear of spread through cuts…..

I am afraid of HIV as it is a threat to my profession. ***Barber, Kanpur, SEC C***

Eating food cooked by HIV + people or sharing food….

We have no problem in eating from their hands, ***Students, Udupi, SEC A***

I do not hate people as it is not a communicable disease , I have read that from newspapers and by watching TV.I know that it cannot be spread due to handshake, sneezing, eating together etc. I know that there is no vaccine available for HIV till date. ***Transport Company Employee, Kanpur, SEC B***

All the three locations were found to be at different levels of fear.

In Aurangabad there was fear of casual physical contact observed among all the respondents. They were afraid of talking or even staying with the person in the same house. The social fabric is woven around regular communication within the neighbours and family and also of the family staying together. In the context of this society therefore even talking and staying together have emerged as probable causes of spread of disease.

The vegetable vendor is of the opinion that such a person should not be allowed to use the common facility. His view has been strengthened by a case which he is aware of where the person died without getting any support from his family. The vegetable vendor also feels that sharing food with such a person is possible but it is not possible to stay with the person implying that if it happens to any one from his family he will have to stay separately. Community leaders too are of the view that the person should be kept away from the community but can be supported for the treatment. The barber would like to stay away from such a person even if he is a close childhood friend. He does not want to have any relations with such a person and would like that the person lives in complete isolation.

Except in case of students who may want to sound philanthropic the general view was of extreme isolation of the infected person – he should be debarred from work and any public place. Fear more than shame or anger is the main reason to stay away from the person.

Kanpur was a case in learning of how excessive awareness generates more curiosity and more fear. Media has generated awareness about the disease as being non communicable through touch and other close physical contact. The general community is aware of the same. But the community is already apprehensive whether these are the only routes or that there could be some more which have yet not been discovered like cutting of hand while cooking food, an HIV positive child biting another child or sneezing by an HIV positive person. Fear is fuelling the stigma.

Willingness to consider the infected persons to be a part of their current lives is non existent. It is a disease which happens to either those who visit sex workers or to the weak and poor people of society – since it cannot happen to them or their family they cannot envisage a situation where they would be sharing their home or food or even a conversation with an HIV positive person.

In Udupi, though there is no fear that the community has regarding physical contact with the infected person, in fact they are willing to accept them as part of their households too but they would like to practice prevention by keeping utensils and clothes separate. Awareness about the routes of the infection exists in the community and it is a conscious and well understood awareness rather than a media generated superficial awareness which existed.

The community is able to consider the infection as a normal one similar to cancer so there is no fear about the spread of the infection due to casual physical contact. They were however inclined towards taking precautionary measures as they normally would for any other disease. They were not fearful of the infected person staying in the same house as them; on the contrary they believed that the infected person required shelter and would be able to lead a better life if he/she can stay with the family. They also held the view that "A PLHA would be able to live longer if given shelter and support by family."

4.6.1 Indicators of Fear

On the basis of the findings of the three research locations the set of fear indicators that has emerged is:

- Talk to a person with HIV AIDS
- Stay in the same house with a person having HIV AIDS
- Sit next to someone who is showing signs of AIDS
- Touch a person living with HIV or AIDS
- Eat food prepared by a person living with HIV or AIDS
- Care for a person living with HIV or AIDS
- Child playing with child who has HIV or AIDS
- Cutting of hand while cooking food
- An HIV positive child biting another child
- Sneezing by an HIV positive person
- Sleeping in same room as someone who has HIV or AIDS
- Sharing toilet with a person living with HIV or AIDS
- Sharing eating utensils with PLHA
- Sleeping in same bed with someone who has HIV or AIDS
- Wash clothes with those of PLHA

SECTION 4.7: BLAME

Person suffering from AIDS has himself to blame….he is immoral…

I totally blame the person who is affected with HIV because after repeated announcements on TV still people go to wrong places which is incorrect, The person infected is fully responsible for this, ***Owner of pan bidi shop, Aurangabad, SEC C***

I feel angry towards them as they are bad people, they should feel ashamed, ***Barber, Aurangabad, SEC C***

I am angry at the HIV infected persons and hate them because by mistake if some customer comes to know that I have cut hair or shaved an HIV person nobody will visit my shop. "What if somebody walking in my shop for shaving has HIV, I will never came to know" that's why I usually wash everything with antiseptic water and have stopped using traditional blade (Sutras)", I can not ask my customers whether they have HIV, ***Barber, Kanpur, SEC C***

It is not punishment of God, People should not involve in unsafe sex but sometimes it does happen, Maybe they do not get it at home, ***Vegetable Vendor, Aurangabad, SEC C***

Commercial Sex Workers – In other words, it is the women who are to be blamed..

Women get this because they are prostitutes; they spread this disease, ***Owner of pan bidi shop, Aurangabad, SEC C***

It occurs through prostitution only, ***Youth Congress President, Aurangabad, SEC A***

I feel angry towards the person because he has done a very wrong thing by going to outside females, ***Vegetable Vendor, Aurangabad, SEC C***

The person infected should be provided with proper health care and medicine. I feel sorry for HIV Positive people, because they will die soon. The sex workers are to be blamed for spreading the disease in Kanpur. The business of sex has increased in last 10 years which is the major reason for spreading this disease. ***Vegetable Vendor, Kanpur, SEC C***

A fatalistic attitude prevails…

The disease happens because it is destined to happen. ("Karmo ka phal") and why should any one else pay for that. ***Barber, Kanpur, SEC C***

There is empathy is some quarters.. even for women suffering from HIV..

I feel sorry for them and would like to help them go and seek medication, ***Youth Congress President, Aurangabad, SEC A***

I feel sorry for person infected with HIV AIDS, ***Group of 3 Students, Aurangabad, SEC A***

We feel empathy for the infected people but have a lurking a fear from our family, "What would they think if they will see us along with an infected person or talking about AIDS" It is not a respectable topic for discussing in open at least in front of family members and known people. ***Students, Aurangabad, SEC A***

The husbands of positive women are to be blamed for their condition - female HIV+ should have reservation in some kind of professions so that they can have financial support. ***Students, Aurangabad, SEC A***

There were differences with respect to the blame stigma. Whereas community in Aurangabad blamed the infected person for his misdeeds, in Kanpur they preferred to take a neutral stand and in Udupi they did not harbour any such feelings. They had no negative emotion of blame towards the infected persons.

Community in Aurangabad has a strong perception of the link of the spread of HIV with visits to prostitutes and immoral behaviour of the infected persons. These are considered to be a taboo behaviour for a married person. These are very relevant indicators for the community level perception about the infected person. Everyone in the community except community leaders who tend to speak politically correct statements blame the infected person for their immoral behaviour and feel anger towards them.

In Kanpur the community has a fatalistic attitude towards the infection perceiving it to be the result of ones bad deeds. However, their empathy also stemmed from the perception that they too considered that HIV is a disease of the poor and weaker sections and as responsible citizens they should extend a helping hand. They were willing to discuss the subject with their peers and outsiders but lacked the courage to talk about it in front of their family members. There is a wide gap between action and words which needs to be bridged through appropriate intervention programs as it is these students who can be messengers of change in the family and society. The peer education program can be an effective intervention.

Pointing Source to be Women…

An underlying blame which can be discerned is the belief that women as sex workers are to be blamed for the spread of infection to men. There is a definite school of thought in the community that men going to prostitutes are not abnormal but it is the existence of these kinds of women and increase in their numbers which is really responsible for the spread of the disease. The source of the disease is being attributed to women. Using the same analogy even when women in the general population are infected by their husband's community would have a tendency to believe vice versa and may suspect the woman to be a loose character equating her to a sex worker.

4.7.1 Blame Indicators

- The HIV positive person has himself to blame as he/she indulged in a wrong act
- Women are the main perpetrators of the disease
- Not blaming the HIV positive people and feeling sorry for their condition
- People with HIV are promiscuous
- Percent of people who blame persons living with HIV/AIDS for their illness.

SECTION 4.8: SHAME

HIV +ve people should be ashamed of themselves….

People with HIV AIDS should be ashamed of themselves, ***Vegetable Vendor, Aurangabad , SEC C***

Evil minded people get this disease, their thoughts are dirty, they should be ashamed of themselves, ***Youth Congress President, Aurangabad, SEC A***

They should be ashamed of themselves; they are to blame for it themselves not the family, ***Group of 3 Students, Aurangabad, SEC A***

It is shameful to be associated with such people

It will be shameful for me to support such a person, ***Owner of pan bidi shop, Aurangabad, SEC C***

HIV +ve people should not be looked down upon… we should behave properly with them…

If we treat the AIDS person properly there would be no problem but if we insult them, there would be a problem. We can increase their life with good behaviour, if their life is 5 years we can increase it to 10 years. ***Civic Authority, Aurangabad, SEC A***

In Aurangabad, the community associates shame with the HIV infected person. Shame of being associated with an HIV infected person has also emerged as one of the major considerations of the community as they consider the person to be immoral. They were willing to break their friendship with a childhood friend if he had the infection. No sympathy exists currently except from students who may feel that in any case it would not impact them directly. Not many people were aware of infected persons. HIV is not spoken about publicly; only one person was aware of a case. Community was of the view that HIV persons should be kept isolated and not be allowed to work or participate in any community functions. This is an important indicator as the social processes of an individual and his family involve the community.

4.8.1 Shame Indicators

- Percent of people who would feel shame if they associated with a PLHA
- I would be ashamed if someone in my family had HIV/AIDS
- People with HIV should be ashamed of themselves

- People with HIV deserve sympathy
- Percent of people who are aware of any one who has the infection
- People with HIV/AIDS should be allowed to fully participate in social events in our community.

SECTION 4.9: JUDGEMENT

PLHA is dirty..

The PLHA are not physically dirty but their thoughts are dirty, the act is dirty, ***Group of 3 Students, SEC A***

An existing PLHA does not have the right to transfer it to others even his own spouse...

PLHA is an unfaithful person, We should keep away the HIV infected person for acting immorally, If a person is affected he should not transfer it to his spouse but the spouse should take care of him ***Owner of pan bidi shop, Aurangabad, SEC C***

PLHAs do not have the right to be employed anywhere...

The HIV person should make his status known or else others will also get infected, they should not be employed for any job because they will fall sick frequently, they can do some small jobs to live. ***Pan Bidi Vendor, Udupi, SEC C***

No one should have relations with such a person, they should not be allowed to work nothing should be shared with them, ***Barber, Aurangabad, SEC C***

PLHAs belong to economically weak sections...

It happens to only economic weaker or poor people. ***Students, Kanpur, SEC A***

In Aurangabad there is a strong judgement against the PLHA – he is a dirty person and therefore should be kept away from society.

In Kanpur, too the view is that it happens only to bad people. This further perpetrates the hypothesis that the open mindedness among the community is only at a surface level, more of a topic for discussion of some information gathered from watching TV rather than actual belief. The barber considers HIV to be a result of the bad deeds of a person. The views of the barber encapsulate the community views well – as long as it is a disease which has no impact on their family or themselves as they are comfortable to talk about it and also mention having sympathy for the AIDS victims. The moment HIV/AIDS has a direct impact on their lives they would like to stay away from the infected persons and start condemning them.

Since an infected person is of a bad character and also there is fear about transmission of the infection all the community members were of the view that they should be isolated. The pan bidi shop owner is of the view that the PLHA should not be allowed to mix with society. He is also not sympathetic towards him in terms of having relations with his spouse which implies that there does not exist any negative

feelings towards any woman about making her life difficult without any reason. Students consider HIV/AIDS to be an outcome of a dirty act. However they do not feel that the infected persons should be isolated from the society, it is enough to keep them at a distance. They have voiced their support for the infected.

However an opposing view prevails in Udupi - The community is of the view that the person should be taken care of by his family and given a shelter at home. This would help him to live longer. He should not be isolated.

All is fair in Love and Blame.....

Community also holds the view that ideally if a person is aware that he is infected he does not have the right to pass it on to his spouse and infect her. However this does not seem to be practiced – even when a man is diagnosed with the infection and by the time since his spouse has also got infected. The blame squarely falls on her rather than the man himself. Idealism is professed but seldom practiced particularly when it comes to women. Community also held the view that a woman has no life of her own– as long as he is alive she needs to look after him and serve him even if it means getting herself infected.

4.9.1 Judgement Indicators

- PLHA are dirty
- PLHA have dirty thoughts
- No one should have relations with HIV infected persons
- An HIV infected person is an object of ridicule
- An HIV infected person should be asked to stay away from his family and society
- An HIV infected person should be abandoned even by his spouse
- If a woman gets infected by her husband she should not abandon him but take care of him
- HIV is a disease of poor people.
- An HIV positive person deserves no respect in society

4.9.2 Disclosure Indicators

- If you personally found out that you were HIV positive would you tell anyone? If No or Don't know, why not?
- If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret or should this information be available to the community?
- If a member of your family contracted HIV/AIDS, would you want it to remain a secret?
- If a member of your family got infected with HIV and was not showing signs of AIDS, would you advise them to disclose their status in the community?

Disclosure is necessary for prevention of others… and also himself…

HIV people should inform others about their status when they come for a shave. There is no need to keep the HIV people separate, ***Vegetable Vendor,Udupi,SEC C***

PLHA should disclose status so that they may seek healthcare, ***Youth Congress, Aurangabad, Sec A***

We should not separate them from the society; in fact we should provide them with medicines. We should not provide them with any identity card etc. other wise they would think that they are not normal, ***Students, Udupi, SEC A***

Disclosure is a need state which has emerged in the community interviews at Udupi, Community prefers that the infected person should disclose his status so that he may be able to get proper treatment and care and also others can exercise the necessary precaution. Indicators on disclosure can be tested for their strength.

SECTION 4.10: ENACTED STIGMA

Some known positive cases were mentioned in passing during the conversation…

I know of one of the vegetable vendors in the main central market who had AIDS and he lost all his customers and had to close his shop. His wife and family left him because of which he got admitted in the Govt. Hospital and died later. None of his family members went to claim his body from the hospital, even police did not help, ultimately very few community people went and cremated his body. ***Vegetable Vendor, Aurangabad, SEC C***

The disease is still not discussed openly. Level of disclosure of the disease is very low. In Aurangabad only in one case there was some information about enacted stigma. In Kanpur, none of the community members were aware of any one who had HIV/AIDS in their immediate neighbourhood or family or place of work. They were not able to describe any kind of enacted stigma that they had witnessed. However they themselves were of the opinion that these persons should be avoided as it is neither good nor safe to be with them. They are therefore more or less hinting towards isolating the infected people from mainstream society.

The Udupi community was open about discussing HIV/AIDS and level of disclosure about the infection was also high unlike Kanpur and Aurangabad wherein it was neither discussed nor disclosed publicly. Disclosure leads to enacted stigma. Though the community may be open-minded about the participation of the infected person in the community activities and consider him/her to be normal, it would still be worth measuring the extent of such belief and the strength of the enacted stigma indicators.

4.10.1 Enacted Stigma Indicators

Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS?

- Lost customers to buy his/her produce/goods or lost a job.
- Abandoned by spouse/partner.

- Abandoned by family/sent away to the village.
- Lost respect/standing within the family and/or community.
- Given poor health services
- Teased or sworn at
- Visited less or no longer

SECTION 4.11: SUMMARY OF FINDINGS OF THE THREE RESEARCH LOCATIONS

The three research locations represent a complete spectrum in terms of demographic, awareness, fear and blame, shame and judgement related stigma.

PARAMETERS	AURANGABAD	KANPUR	UDUPI
Economy	Thriving industries (MNCs like Skoda, Colgate, Videocon etc.) Tourism Industry Growing	Industries dead Acute Power shortage Only Masala industries thriving	Agriculture Floriculture Selling farm produce
Unemployment	15-20%	> 20%	<10%
Religions In poor areas	Hindus and Muslims mix – 70% Hindus	Predominantly Muslims in poor pockets	Hindus and Christians
Education level In Community	73%	69%	80%
Community Hygiene and Cleanliness	Low	Very Low	High
General Medical facilities	Sufficient	Less	Sufficient
Women's Status	Respected, free to move outside house	Physically tortured Confined inside house	Earning member Has Power in family
Awareness of known Cases of HIV	Low	Low	High
Fear	High	High	Low
Stigma	Disgust, Shame Dirty	Blame	Prevention
Isolation	Yes	Yes	No

These indicators that have been identified have been further validated through focus group discussions with the community for their inclusion in the base line research.

Section 5

Stigma Indicators: Community Level

SECTION 5.1: COMMUNITY FGDs

Six focus groups were held in each of the three locations. The groups represented different socio economic classes. One group each was conducted for males and female for SEC B, SEC C and SEC D.

Location	Male Groups	Female Groups
Aurangabad	3 (SEC B, C, D)	3 (SEC B, C, D)
Kanpur	3 (SEC B, C, D)	3 (SEC B, C, D)
Udupi	3 (SEC B, C, D)	3 (SEC B, C, D)

Each group comprised of 8-10 respondents. The respondents were selected from the same areas where the community transect walks had been conducted.

Criteria for selection of respondents

- Age 24-35 Years
- Occupation
- Industrial Worker
- Serviceman in Private, Public and Govt. Sector
- Supervisors
- Teachers
- Petty Trader/Small Shop Owners
- Mechanics
- Paan-Bidi Wala and other such occupations depending on the local region.

Total Number of Respondents met with in Community during Transect walks and FGD stages:

SEC Category	Transact Walk Number of interviews in three locations each	FGDs Number of interviews in three locations each	Total
SEC-A	4	None	4
SEC-B	2	45	46
SEC-C	11	44	55
SEC-D	None	46	46
TOTAL	**17**	**135**	**151**

5.1.1 Probe Areas for Community Groups

The main purpose of the focus group discussions was to validate the indicators which had been identified during community interviews in the transect walks. Identification of new indicators was also sought. In a focus group situation the community may be able to elicit more views as they feel free to discuss matters openly which otherwise are taboo. Feedback and opinion on health communication messages in the media and most preferred media was also gathered. (See Annexure for Discussion Guideline and Profiles of participants).

SECTION 5.2: AWARENESS ABOUT HIV AIDS - Findings

Community Groups - SEC B

Community interviews during the transect walks with teachers, students and doctors pointed at the causes of the infection as unsafe sex, use of infected syringe and from mother to child. In a group situation, however, respondents were also able to describe the probable path of infection – as one of the female respondents in Kanpur and another one in Udupi mentioned that it is contracted when people go to larger cities for work like Delhi and Mumbai.

Respondents were not only able to tell the causes of the infection but were also able to describe the symptoms; the stage at which HIV turns into AIDS and were also conjecturing upon how long a person can survive after getting infected. There was confusion about the life span of an infected person – it ranged from 20 years in Udupi to 10 years in Kanpur.

Community in the higher socio economic classes is aware about the routes of infection but would like more information on the likelihood of longer life, difference between different stages of HIV AIDS and symptoms. As awareness about these aspects increases – the fear towards the diseases may start abetting. These awareness indicators should be monitored for change.

SEC B - Kanpur

Unsafe sex, Blood, An urban phenomenon now infiltrating the rural areas…

It happens through unsafe sex, using needles, etc **SEC B, Male, Kanpur**

If someone is given blood and the person who gives the blood suffers from AIDS, the one who receives will also get infected. If anyone has sexual relations with a person suffering from AIDS he will also get infected I have not seen it but heard that when people go to the city for work they have relations with sex workers from where they get affected .. . We can also get it of a needle from an infected person is used **SEC B, Female, Kanpur**

When the body loses the capacity to fight diseases it is AIDS, it cannot be cured. You come to know after 10-12 years that you have been infected but if a person is positive he can still survive for a long period **SEC B, Female, Kanpur**

SEC B - Udupi

Symptoms are fever, no cure, but a person is able to live…

We have seen many patients also who are suffering from this. Many patients have died also. And this AIDS has become very common know that it is something like a fever. They tell that disease is got by multiple sex and if we are not able to avoid this then we have to use Condom for keeping it away from us. No medicine for HIV… **SEC B, Male, Udupi**

First fever will come. It will go and come again and again. Mainly they will feel cold. Loose motions. An HIV person can survive for 20 years. The virus lives inside him… Before 6 months of their death they will become very weak and they will have to catch the bed. No if it is HIV positive all this will not happen, once it will change into AIDS then no medicine will work on them. I was getting fever twice or thrice so when I had been to Doctor he asked me to take HIV test and when I did the report was negative. **SEC B, Male, Udupi**

We should not have sex with other men except our husbands… HIV means the starting stage and AIDS means it is the disease. **SEC B, Female, Udupi**

SEC B - Aurangabad

All sources mentioned …

The mediums through which Aids get transmitted are increased sexual relationship, taking drugs and sharing syringes and unsafe blood transfer. **SEC B, Male, Aurangabad**

It is a dangerous disease because there is no treatment for this disease and the ultimate end is death. The virus of AIDS is present in the blood and can be transmitted by blood transfusion from Mother to Child, Due to sexual relationships and through infected injections **SEC B, Female, Aurangabad**

Innocence at Peril?

The belief is that HIV happens due to multiple sex partners, particularly from sex workers in the city, therefore indirectly it is the woman who is the root cause. Udupi wives and girls were quick to mention that they should avoid having sex with anyone other than their husbands to avoid the disease. Husbands are always considered innocent by wives.

Community Groups - SEC C

It was observed that in the group situation, people generally like to show off their knowledge levels – in a city like Kanpur which had been tight-lipped about being even aware of the disease at the time of the transect walks during groups they felt free to talk as it was not so much of a taboo considering others were also freely talking. They not only were able to describe the routes of infection but were also able to mention that it reduces the immunity of the body and wounds take longer to heal. (Expressed both in Kanpur and Aurangabad).

Community is aware but would like to move to the next level of impact of the disease on the body system.

SEC C - Kanpur

Wrong sex, needle..

AIDS reduces the immunity of the body, if there is a wound it heals after a long time, it happens if you do wrong sex, or through an infected needle or through the barber's shop **SEC C, Male, Kanpur**

It can happen through infected needle or infected blood or from mother to child or by wrong sexual relations **SEC C, Female, Kanpur**

SEC C - Udupi

Sex with multiple females..

It will happen when we will have sexual relations with many females we will get it. It could come from shaving blade. From injections also we can get it. The virus will increase in the blood and it will make the person weak. It has no treatment. **SEC C, Male, Udupi**

It will spoil the life. It will be caused if men have connections with other ladies they will get it. It will come from syringe and blood also. It is a bad disease. It is not treatable with medicine. It comes mostly from Bombay. **SEC C, Female, Udupi**

SEC C – Aurangabad

Wrong things outside home..

It is a disease that has no medicine for making the person recover from it. If the person makes wrong things outside of home then he is affected - otherwise not. The different medium of AIDS transmission are Injection (infected ones used without being cautious), Visiting prostitutes, Increase in sexual relationships and Blood transfer. **SEC C, Male, Aurangabad**

Through infected injections, from mother to the child, and by sexual relationship may be even through mosquitoes the wound of the HIV patient does not recover soon. Their wound goes on increasing...**SEC C, Female, Aurangabad**

Community Groups - SEC D

In case of the lower SECs unsafe sex emerged as the most associated with the disease during the transect walk stage, however, during the focus groups their concern for there being no treatment for the disease and it being life threatening was most pronounced. In Kanpur, although people had denied knowing any AIDS cases during the transect walk interviews, when in a group situation they were also citing cases which they had heard of – this too among females. In fact, in all the three research locations across the lower SECs in each group someone recounted a close relative, friend or a neighbour having suffered from this disease and died. This was also the case in female groups – in fact females in Udupi were apprehensive of marriage – they mentioned that the trend of getting blood of both boy and girl tested before marriage has started picking up.

Community in the lower SECs viewed itself most prone to the disease and were keen to find out ways in which to protect itself. They felt the need for detailed information on prevention and available treatment.

SEC D - Kanpur

Wrong sex…

This is a life threatening disease, I am scared of this disease, it happens due to wrong sexual relations. Also through infected blood. There is no disease which is as dangerous as this one. **SEC D, Male, Kanpur**

I came to know from TV that AIDS is a life threatening disease, it has no cure, it has happened to many people also, I have heard about it but not seen anybody as yet **SEC D, Female, Kanpur**

It happens by using infected blood or by having sexual relations with other people but it cannot spread by talking or sitting with the infected person **SEC D, Female, Kanpur**

SEC D – Udupi

Symptoms are weakness fever, cough..

They will get fever and cough. It will not get cured soon. They will become weak. I had seen one person who had this disease and he died and that was passed on to his son who was studying in 8th Std. If ones blood is given to other person this disease will spread. They will get to know after 6 months of blood transmission. I feel that even when we use condom also we will get this disease. There are treatments for it but that is only to enhance our life but death is definite in this disease.

SEC D, Male, Udupi

They tell us in TV and radio that in Karnataka AIDS has been spread more and we have to be protective. Every month we will have meeting in our trust and so they give us information about this disease and other diseases also. Earlier they were telling when they go to Bombay they will get but now it has been increased in Kundapura. And before marriage they have to check blood of both girl and boy. We feel that we should not marry at all. **SEC D, Female, Udupi**

SEC D - Aurangabad

There is no cure…

The problems that are serious in the society are AIDS, Cancer because for AIDS there is no medicine and the affected person finally dies. It damages the immune system of the body. It also detains the capacity of RBC and WBC corpuscles. **SEC D, Male, Aurangabad**

From mother to the child, through sexual relations and through infected injections… no correct and complete information has been given as to how it spreads **SEC D, Female, Aurangabad**

Awareness Indicators To be Tested:

1) Routes of Transmission
2) Difference between HIV and AIDS
3) Impact on body system – reduced immunity and weakness
4) Life expectancy after infection
5) Preventive measures
6) Aware of treatment and medicines
7) Number of persons aware of an infected person

SECTION 5.3: SOURCE OF AWARENESS ABOUT HIV AIDS

Community Group – SEC B

In the transect walk stage mass media like TV and newspapers had been cited as the main source of awareness. During the groups however, a detailed probe on the source of awareness also resulted in description of communication messages liked. In Kanpur awareness has been generated through serials like Jasoos Vijay and mainstream ads depicting celebrities – though an ad depicting an elder brother explaining the younger brother has been liked more. In Udupi, the community has been receptive to awareness programs by the youth and in schools. They were also aware of VCTC centres. In Aurangabad it has mainly been the ads in the TV, newspapers and hoardings.

Community is more open to getting needful information from family like situations shown in serials and ads and also one to one meetings. In Udupi the absence of such interventions has been felt and in Aurangabad, where the level of interest and awareness generated is only of a basic level, it has not yet touched an emotional chord with the community for them to act on.

Preferred media for receiving messages needs to be checked.

SEC B – Kanpur

Family settings preferred..

Ifran Pathan, Dhoni, Amitabh, plays on Doordarshan all are informing about AIDS, there are banners also. I really liked the ad about the brother explaining to his younger brother that there is no shame in explaining. **SEC B, Male, Kanpur**

We watch TV – they tell us that if we have wrong sexual relations or get infected blood from somebody we will get infected **SEC B, Female, Kanpur**

We read in newspapers that someone has died of AIDS or we come to know from the doctor after a person has died all this information keeps on coming in newspapers. I also get to see all this in Jasoos Vijay on Sundays **SEC B, Female, Kanpur**

SEC B - Udupi

Youth Programs Effective…

In the colleges through students also they gave this awareness. They took some processions. They did this Prabath Beri programme and through Yakshagana also they told about this. They had kept some programmes in Primary schools and High Schools. They do these programmes at bus stops and one person will hear and one will not hear. If the bus comes one will go and till the bus come one will be listening to it …**SEC B, Male, Udupi**

Yes in the TV they say if we come to know that one person has HIV then we should not discriminate him we have to treat him as a normal person. And there is one society called VCTC. They are showing the programmes in which they are telling that a baby will be cured if it has AIDS in mother's womb. In every taluk VCTC trust is there. **SEC B, Female, Udupi**

SEC B – Aurangabad

Celebrities and Local Newspaper preferred..

Television, News, Chatting with friends, paper advertising, banners and hoarding. I like the advertisement presented by Shahrukh Khan, Amitabh B., Sachin Tendulkar and Shabana Azmi. **SEC B, Male, Aurangabad**

It was through advertisements that we came to know that AIDS is not a communicable disease. The first advertisement on AIDS was launched in Newspaper in 1990, and after 1996 it was first time launched on *TV. This awareness should have been created long ago but it is only now that the Government has realised a need for it.* **SEC B, Female, Aurangabad**

Community Group – SEC C

Awareness among the middle SECs not only comes from mass media but also through cases in their vicinity when a person dies or through frequently held health meetings in their neighbourhood, medical camps organized by companies or during hospital visits. In Kanpur community preferred cricketers and also serials and family based ads for obtaining information as these can be viewed sitting with the family without feeling embarrassed.

In Udupi the disease is openly discussed hence an awareness source is not specific, in case of Kanpur serials on the topic are doing the needful and making an emotional connect, however in Aurangabad the disease is still in the domain of public health and also viewed as such – it happens to others not me. More family involving communication themes are needed for connecting with the community.

SEC C - Kanpur

Celebrity, Family Dramas, Known Cases..

Newspaper, TV, magazines all provides information about AIDS. Shabana Azmi is a doctor in an ad, the serial "Apradhi" also informs about it, there are hoardings also, Ifran Pathan and Dhoni say that touching an AIDS patient does not result in the infection; also Virendra Sehwag says that we must not hate the AIDS patients. In another ad the elder brother explains the younger brother about AIDS - this is very good….we can watch these messages with the family without feeling embarrassed… **SEC C, Male, Kanpur**

I know of a woman who has died of AIDS - she was very sick, had fever and was also feeling dizzy. Afterwards I cam to know that she had AIDS **SEC C, Female, Kanpur**

When a person's body becomes weak, there is blood coming out of her tongue, he is suspected of having AIDS. We come to know from the TV about AIDS and how to protect ourselves from AIDS like using condoms, also come to know from Newspapers and small health meetings when the doctor informs us about the disease **SEC C, Female, Kanpur**

SEC C - Udupi

TV, Posters in Hospitals, Local News..

We have seen in the hospitals and on TV also they show and tell about it- that we have to use Nirodh and keep ourselves away from this disease. **SEC C, Male, Udupi**

Through newspapers we read and find out that they have AIDS. Sometimes they put that in Kundapura there are many HIV positive people; I knew 2-3 people but they have died. They were earlier there in Bombay and they came here for some days and that man died. And I know one person they had 4-year-old child and his parents died and now that child is taken care by his aunty.

..**SEC C, Female, Udupi**

TV, Medical Camps..

Television, Newspaper, Medical Camps arranged by various companies. **SEC C, Male, Aurangabad**

TV is the medium of awareness through which I have recd some knowledge, but I do not know what the preventive measures to be taken are. **SEC C, Female, Aurangabad**

Community Group – SEC D

In case of the lower SECs it is not only TV and newspapers but more close actual experiences which provide a source of awareness. In fact the suspicion about AIDS in these strata of the society is so high that even if a person is suffering from some other ailment he is diagnosed as having AIDS which leads to fear and subsequent death. Messages about prevention of spread appeal to them – like Shahrukh Khan informing that AIDS cannot spread by touch and he is shown touching the kids. More than sources of transmission the lower strata is concerned about prevention and medicines.

SEC D - Kanpur

Family Dramas, Local News, Health Workers…

Apart from TV we also discuss AIDS with friends. I have also seen in some serials on TV like Jasoos Vijay. If a person indulged in certain behaviour he contracted AIDS. **SEC D, Male, Kanpur**

It is also reported in newspapers – once a person gets this disease he gets many other diseases, also, I know of a couple who died and their child also died on suffering from AIDS, the husband knew it but he did not tell his wife, he had fever and had got it checked from the doctor but he hid it from his family, everyone who has it hides it **SEC D, Female, Kanpur**

Some health workers had come to our neighbourhood and informed us that for a person who suffers from AIDS – the skin would start peeling and the person would become dark, I know of an unmarried girl who got this disease, she died within six months of knowing about the disease **SEC D, Female, Kanpur**

SEC D – Udupi

TV, Reported Cases in Health facilities…

Through paper we get to know. Word of mouth. And one person was a truck driver and he suddenly became weak and when he had been to Doctor it was said that he must be having AIDS and he left. Then in 2 months he died. And then when we tested him it was told that he had white jaundice. For this person who had come from Mumbai also it was told that as he was staying there he might have got AIDS. **SEC D, Male, Udupi**

Now newly it is Chicken Gunya, Malaria and AIDS about these 3 only they are telling more on the TV. About chicken gunya scientist are finding out medicines that we have hopes but for this AIDS there is no medicine at all. **SEC D, Female, Udupi**

SEC D - Aurangabad

Posters, TV…

Posters seen at the hospital, TV, News, Magazine. **SEC D, Male, Aurangabad**

Through TV, posters in the private and government hospitals. I ked the advertisement of AIDS with Shahrukh Khan wherein he conveys the message that it does not spread by touch and he is shown touching the kids. **SEC D, Female, Aurangabad**

Current and Preferred Sources of Awareness which need to be checked:

- TV
- Newspapers
- Messages by Celebrities
- Serials
- Health meetings, medical camps, Visits by health workers
- Banners in Hospitals

Messages with social and family themes have a more amenable impact on community.

SECTION 5.4: FEAR INDICATORS VALIDATION

Community Group – SEC B

In one – one situation during the transect walks fear was expressed in Kanpur as well as Aurangabad regarding staying with the infected person, eating food cooked by infected person, using the same toilet, children playing together, HIV infected child biting another child, sneezing and even talking. They all held the view that the infected person must be made to stay separately – even if he is allowed to stay together as in the case of Udupi and touching and talking can happen they would still be treated as separate as a matter of prevention.

In the group situation an agreement or disagreement about certain fear indicators was sought with more conclusive evidence. Though they accepted that technically it is not possible for the disease to spread through touching and talking or sharing food yet they agreed in Kanpur that they would feel scared to stay with the infected person particularly when children are involved. In Udupi they were more articulate and even mentioned some more indicators like sweat of the infected person would not even spread the virus. The fear was more due to the fact that it happens through a natural need like sex.

In Aurangabad too the community believed in all the indicators and some new indicators like spread through saliva during kissing also emerged.

In the higher SEC too all the fear indicators were prominent except for Udupi where they felt that these indicators have no meaning and there is no need to fear as the cause is only blood transfusion.

SEC B – Kanpur

Stay away..

It does happen by touching or eating together, if anyone gets it we will explain that and tell them to get treatment done ..But I am not going to stay in close quarters with them. If their child bites my child and there is blood, my mind will get out of control. I would rather leave that place and stay in some other place. **SEC B, Male, Kanpuro**

If someone in my family gets it I will not be scared because I know the person and also know that the disease does not spread by sitting or eating with this person. **SEC B, Female, Kanpur**

If someone in my family gets it I will be scared that my children may also get it. I will not allow my child to play with an HIV child because he may bite. **SEC B, Female, Kanpur**

SEC B – Udupi

Will Share Food, Talk, Touch…

It will not spread by touching each other. Even not by eating with each other. It spreads only through blood. If the blade is not changed it may come from that. It will not come even when we will use their clothes or sleep next to them. It will not come from sweat also. If we use their toilets also it will not cause. The virus will have no life when it will come out from blood. It will have life in the blood. . But as it is the disease that we will get from sex, people are fearful. **SEC B, Male, Udupi**

AIDS only we are scared of because we have seen many people dying from it. It has spoiled the future of many people. It is more dangerous than cancer. It is something that comes from virus. It will kill us and go. It is not a disease that will spread I can eat with him and talk to him and there will be no problem. **SEC B, Female, Udupi**

SEC B - Aurangabad

Spreads through kissing, sweat, food, using same toilet…

No, AIDS does not spread through mosquito bite. Due to talking-Not due to Kissing –But if the kiss is long and tongues get in contact there are chances of getting affected. We should also try to make the person isolated so that it is safer for other persons. Also keep a lot of distance that is possible because of virus transmission by sweat, soaps, touched foods etc. **SEC B, Male, Aurangabad**

It can be transmitted by lip kissing because there is possibility of the virus to be present in the saliva which will be transmitted by lip kissing. I cannot allow their children to play with HIV affected children as children are much more likely to get affected more easily than adults and no precautions can be taken. I don't fear if the patient sneezes at a distance. However if he is very near then I may fear as there can be disposal of virus at the time of sneezing. After his using the toilet we will clean it with acid and phenyl and then only allow others to use it. Sweat may contain the virus which is passed on to the clothes. **SEC B, Female, Aurangabad**

Community Group – SEC C

In the case of the middle SECs more fear persists even in an open society like Udupi. Except for touching and talking communities in all three research locations had reservations about eating from the same plate as they feared spread through saliva, using toilet, eating food prepared by infected person, and allowing children to play. In fact, in Aurangabad even talking was considered dangerous – they would like to maintain a distance of 3-4 feet.

Lower down the SEC order more fear indicators have manifested in all three research locations.

SEC C - Kanpur

Spreads by Sharing Food Using Same Toilet..

AIDS does not happen by touching or eating together **SEC C, Male, Kanpur**

AIDS does not transmit by sitting or eating with the infected person... If there is blood on cutting of hand while preparing food we will not eat the food if a HIV positive child bites my child that is also not good. **SEC C, Female, Kanpur**

I will also not eat from the same plate as an HIV person because the saliva has HIV, not even using the same toilet or will clean the toilet with water and Baygon before using it **SEC C, Female, Kanpur**

SEC C - Udupi

Toilet, Mosquitoes, Saliva.. ..

We could get from mosquitoes also. We should not eat the food that they have eaten. And when AIDS person cuts and fruits and by mistake if his fingers get cut then should not eat that fruit because it will have HIV virus. We can use the toilet that is not a problem only thing is the mosquitoes should not be there. I think we should not touch him and we should not use his plate and all and we should not touch his clothes also. .**SEC C, Male, Udupi**

When his blood or his spit will get into our body then only we will get this disease. Just to get protected from that disease we have to give him a separate room. We should not sleep because his breath will get into us. We should protect ourselves. . **SEC C, Male, Udupi**

Neighbours say don't allow your child to play with that of HIV parents they say that the food that he eats should not be shared with our children. They don't allow their children to play with him. Few girls from health department had come and they were telling us that we can eat food with them and we can wear their dress nothing will happen .It will not spread from dress and all it is only from blood. **SEC C, Female, Udupi**

SEC C - Aurangabad

Talking Closely, Sharing Same room, Sneezing, Playing with +ve Kids…

Due to talking also it spreads if you are very close to the AIDS person. But if you are at a distance of 3-4 feet from a person it does not spread. Sleeping on the same bed can be dangerous and because of the fear I will not sleep. I will not allow clothes to be washed because infection can pass through**. SEC C, Male, Aurangabad**

We should not talk much to the person .Try to maintain distance. We should try to give normal support. We should keep his things separately. We should not mix too much with him. I will not stay in the same room under any circumstance. I would prefer not to eat food cooked by an HIV patient whether he has a cut on his finger or not. Not allow their kids to play with an HIV child and also be scared of sneezing. Using same toilet or washing clothes is also ruled out. **SEC C, Female, Aurangabad**

Community Group – SEC D

The lowest SECs were more scared about the condition of the AIDS person – he becomes thin – which is a sign of too much indulgence in sex which actually repels them. The sight of the HIV person itself is a fear indicator. The lower SECs are tolerant in terms of touching, eating and staying together and even eating food prepared by them but would not like to stay with them. In Aurangabad the community was categorical – they would not like to even talk with the infected person.

Some amount of resistance has built in the lower SECs but it seems either out of no choice as the infected person has not other place to stay or because they wanted to be seen as kind hearted.

Except for the higher SEC in both – in the middle as well as the lower SEC there is more fear.

SEC D - Kanpur

Person resembles a ghost…

I do not fear the AIDS infected person. Just the name AIDS, you get scared of a ghost because it has no cure and makes the person thin..which is a sign of promiscuity..frequent sex..a person who indulges in frequent sex becomes thin..He can neither eat nor drink.. can there be a cure for the disease if detected in early stages? **SEC D, Male, Kanpur**

I ask the barber to always change the blade when I go for a shave else there is a danger of getting AIDS...I know from the TV that it does not happen through touch or eating together or even kissing it happens only through blood … **SEC D, Male, Kanpur**

They show in the Jasoos Vijay serial that it does not happen by sitting. Staying or eating together, I will also let my children play **SEC D, Female, Kanpur**

SEC D - Udupi

No fear of eating, talking, touching…

I have seen one of my friends staying with his friend who had come from Mumbai and he had AIDS and he was staying with this friend. Finally he died but nothing harmed my friend. **SEC D, Male, Udupi**

We have fear if we get fever, loose motions and weakness. We go to doctor immediately and ask them to check the blood. HIV will not spread like that just if we talk or eat together. **SEC D, Female, Udupi**

And it was in the olden days that people use to get scared that it will spread if we just speak to her or touch her but now everyone has the awareness that it will not spread like that. We can

sit next to them and speak to them also that is not a problem. We don't mind eating the food that a HIV patient has made. **SEC D, Female, Udupi**

SEC D - Aurangabad

Biting, Bathing, Talking…

I am not sure whether AIDS spreads by kissing or not. In marriage also both the family used to see kundali , but now a day's blood check-up is compulsory for knowing the health and HIV status of brides and bridegrooms… Staying in the same house is safe but without using each other things, I will fear eating food because there is fear. I will not let the kids play … Biting is very dangerous because there can be a risk of transmission **.. .** I will not use the same bathroom because it is not safe..it can spread through soaps, shampoo …**SEC D, Male, Aurangabad**

It spreads due to talking… the virus is present in the saliva of the mouth there is possibility of it to get transmitted. If the person gets to be HIV +ve then he must maintain a safe distance from others, should not have sexual intercourse with others, and keep away from others as people are afraid of him… I will fear the HIV infected child a lot because the virus will be in his teeth like that of a dog… no sleeping or eating together or using the same toilet would be preferred .. **SEC D, Female, Aurangabad**

Fear Indicators to be Tested:

All fear indicators identified during the transect walks are valid. In addition new indicators like:

1) Saliva
2) Sweat
3) Mosquito Bite
4) Use of common soap and shampoo have also emerged.

SECTION 5.5: SHAME, BLAME AND JUDGEMENT INDICATORS VALIDATION

Community Group – SEC B

In all the three research locations the cause of the disease being emphasized as multiple sex partners and unsafe sex results in the infected person being looked down upon. Since multiple partners is not an accepted norm in the Indian society, particularly among the upper middle class and middle class, any person who indulges in this practice is considered to be immoral – whether or not he has contacted AIDS. Generally people who have multiple partners hide it from the family and community but the moment they get AIDS it is out in the open that they have indulged in such a practice which is shameful.

Though the community is aware of other routes of transmission, since communication messages about the causes of AIDS singularly talk about unsafe sex and multiple partner route, the perception towards the infected person is derogatory.

Communication messages should emphasize upon the scientific reason - exchange of body fluids route – be it blood or vaginal fluid or semen. Also it should emphasise that it does not happen through kissing (unless there is a cut or ulcer in the mouth or gums are bleeding) or any environmental contact or even through insects like mosquitoes. A scientific explanation may take the perception of sex out of the mind of the community and view it differently.

SEC B - Kanpur

AIDS is shameful…happens to bad people who cross their limits…

It is said that AIDS happens through multiple sex partners but in olden times also people had more than one partner and there were no condoms also then how come they did not get AIDS? .... it is important to first establish the cause for the disease.. if he accepts his mistake even I will care for him.. but if not ..I will not forgive him.. in fact I will abuse him.. actually it is the sex in it which makes it dirty.. that should be removed..even the AIDS person feels shameful because of this word.. **SEC B, Male, Kanpur**

People generally prefer to hide AIDS cases for fear of getting a bad name in society, It is not necessary that it happens through wrong sexual relations only but the thinking of people is such, they only think in this direction **SEC B, Female, Kanpur**

Nowadays boys and girls go out for studying but they cross their limits and do wrong things which they come to know of later when they get the disease, their life comes to a stop there itself, when their family comes to know they also feel bad because the society then views the family with bad eyes **SEC B, Female, Kanpur**

The mentality of people here is such that they do not want to think right about the person - it is necessary to make people aware that this disease can happen to anybody, however it cannot be proved that the person has got it from any other source, it would always be assumed that it is due to some dirty habits.. HIV is a result of the careless behaviour of the person not due to any punishment from God **SEC B, Female, Kanpur**

SEC B - Udupi

Multiple sex is a taboo…therefore AIDS too is…

But some people will have a low feeling about them. They will not give the value to them…that is because the way he might have got the disease is by having multiple sex partners. They will feel that he is bad…That is because our society will not agree to multiple sex. People are there who do this but they hide it from the society… I just heard recently in radio that it is in very rare cases that AIDS is caused from the blade and the syringe most of the cases it is from sex only. ..**SEC B, Male, Udupi**

Mainly he should have mental boldness that he has not got any thing and he is healthy. He should be like a normal person. And the food he takes also matters. He has to take more of greens and vegetables. He should have self-confidence.. society should give it to him. **SEC B, Male, Udupi**

And also we have to think about him, that if he is been treated badly by others after knowing this, he will feel bad and disappointed. And till the time he is alive we have to look after him well. **SEC B, Female, Udupi**

SEC B - Aurangabad

AIDS person should be cared for exercising precaution…

The society is not changing its thinking because there is no cure for the disease. **SEC B, Male, Aurangabad**

If anybody becomes HIV positive the first thought that comes to the mind is that the person must have got it through insecure sexual relations with more than one person. Hence the person is characterised to have immoral character. Even if the cause of the infection is insecure intercourse we should forgive the patient as he has already been penalised for his deeds. If anybody in my house gets infected with AIDS I cannot possibly throw him out of the house, instead I will have to take care of him. I will keep his things separately and carefully. I will keep the person with them but at the same time will maintain a safe distance **SEC B, Female, Aurangabad**

Community Group – SEC C

In the lower middle SEC different views were prevalent for men and women – women are not considered to be immoral as it is assumed that they would have contracted it from their husbands. A man on the other hand, is always assumed to have got it from prostitutes. However, at the lower SEC level they are more accepting of his immoral character – they can also forgive him for his deeds and keep him with them observing all the precautions. They would not like to deny him to live the rest of his life peacefully.

If the messages of multiple partners and unsafe sex are toned down, this level of society is likely to become more accepting of the AIDS victims.

SEC C - Kanpur

AIDS is not hateful but sex is…AIDS person can be pardoned for his sins…

Everyone makes some mistakes in life, we must not hold it against the AIDS person, we must give him our love but 99% of the community hates them and feels that this disease spreads through touching but if my friend gets it I will start hating him because that means he has been to the prostitutes… the association of AIDS with sex makes it hateful.. AIDS is not hateful .. sex is …it should be communicated that AIDS spreads through other sources also.. **SEC C, Male, Kanpur**

The way the family of a drunkard or a drug addict feels shameful in the same way even an AIDS person's family feels shameful but they should help him to cope with the disease rather than rebuking him …if a child does latrine and spoils his legs we clean the shit we do not chop off his legs..it is like if a person consumes poison we all start hating him and leaving him to die.. **SEC C, Male, Kanpur**

The doctor will be able to tell how the person has been infected and whether it is through any wrong source **SEC C, Female, Kanpur**

SEC C - Udupi

A family member may be cared for…

At least for ladies they will think that she has got from her husband but males they know that he has done some bad work . When he is our family member and if he has got this, then I will keep him in my house and look after him well. **SEC C, Female, Udupi**

SEC C - Aurangabad

AIDS person suffers from total loss of respect due to his immoral deeds…

The behaviour from the family for HIV is normal because of the fear of the society. They will try not to let others know. If the AIDS infected person is getting more support from his family then his life period will increase because due to the support he will be mentally happy and also his mind will be free from tension ..**SEC C, Male, Aurangabad**

Dying due to Cancer is much better than dying due to AIDS as the person loses respect in the society if he/she gets AIDS. …the advertisement has placed more emphasis on the sexual relations as compared to the other causes. This has made home in the minds of the people and hence every person suffering from AIDS is considered to be of immoral character irrespective of the actual cause of it. **SEC C, Female, Aurangabad**

If a man gets it then everybody will think that he has got because of his wrong character but if a woman gets it every one will think that she has got because of her husband as people observe the moral behaviour of the individuals. **SEC C, Female, Aurangabad**

Community Group – SEC D

The lower SEC has brought out fact very categorically – whether a person suffers from AIDS or any other disease, he would be shunned anyway unless he is an earning member of the house in which case his presence would be tolerated. Everyone is prone to outside pleasures but if a person realizes his mistake and is willing to take up the responsibility of his family despite his illness, the family would also come forward and support him rather than allow him to languish and die. They do associate shame with the infected person but feel that the person himself should show self confidence and lead his life responsibly – the shame would then be reduced.

This is an important indicator which can be monitored and tested – it will serve to change the attitude of the society towards AIDS infected persons.

SEC D - Kanpur

His family may need him for looking after them…how can they abandon him?

Even when it happens to a known person, there will be a fear inside, but I will continue my relations with that person.. nothing happens by talking or touching..I will also try and find out how he got infected by some wrong doing or accidentally by some shaving or blood transfusion… but ultimately whether it is a known or unknown person there is an element of hatred towards the person.. **SEC D, Male, Kanpur**

Feelings of hatred towards an AIDS infected person can change if he behaves responsibly and fulfils his family duties for e.g. I know of a woman who had cancer, her husband died when her child was 5 year old, he wanted the child to be an engineer, she continued to live due to sheer will power for the next 20 years and got her child educated.. she fought the disease.. similarly if

HIV infected persons are also responsible and fight the disease we will have respect for that person… **SEC D, Male, Kanpur**

Those who suffer from this disease believe that if people know it they will perceive them to be bad people and shun them so they prefer to hide the fact **SEC D, Female, Kanpur**

If we come to know that a person has AIDS it is certain that her husband has got into a wrong relationship with an outside woman **SEC D, Female, Kanpur**

SEC D - Udupi

Economic condition decides support and care…

It is not only for AIDS they should not do this with any disease. People here they do for any kind of disease if a person gets and if he is on the bed they will not go near to him they will leave him to die. If he has money then at least few people will help him and all but if they have no money then they will leave him to die. **SEC D, Male, Udupi**

If we move around with that patient people around us will tell why should you go with him he is having AIDS and if we don't listen to them, they will go to our house and tell our parents that why is your son roaming with him. They are very selfish. **SEC D, Male, Udupi**

When he will leave the hopes of living so he will start drinking. And he will kill himself. **SEC D, Female, Udupi**

Yes it will become a problem if we have any girls in our house for marriage. Because people will think that if somebody has HIV in her house then they will think that even she will be having it now.

SEC D, Female, Udupi

SEC D - Aurangabad

Weak Willed People Get It…

When I think about an AIDS person I feel lot of fear, I think that he is a bad person and also feel that he is of weak character. **SEC D, Male, Aurangabad**

Dying due to T.B. is much better than dying due to AIDS as only people of immoral character get AIDS .. **SEC D, Female, Aurangabad**

In all of the advertisements it shows that due to sexual relationship peoples are affected by AIDS. .If they show all the medium through which AIDS is infected then this misunderstanding is not there in public They will be having the right path to think… the person feels a shamed because the society will think that the person is suffering from HIV because of his immoral character even if it is not his mistake. **SEC D, Female, Aurangabad**

Shame Indicators which can be monitored are:

1) If the communication messages emphasise on transmission through blood rather than through sex and multiple partner route feelings of shame associated with an AIDS infected person would decline.

2) If the AIDS person continues to discharge his responsibility towards his family and society properly feeling of shame associated with an AIDS infected person would decline.

SECTION 5.6: JUDGEMENT AND ENACTED STIGMA INDICATORS VALIDATION

Community Group – SEC B

The respondents were forthcoming in sharing their experience about incidents they were aware of regarding the treatment given to the AIDS infected persons by their families. It has been mentioned across all the three research locations that they are aware of cases wherein the AIDS infected persons have been separated from their family and even their spouse in some cases. They have been left to die alone. However, the community feels that abusing and not supporting the AIDS infected persons is not correct. They should also be allowed to participate in social functions if their presence is required for certain rituals. With the changing mindset of the community regarding fear and shame cases of separation and abandonment must decline.

SEC B - Kanpur

If we know that a person has AIDS we should behave well towards the person, not abuse him else he will not be able to live. **SEC B, Female, Kanpur**

SEC B - Udupi

Yes in my village one lady was there, her husband died because of AIDS and she had to come to her mothers place to stay and what her brother's wife did is she took a separate house and left that house. That is because she had doubt that even she might be having AIDS. And even she had a small kid so they had a fear that something will happen to it. **SEC B, Male, Udupi**

But I had one of my friends who had this and when he knew that he is having this disease he did not touch his wife and that man died and now also her wife is healthy. But this happens in very few cases. Less people will do like this because they will feel that their wife should be safe. **SEC B, Male, Udupi**

SEC B – Aurangabad

In our hospital one couple came for checking and in this testing result the husband was found to be suffering with AIDS .The Wife divorced the husband immediately. Another friend of mind Mr. Ravi got AIDS and he was separated from his family **SEC B, Male, Aurangabad**

If the patient is the relative of the host whose presence is very necessary as per the rituals we cannot ignore him just because he is an HIV +ve. **SEC B, Female, Aurangabad**

Blame her and glorify him.....always.....

Community chose to highlight cases where the wife had abandoned or divorced her husband – husband was left alone to cope with the disease. They also glorified cases when a man abstained from sex with his wife after knowing he is infected. The woman does not seem to have the right to leave him and if she is spared by her husband it is not because that is her right but because he is an understanding kind hearted person who is making the supreme sacrifice.

Community Group – SEC C

The lower middle SEC is aware of cases of separation and abandonment also but they have also mentioned about cases of sympathy from the family and community which is a tiny ray of hope. The AIDS victims themselves isolate from the family and community fearing abuse and ridicule. The SEC C are optimistic however about bringing about a change – the family is the unit which can bring about this transformation – if the future elders in the family are supportive even their younger generation would be unlike elders of the present generation who are very rigid. In Udupi they feared that if the family does not lend support the person may even commit suicide.

SEC C - Kanpur

No right to be a mother…

An AIDS person should not be allowed to stay in the neighbourhood he should stay away else the environment would get spoiled. **SEC C, Male, Kanpur**

The woman I knew about was confined to her home, she stopped meeting with people, her family also stopped behaving properly with her, her husband abandoned her and her children were taken away from her .. If anyone comes to know of a person with HIV they stop meeting that person and protect themselves from the person. **SEC C, Female, Kanpur**

Only if the mother of the family understands she can tell that to the daughter in law and she in turn will tell the children, only if the family members say we can understand better not just the doctor. **SEC C, Female, Kanpur**

A person needs sympathy to live so he must be treated properly by his family members, know of a case when wife and husband both were infected, the wife died and the husband was contemplating suicide by jumping, the community and family took him to the doctor for treatment. **SEC C, Female, Kanpur**

SEC C - Udupi

Separate Ashrams for Abandoned Women…

They have shown in the TV that those ladies who have this disease have separate Ashrams for them. **SEC C, Male, Udupi**

When he is already dying why should we kill him more. If we treat him well he will live for some more days. If we trouble them they could commit suicide also. **SEC C, Female, Udupi**

SEC C - Aurangabad

Not Even Allowed to Die…

I am aware of a HIV Person who has left his family. The person did not go to his house after he was infected by AIDS and afterwards he died. One did not go to doctor's clinic because he knows that there is no medicine for it. And afterwards he went to his village, all the people behave with him like an enemy. **SEC C, Male, Aurangabad**

I would not like to invite him in the public functions because other persons would like to stay far from him. And if such things will happen they will make him feel guiltier. Even the guest will be complaining that if you had to invite the HIV Positive person then why did you invite us. **SEC C, Female, Aurangabad**

I had seen an interview in which the woman said that she had lost her family and had been given divorce by her husband despite the fact that she had been infected because of him only. She has a 7-8 years old marriage history. The family on the contrary blamed her that she is of immoral character. She had tried to commit suicide three times but in vain. At last she wrote a letter to Abdul Kalam asking permission to commit a suicide as no one was listening to her. Even when she tried to lodge the complaint against her in-laws the police officials ill-treated her. **SEC C, Female, Aurangabad**

Forced Submission …Forced Existence..

Women have been denied staying with their children, blamed for their husband's condition and worse of all local channels seem to popularize separate ashrams for her , which reinforces that she has no right to shelter in her in laws or natal home once her husband dies

Community Group – SEC D

In the lower SEC since it is the economic condition which drives most emotions, though there are case of indifference and abuse yet there are also cases when the person continues to fulfil his responsibility towards the family and is accepted within the family. They firmly believe that it is only the family support which can remove the stigma attached to HIV and enable them to get the moral confidence for living the rest of their life.

SEC D - Kanpur

Family should take the lead…

We will behave nicely with the infected person, will not meet him closely and also prevent ourselves from getting it but we will not abuse him … **SEC D, Male, Kanpur**

The girl I know of used to cook for the family as her mother used to work, when she used to fall ill she used to take medicines, but the family members did not know that she had AIDS. **SEC D, Female, Kanpur**

The head of the family (father and mother) should tell all the family members that how they should behave with an AIDS infected person. **SEC D, Female, Kanpur**

SEC D - Udupi

Excuse for abuse…

What people will do is, if that patient is getting cured also he will be insulted by the people around him. They will be telling him that he has got this disease and he will die very soon. That will make him disappointed…The boy whose father died of AIDS.. They are treating him very bad. They will not let him sit next to him. They are insulting him. He is not been involved properly into everything that happens. These people will never change. Whatever information's or awareness we give people will not change. They will push the patient far. **SEC D, Male, Udupi**

SEC D - Aurangabad

Should be cared for…

My father is affected but we don't think that he is affected by wrong sexual relationships...My friend is also affected. He is staying at his village. He is separated from home and his village. He is very fearful about himself and his wife has also left him. **SEC D, Male, Aurangabad**

If the person is getting support from the family, then the person is mentally normal. If we are trying to take good care of the person then it will make him very happy .But if we start torturing them he will not think of living anymore. **SEC D, Female, Aurangabad**

Judgement and Enacted Stigma Indicators That Can be Monitored:

1) Family support provided to the infected person enabled him/her to lead a better life (% cases known)
2) A person with earning capacity or with a responsible role in the family is not stigmatized (% agreement)

SECTION 5.7: DISCLOSURE INDICATORS VALIDATION

Community Group – SEC B

The middle SECs would try and hide the infection from close family members, take medicines, and cope with the situation rather than disclose it. They would like to continue with this situation till the stage when it becomes obvious due to loss in weight and discolouring of skin or other outward physical signs. Since the middle class can afford the treatment they would try and keep it under wraps because the middle class is less tolerant of promiscuity and multiple sex partners, therefore they are likely to suffer from abandonment. They might disclose it at a later stage only. However, the community feels that he should disclose so that they may stay away from him.

Becomes weak.. obvious signs..

SEC B - Kanpur

It is obvious that a person is suffering from AIDS because his body becomes weak.. **SEC B, Male, Kanpur**

Anyone who suffers from HIV should voluntarily inform others about the disease so that they can stay away from him. **SEC B, Female, Kanpur**

SEC B - Udupi

Low class will know about it and they will tell others about it but when it comes to middle class they will not tell if they know that they have this problem. They will just be taking medicines. **SEC B, Female, Udupi**

SEC B - Aurangabad

When disclosure comes to matter I think that the person in front of the society will not be open and try to become a role model by being honest. He will never let other persons know because of the fear of the society in his mind. **SEC B, Male, Aurangabad**

A person who is AIDS affected becomes very weak due to loss of weight. He develops pimples in the underarms, and cannot intake food due to loss of appetite. I had seen an HIV patient in my hometown. The cause of AIDS was unknown but he was very well treated. All possible treatments were tried by all the reputed doctors. The family gave all moral support which it could. The relatives and friends also gave regular visits to the person. As the days passed he became more and more weak , lost his appetite and was reduced to bones, and passed away. **SEC B, Female, Aurangabad**

Community Group – SEC C

Even in the case of the middle SEC the opinion is that he should disclose till it is not needed after that he himself should take his family in confidence and take precautions not to harm them. In any case if he does not disclose it in an appropriate time it would in any case become evident later due to his weak physical state.

Should voluntarily shun..

SEC C - Kanpur

This disease cannot be hidden as the person will start losing his body. **SEC C, Male, Kanpur**

You cannot hide this disease, as the person becomes weak day by day and it becomes noticeable, he should inform others about the disease else who would look after him. **SEC C, Female, Kanpur**

If he is a person who loves his family, he will tell them that he has this disease and he will ask them to not to touch them and all. But actually he should tell everyone about this because every one has to be away from him....he knows that he has that and he himself will not come near. But when he comes near to us then we will have to tell him that he should not come and sit with us and it may spread on to us. **SEC C, Male, Kanpur**

SEC C - Aurangabad

Should not disclose because if he discloses then there are chances of ill treatment of society towards him. So in order to prevent it he should not disclose about it. Even when the symptoms are not visible they should not disclose it. **SEC C, Female, Aurangabad**

Community Group – SEC D

In the lower SEC too the view held is that he should inform his family members about his condition so that they can provide proper care and treatment.

Should disclose to family..

SEC D - Kanpur

If a person comes to know that he has the disease he should inform his family members so that they can provide him with proper treatment on time. **SEC D, Female, Kanpur**

If he tells then only it is good. Then only we will look after him well. Otherwise he will be thinking that we will keep him separate and we might not speak to him and all. **SEC D, Female, Kanpur**

SEC D - Aurangabad

A friend 's father of mine was known to have AIDS after his check-up .But due to doctors suggestion his family members keep him with themselves. But he has got very weak, and he vomits after he eats anything. **SEC D, Male, Aurangabad**

Disclosure indicators which can be monitored are:

1) An HIV person should keep the information of being infected to himself else he would be ill-treated by his family. (% agreement)
2) An HIV infected person should share the information of his infection immediately with his family so that he may be provided with good care. (% agreement)
3) An HIV infected person should wait till the last stages when the body becomes weak and it is obvious that he is suffering to tell his family. (% agreement)

SECTION 5.8: MEDIA EXPOSURE

Community Group – SEC B

SEC B audience not only watches the local channel and Doordarshan National Channel but also the C & S channels. They read local news papers more – not the English dailies. They are influenced by celebrity ads particularly shown over TV. They also watch health programs regularly. Community discourse personalities like Asaram Bapu and Baba Ramdev are also likely to influence their thoughts and actions.

Community Group – SEC C

Apart from the TV channels and local newspapers the lower middle SEC also prefers listening to the radio – it can be heard at the time of power cuts and also TV penetration in these strata is lower than SEC B. In all the three locations radio is the preferred source. Second is the newspaper. They are also influenced by celebrities but more of those involved in the welfare and providing employment and self help opportunities to the poor. On ground activities by local clubs are also appreciated.

Aurangabad prefers Marathi local channels and celebrity ads as well as local newspaper.

Community Group – SEC D

The SEC D advocates use of live street plays, family oriented serials and spiritual leaders like Ramdev Baba and Asaram Bapu on Aastha Channel more than other media.

Pulse Polio Popular, Local Newspapers, All TV Channels..

SEC B - Kanpur

The local channels inform that at present malaria is in full force, we are informed about Hepatitis B, and AIDS ads are also seen on all the channels. **SEC B, Male, Kanpur**

The polio ad of Amitabh Bacchan – Do boond zindagi ki was very informative. **SEC B, Female, Kanpur**

SEC B - Udupi

Watch Udaya TV..Kadambari serial, usually watch in evening after 6, also watch programs there is programme called Arogya Jeevana that comes on HIV. **SEC B, Female, Udupi**

They show about pulse polio and all that is also good. Because they are showing at what age they have to give polio vaccines. And we can give injections to the children at right time and that is why there is no polio in our India. **SEC B, Female, Udupi**

SEC B - Aurangabad

The channels that I am frequently watching are Zee TV, Aaj Tak Zee cinema, Channel 7,Zee News, Star Sports, Zee TV Marathi,, Alpha Marathi, Star News; I read newspapers Samna, Sakal, Lokmat. The magazines I am reading are India Today. The best medium to spread the information is TV, Because of the celebrity the ads have a direct impact on our mind. Amitabh, Sachin, Shahrukh Sanjay Dutt, Om Puri, Nasiruddin Shah, Shabana Azmi, Nana Patekar, Amol Palekar. But if the celebrity and an AIDS suffering person both are coming on an advertisement together we think it's more effective. **SEC B, Male , Aurangabad**

T V is the most effective medium to provide all the awareness information as people watch T V more than reading Newspaper . Also personal meetings face to face communication must be arranged as they have more impact on the minds of the people.. Preferred celebrities are Amitabh Bacchan, Sharukh Khan, Sachin Tendulkar, Baba Ramdev and also Asaram Bapu. Preferred timings are from 8.30pm to 11.00pm on Star Plus and morning timing is 7.00am to 8.00am at Sanskar Channel. News Channel popular is Aaj Tak. ..**SEC B, Female , Aurangabad**

SEC C - Kanpur

Read Dainik Jagran, watch TV, read magazines – Filmi Duniya.. **SEC C, Male, Kanpur**

Watch Doordarshan, Read Dainik Jagran newspaper and also listen to radio at times – radio is the best medium for the information because everyone has it and we can hear it anytime even when there is a power cut, also not everyone has a TV **SEC C, Female, Kanpur**

SEC C - Udupi

In TV they tell about Pulse Polio. Amitabh Bachan, Tara and Sachin Tendulkar will come and tell about this. Rotary club people also come to the villages and give the awareness and give injections and tablets. They put it in the papers also…For Chikan Gunya in the TV they had told that we would get fever and get pimples on the body. **SEC C, Male, Udupi**

More than TV I think News Paper every one will buy and read. And also they have to tell through Radio also in village everyone will be having radio. They have to give it as a programme in-between the songs. At 7.30 when the songs will come at that time they will have to say. **SEC C, Male, Udupi**

We have to make these changes through trusts and societies. Like a person who is believed more by the public. Like Veerandra Hegde priest from Dharmastala he has not at all come on TV if he will come and tell then people will believe and listen to his words. They should tell that it would spread only from sex and blood so you can eat or sleep with AIDS patients. And that they have to treat AIDS patient well. **SEC C, Female, Udupi**

SEC C - Aurangabad

The Advertisement which I like the most about health is Shabana Azmi's for Aids Precaution. The advertisement on chicken Gunia at Zee Marathi Channels also gives a rise to alertness. Something special which has impact on my mind is the "Hathse Hath Mila" advertisement campaigned by Diya Mirza. Also advertisement by Amitabh Bachan on Pulse Polio. **SEC C, Male, Aurangabad**

Star News, Zee News,Aaj Tak, Doordarshan, Sahara, Zee TV, ETV, Ramdev Baba, Asaram Bapu, all local newspapers are read.. **SEC C, Male, Aurangabad**

SEC D - Kanpur

Read newspapers – Dainik Jagran, watch TV- Doordarshan, Star News, Aaj Tak, Zee News, IndiaTV … **SEC D, Male, Kanpur**

Amitabh Bachan, Raveena Tandon, Shabana Azmi, Rahul Dravid all have provided information about AIDS. **SEC D, Male, Kanpur**

They should show street plays in villages to make the people aware of the causes of spread of AIDS. **SEC D, Female, Kanpur**

Watch Sony, Zee, Star News and also Aastha channel and Ramdev Baba for yoga, also they can inform through serials like Kyonki Saas bhi Kabhi bahu thi, we can understand best from the TV. **SEC D, Female, Kanpur**

SEC D - Aurangabad

Channels which I see are Zee TV, Zee Cinema, News Channel, Star One, Doordarshan, ETV Marathi, Aaj Tak.. Indian Laughter Challenge, Shabbas India.. Newspapers are Sakal, Lokmat. If I see the advertisement given on Astha/Asaram Bapu this advertisement will have a greater impact, because these people have right images. **SEC D, Male, Aurangabad**

My favourite Celebrities are Shahrukh Khan, Shabana Azmi, Parvati (Kahani Ghar Ghar Ki), Hema Malini and my favourite programs being Star Plus 'K' series, Amitabh B, Tulsi (Kahani Ghar Ghar Ki) and Lata Mangeshkar. **SEC D, Female, Aurangabad**

SECTION 5.9: MESSAGE SUGGESTED

Community Group – SEC B

Community was not very certain about what messages they would like to hear. Some of them said using spiritual persons to spread the message that AIDS is not dirty would have an impact. Interviews with HIV positive people and their description about the normal lives which they lead should be done to reduce the perception among the normal masses that it happens to only immoral and dirty people.

Community Group – SEC C

The message which the middle SEC would like to see is that of family support informing that they need care and support and AIDS is not communicable like other diseases.

Community Group – SEC D

SEC D is not influenced by celebrities – they need constant messaging through regular discourses on TV by spiritual leaders, at health centres, small meetings and through clubs. They would like the message to provide information about the symptoms and also not to isolate the AIDS patients from their families or be shunned by society. They feel that the elder member of the family needs to be educated through such messages.

SEC B - Kanpur

AIDS is not dirty…

All the responsible persons like those who hold public discourses like Asharam Baba, Hardev Baba must be used to spread the message that AIDS is not dirty. **SEC B, Male, Kanpur**

Youth should be explained about the dangers of this disease and not to do wrong things. **SEC B, Female, Kanpur**

Women of the house should be explained personally on a one-to-one basis about the reasons. **SEC B, Female, Kanpur**

Shahrukh Khan, Shabana Azmi, Raveena Tandon are very credible, also Anil Ambani and Ramdev Baba. **SEC B, Female, Kanpur**

SEC B - Udupi

They lead a normal life…

They should not make a society of HIV positives, which has been done. We don't form any kind of society with any kind of other patients and why with this disease. . They have to do road dramas and give the awareness. Mainly in the TV it has to come. Magazines have to come about this topic in the local language. **SEC B, Male, Udupi**

Or even an HIV positive person should come and tell that I am positive and I am living a normal life. We will have to make people give them confidence and tell them that they have to

lead a normal life and make them involved in every work that we do. And also we should see that there will be some trusts which will help them to lead the life. **SEC B, Female, Udupi**

SEC C - Kanpur

Family Should Care…

Amitabh Bachan, Sachin Tendulkar even APJ Kalam should come forward and address the head of the family.. also Asharam Bapu should take this up in discourses..all should emphasise that the family should not neglect the AIDS patient… **SEC C, Male, Kanpur**

SEC C - Udupi

Doctor should explain…

According to me Doctors should only tell. Because whatever disease we get only if Doctor tells we will believe it. **SEC C, Male, Udupi**

SEC C - Aurangabad

It is not communicable…

We should propagate the message that it is not a communicable disease like chicken gunya that if one member gets it ,every body in communication or contact will be getting it. **SEC C, Female, Aurangabad**

The preferred time when the ad should be displayed is 800 pm, to 1100 pm on Star plus. The stars like Amitabh, Bipasha, Parvati/Tulsi (Kahani Ghar Ghar Ki). In the morning time we also see programmes of Baba Ramdeo and Asaram Bapu. They can create a good impact on the society at large. **SEC C, Female, Aurangabad**

SEC D - Kanpur

They should not be shunned…

Community health centres should take up the responsibility of making people aware of the causes of the disease …the symptoms of the disease.. if we know the symptoms it will help in getting the fear out of our minds. **SEC D, Male, Kanpur**

The message should be woven around a family in which members suffering from AIDS are not isolated or shunned and they should be looked after and cared for not isolated, the family members are behaving with them as before, we should also be made aware of the symptoms of the disease – how would we come to know if we get infected. **SEC D, Female, Kanpur**

Ramdev Baba explains everything well - he will bring a lot of change in society. **SEC D, Female, Kanpur**

SEC D - Udupi

Repeated Messages for Impact…

Doctors have to do some programmes and tell them about this health problem. They should do the street shows or some dramas and tell them through that. They have to call people for some

meetings and tell them and that also they have to go and tell all this in the next door of the patient's house. **SEC D, Male, Udupi**

Now earlier we use to not have awareness about this Polio but now everyone knows about it and the information is also given again and again. Like that only something has to be done for this. And also this Rotary Club people are providing a lot of information about it. And also they are giving free medicines and free treatment that is why it is reaching them. **SEC D, Male, Udupi**

I will tell one thing openly that my brother is having this disease and I have come here to get information how to look after him. **SEC D, Male, Udupi**

In our trust they have kept one programme for HIV people. That is HIV positive people will only go to every village or every house and they are giving this message that they should not push those patients and allow them to live happily. They go and tell them that they have HIV and they are living happily. So they will not get scared, they will have courage. **SEC D, Female, Udupi**

SEC D - Aurangabad

I don't think that advertisements are helpful even if they are given by big celebrities because they only say for which they are paid for. We watch these advertisements only because the celebrity is present in it. Otherwise there is nothing. **SEC D, Male, Aurangabad**

Media Suggested

- Local channel
- Doordarshan National Channel
- Local news papers
- Health programs
- Asaram Bapu and Baba Ramdev
- Radio
- Local Clubs
- Live street plays
- Family oriented serials

Message Suggested

- AIDS is not dirty
- Interviews with HIV positive people and their description about the normal lives which they lead
- Family support informing that they need care and support
- AIDS is not communicable like other diseases.
- Symptoms of the disease
- Not to isolate the AIDS patients from their families or be shunned by society.
- Elder member of the family needs to be educated through such messages.

Section 6

Perception of Stigma & Discrimination: The Family Stand

SECTION 6.1: PERCEPTION OF STIGMA AND DISCRIMINATION – THE FAMILY STAND

The family is an important social institution in India. Though the joint family system is disintegrating in urban India, the emotional ties with the extended family and its members continue to be as strong as ever. In many instances, approval/disapproval of the extended family – even if they are not in the vicinity – is an ever-present issue for individuals. This strong emotional connect with the family is even more palpable in the case of persons who have been infected with HIV. Just how important emotional support of the family, if not material support, is to PLHAs and WLHAs became evident at each of the three locations.

SECTION 6.2: METHOD OF CONTACT WITH FAMILIES OF WLHA

The objective of the research was to identify the stigma and discrimination the WLHA faces from her family – the natal family or the in- laws family. Families who do not support WLHA members were however unwilling to talk as they had already broken all ties with them. Moreover it was also difficult to locate such families as the members of the positive networks were either having some support from their families or had been abandoned altogether. We could therefore speak with only family members of WLHAs who were supportive of them.

This is a limitation for the present research as getting views of families who do not provide support to the WLHA would have been a critical piece of information. However, even among families who were supportive the research team did try to sense any kind of selfish motive for the support as would be described during the chapter.

The interviews were conducted in the positive network office.

SECTION 6.3: SUPPORT OF FAMILY MEMBERS – A HIDDEN MOTIVE?

The process of making the family members to agree to come to the centre was itself a difficult one as none of them were willing to spare the time except in the cases when the father of WLHA was available and had agreed for the interview. In other cases it was only after repeated requests by the networks and promise of paid conveyance and financial incentives and meals for the day that they were finally coaxed to come for the interviews.

In a few cases blatant demands were made – the entire family including the brothers and sister in law of a WLHA turned up at the venue and produced old tickets to prove that they had travelled long distances to be interviewed for the sake of their sisters. When the organizers challenged the old tickets they created a scene and demanded

cash to be paid to them instantly and also accused the centre of exploiting the HIV victim. In almost all cases they demanded money over and above what was being provided to them by cutting a sorry figure in front of the research team.

The above behaviour clearly shows that even when a family does provide shelter to a WLHA member, it is not always done as a gesture of family bonding. Some families probably expect pay-offs or returns in cash or kind as compensation for the shelter and other support that they provide.

SECTION 6.4: FAMILY MEMBERS INTERVIEWED

In Kanpur, WLHA had been abandoned by their families – there was no one whom we could speak with except in case of Taramati whose natal sister in law was supporting her and also had consented for the interview. In Udupi too though the WLHA had not been abandoned by the family, yet family members were not forthcoming in consenting for a visit in fact even the two interviews which have been done have been conducted at the home of the family member. In the case of Aurangabad, families were willing to come forth and talk but the promised incentive at the end of the day seemed to be a bigger motive.

SECTION 6.5: FAMILY MEMBERS – PROBE AREAS – THE MLHA MYTH PROBED

The respondents were probed for their awareness, perceptions and attitudes towards HIV/AIDS in the context of member/members of their family having contracted the disease. One of the key issues which was probed with families was their behaviour towards the husband of the WLHA – who could be their son or brother and their behaviour towards the WLHA herself.

SECTION 6.6: AWARENESS OF CAUSE

Family Comes Face to Face with the disease only when it is disclosed to them…

Family members generally come to know about the causes of the disease once they are informed by their brother or sister that they are infected. Even in these cases, awareness about modes of transmission, implications of the disease, etc. is low.

Take the case of Suman Shende in Aurangabad whose son and daughter-in-law are both PLHAs. When probed about HIV, she could only say that "it is dangerous…now that I know about the disease, I realise it is something big but earlier I didn't know about it". She had absolutely no knowledge about the fact that the disease could be transmitted through sexual relations; or that condoms could prevent the transmission.

"No one tells us clearly (about the disease), so we don't understand." **Mother-in-law of S Salgaoncar**

Extended Family Does Not Bother to Know More..

However, only those family members who are informed are fully aware. The rest of the extended family – even if they suspect that one of their relatives is infected – does not bother to find out and would rather avoid the WLHA and her immediate family and not have any ties with them.

There is poor awareness of the cause of the disease among the family members of those who have been affected by HIV, particularly in Aurangabad and Kanpur. The situation in Udupi is different as the family members of the PLHA here were aware of the causes.

SECTION 6.7: FEAR

Fear of Talking…Touching…Biting. Eating…Those who do not do it feel they are sympathizing…

"You cannot talk about illness, there is fear. I have sympathy for my child. I look after her and her family financially for food, clothes everything." **Mother of Bharti Nayak**

"I know that it is not an infectious disease and there is no harm in mixing with the infected persons." **Brother in law of Jaya Bedekar**

Some have a hidden motive… greed overcomes fear…she was enjoying the small sum of money the WLHA was earning and making her do the entire household work…

"I am not afraid of contracting this disease from her (my sister-in-law). If I was, would I keep her in my house?" S**ister-in-law of Taramati (Kanpur)**

Some make tall claims outside but discriminate within the walls of the house…

"I take food prepared by my sister though no one in her in-laws house does." **Brother of Pramila (refuted later by Pramila)**

Children are always considered vulnerable.. Social Ostracisation due to fear…

"I am always scared that my children will get infected in some way because we all stay in the same house as my brother in law and his wife (we have constructed a wall in between. " **Sister in law of Lata Tope**

"When my family had just come to know they asked us to live separately, they felt that their children would get infected if the same mosquito bites them both." **Husband of Malti**

"My wife does not allow my brother or his family to come to our house as she feels that our child will get infected, she also does not allow me to visit him often" **Brother in law of Jaya Bedekar**

"My wife's status is known only to my elder brother, not his family. I have also not told about my status where I work because I handle food in a canteen and if people know of my disease I will lose my job" **Husband of Jaya Bedekar**

Discrimination towards child most hurtful to WLHA…

"People behave badly with me and my wife, they don't allow their children to mix with our children". **Husband of Jumana**

Difficult to come to terms with…

"I came to know about my daughter in laws state when she was pregnant, when I got my son tested I found that he was also positive but I have kept their reports confidential and also not informed my daughter in laws parents because they are illiterate, do not understand much and will not be able to take the shock" **Father in law of Lata Tope**

Most of the family members of HIV-infected persons who have a PLHA living with them did not admit to "fear" of the disease. This is perhaps because they are resigned to the fact that they have to live with the problem. In most cases, even when the PLHA is allowed to stay with the family, there is a segregation or physical barrier, such as a wall. Sometimes children are allowed to play together, but in some households some members would like to keep their HIV-positive family members at a distance and avoid contact as far as possible particularly with respect to children mixing up.

Extracting her flesh till the last pound ….

WLHA is often reduced to an object of sympathy at her natal home – she is made to realize that she is a burden and of no use, if she is able and economically of some use she is exploited, her children are deprived of a normal playful childhood, if her parents are old she prefers to battle it alone she cannot even access their emotional support lest she ends up disturbing them.

It is worthwhile to examine whether fear plays out similarly when the case is the son or brother of the family.

Over protective towards sons…

In the case of S.Salgaocar her husband is the only son of her mother in law – she does not consider him to have any bad habits, says he could have been infected by the needle though her son admitted that he would got to prostitutes. She says she will look after him on her own and has not even disclosed to her own husband.

In another case the elder brother of Jaya Bedekars husband provided economic support and is caring towards his brother even if it does not meet his wife's approval.

There is no sense of fear when it comes to their own brethren or son. Only the outsider which is the WLHA finds herself without any takers in the in law family and natal family with fear being attributed as the cause.

6.7.1 Fear Indicators

- Fear of talking
- Fear of mixing with infected person
- Fear of visiting home of infected person or letting infected person visit them
- Fear of children getting infected by mixing with HIV children of sister/brother
- Fear of handling food or taking food prepared by infected person
- Fear of disease being incurable

SECTION 6.8: BLAME

Health service providers are the first perpetrators of blame…the seeds of discrimination are sown at this stage itself…

"Doctors have told me take away your daughter in any case she will die, unnecessarily we can't take risk with our other patients." - **Mother of Bharti Nayak**

Dowry is often the first step towards domestic violence…being an HIV "aids" it further…

"The boy's family had demanded Rs. 35000 at the time of marriage, since we could not arrange it they have been ill treating my daughter and also have broken ties with us " **- Mother of Bharti Nayak**

"She faced beating from her husband after marriage, his character was not good." **Sister in law of Bharti Nayak**

"My sisters in law are bad people, they have not given her any right in their property after her husband died, I told my father and got her back from there." **Brother of Pramila**

Family blames WLHA's husband for her condition…

"My sister's husband is to be blamed for her condition, she informed me immediately when she tested positive." **Brother of Bharti Nayak**

Some husbands are insensitive considering themselves to the Lord and Master of the WLHA…

I will not disclose our status to my wife's family as they would insult me, they always considered me a bad person, they will stop me from coming to their house. My wife should also not go back; she should stay with me and look after me. I continue to have sex with her without condom as I don't like it otherwise – she has also contracted it from me, so what? **Husband of Savitri**

But most of them are willing to accept that they are at fault….

"I used to go to the outside women and am ashamed of my behaviour, I am responsible for my wife's condition. " **Husband of Jumana**

"I don't know how I got the disease but my wife is suffering because of me. I treat my wife properly and take care of her and the children with my meagre income of Rs. 3000 per month". **Husband of Rekha**

"I accept the total responsibility of giving the disease to my wife, I used to have sex with her after knowing that I am infected but the condom burst so I got her tested." **Husband of S. Salgaoncar**

There is some respite in cases when the son is known to be wayward and the WLHA is a dutiful daughter in law ….

"I don't doubt my daughter in law because I know that she has got it from my son." **Mother in law of S. Salgaoncar**

"Though my wife tested positive before I did, (at the time of her pregnancy) yet I do not doubt her, I have total faith in her, she must have got it from me." **Husband of Jaya Bedekar**

"I was shocked to know about my brother's HIV status since he is a very good character and has no bad habits. Also his wife is a good character." **Brother in law of Jaya Bedekar**

"I felt very sad when I came to know about the status of my elder sister in law, we have not disclosed her status to the neighbours though her husband's status is known. No one in the family blames my sister in law because everyone knows that her character is good but her husband is an immoral character ". **Sister in law of Lata Tope**

"I know my son has done wrong things. I never doubted my daughter in law; she always was accompanied by me wherever she went ". **Mother in law of Lata Tope**

The blame stems from the belief that HIV can happen only to immoral persons. If the husband of the WLHA is known to be of bad character and his wife has been in the good books of her in laws being the dutiful daughter-in-law, she may not be blamed. But as in the case of Bharti Nayak since the in-laws were already unhappy with the dowry brought by her they shifted the blame to her and also threw her out of the house, but not their son. She was then accused of bringing shame on the family.

Not only the family, the husband also in some cases has no sympathy for his wife but continues to force her to have sex with him and also look after him – she is no position to negotiate or refuse sex with him. She also continues to stay with him as she is not sure of whether she would get shelter elsewhere. In other cases, the husband is willing to take the blame for her condition. There is a mixed response about the blame quotient.

HIV - A New Weapon in the hands of the husband and in laws

Women are already suffering from domestic violence for dowry, childlessness and other reasons. She is also already tolerating a wayward husband - She has to willingly embrace HIV from her husband - The HIV condition coupled with already existing domestic violence overflows her cup of woes - it gives a good opportunity for the in laws to throw her out of the house and deny her property rights - there are cases where she is not blamed but the son is – either because she is required to look after the positive son or when she is an earning member.

Does similar blame play itself out when it comes to the son?

We met with Mr. Prakash Bhide (Working as contract labour in a white goods factory). His spouse is still negative as he exercises caution. He shares the status with parents, wife and two young brothers. He does not share with wife's family, wants to keep it confidential for fear that they may take back their daughter, he needs her to take care of him. He is not blamed by his family as he continues to earn and support them (he has not even disclosed to his employers) there is no discrimination and they continue to treat him normally.

He is not blamed for being immoral as long as he is earning the daily bread for the family.

In another case of Raju a masala seller in the trains in Kanpur – his mother looks after him as he has become very weak – he can work only for 5-6 days in a month. He is known to visit prostitutes regularly yet his mother does not blame him.

Even when the son is not earning he is cared for… mothers have a soft spot for the son…But when there are no parents elder brothers may or may not support the MLHA-even if he is earning well. Yet friends do not desert them they do have someone whom they can depend on.

Take the case of Rajan a hotel manager in Udupi..

"I don't have any parents, was staying with my uncle – my uncle blames me that because of you my son is not getting married, Now I am staying with my brother but his wife does not like it, her sister is staying with her, she is always thinking that it will transmit to her sister, They have asked me again and again to stay in an Ashram, I felt very bad when my bhabhi asked me to leave the house, My clothes and utensils are kept separate, My two friends are supporting me financially, My boss knows about it and he also supports me, The neighbours also know about it but they support me…"

6.8.1 Blame Indicators

- HIV can happen only to immoral persons
- HIV infected persons are dirty
- WLHA is responsible for the condition of her spouse
- WLHA has brought shame to the family
- WLHA has the right to refuse sex to her husband who is positive
- WLHA has the right to take some rest and not expected to take care of her husband
- WLHA has the right to property after her husband dies
- WLHA has right to shelter after her husband dies
- WLHA should be provided shelter at least in her natal home

SECTION 6.9: SHAME

Her presence in the family would bring bad reputation to the family…pose problems in fixing marriages for other eligible brothers and sisters..the infection is kept under wraps….particularly for the daughter in law – she cannot even share it with her parents and is totally at the mercy of the inlaws…

"We were shocked with the behaviour of the in laws; they said their other son's marriage would become difficult and we should take her back. After some time they also threw her husband out, now I have arranged a rented accommodation for both of them near my house. No one ever says that the husband is responsible; they have blamed my daughter not their son." **-Mother of Bharti Nayak**

"My daughter's in laws were scared that if people get to know then her brother-in-law's marriage might become difficult."- **Mother of Bharti Nayak**

"My wife has also not informed her parents- we pretend everything to be normal, we feel ashamed to share such information, Even my fours sisters do not know about it. My last sister has to be married and I do not want that my status or my wife's status should cause any hindrance in her marriage, we are tight lipped; only my mother knows, even she has not told my father." **Husband of S. Salgaoncar**

From the family's point of view, having a HIV-positive member in the family is a matter of shame. They generally do not disclose their status to outsiders and sometimes even to members within the immediate family for fear of losing social status and incurring social ostracism. Family support itself is viewed by some respondents as being linked to one's social status. In all three locations, disclosure of the disease among members of the larger community was guarded by family members. This further increases the WLHA's isolation as she cuts herself off for fear of being ostracised lest anyone comes to know about her status.

Chained to her fate…

She cannot disclose it to her natal family also if there are other brothers or sisters in the husbands family to be married off – she has to bear the ill treatment and discrimination silently – there is no medical care initiated for her – the son can always get his treatment by going outside into another town too – but she is confined to the house and made to do the household work despite her need for medical care …

6.9.1 Shame Indicators

- Percent of people who would feel shame if they are associated with a WLHA
- I would be ashamed if someone in my family had HIV/AIDS
- People with HIV should be ashamed of themselves
- People with HIV deserve sympathy
- % of people who are aware of anyone who has the infection
- People with HIV/AIDS should be allowed to fully participate in social events in our community.
- HIV persons in the family impact the social standing of a family

SECTION 6.10: JUDGEMENT

Character is suspect…

"We have not told anybody, especially people around us, everybody knows she is ill they do not know what is the exact illness, if they know they will segregate our whole family."- **Mother of Bharti Nayak**

"I love my sister very much and do not doubt her character, my brother in law is a driver and his character is suspicious. I have informed my younger brothers' families about my sister and asked them to support her. I visit her often. I have not told my uncles as they may even restrict my visits to their house. I also give her economic support." **Brother of Bharti Nayak**

Natal family provides support makes her conscious that they are doing so…

"She is not able to work due to bad health. She can hardly eat, she has no appetite. She has a kind of hatred for her self" "We will take care of her child like our own child, we will save money from our child's expenses and look after her child." **Sister in law of Bharti Nayak**

"I feel sorry for my grand daughter and shall support my son and daughter in law as much as I can, I feel very sorry for them." **Father in law of Lata Tope**

"I will take care of my sister even when my father dies." **Brother of Pramila**

Economic Independence turns the tables…

"People would say that Taramati (my sister-in-law) is not a good girl but she has been living with us for all these years…we know that she is good… But ever since she has started earning nobody says anything about her." **Taramati's sister-in-law (brother's wife) on comments being made by people when Savitri returned to her brother's house after being thrown out by her inlaws**.

Family members perceive that they will face social ostracism if it becomes known that somebody in the family has HIV. As a result, PLHAs try not to reveal their status even to their family members unless they are not in a position to take care of themselves and need the financial and care giving support of their families. Families are forthcoming to help their children and also provide them with a shelter as long as their status is kept a closely guarded secret from the larger family. They do not want to bear the insult or segregation from the larger family which is inevitable once it is known that they are HIV-positive.

However, it was observed that WLHAs who are earning may also be accepted because they are providing some economic support to their families. For instance, Taramati's sister-in-law's acceptance may have been triggered due to this fact.

A hidden motive was also detected in case of Bharti Nayak's sister in law and brother. Though they made lofty statements about caring for her and supporting her fact of the matter was that all the three brothers had gone their separate ways once she was brought back home by her father who died soon after. They continued to "support" her from a distance but when they got an opportunity they cashed on it– they were found to be blatantly asking for money for their travels at inflated costs and providing false documents during the research. Even the mother who declared her love for her daughter did not stay with her (Bharti Nayak) though she he herself is a widow.

Whatever the reasons for providing support, most PLHAs feel that even moral support would give them the desire to fight the disease. But in the face of hostility from their family members, the feeling of self-disgust and shame is further enhanced.

Poor economic condition in most homes makes the task for the natal family difficult – some of them support her willingly while some do it grudgingly while some do not do it at all leaving her to her fate. She is not the priority for any one – she is the last one – if they have the means they may offer her support – else they are not really bound to do it.

6.10. 1 Judgement Indicators

- Non disclosure of status to extended family
- An HIV infected person should be asked to stay away from his family and society
- Children of the WLHA should be cared for
- If a WLHA is being given support by the family she should try and pay them back in some way either by working outside or by working at home.

SECTION 6.11: ENACTED STIGMA

Denial of basic human rights – food and shelter…

"Once they know about the disease the in laws even stopped giving food to her."- **Sister in law of Bharti Nayak**

"Yes, I understand that my son and daughter have to be given good food and looked after for the next 4-5 years." **Mother in law of S. Salgoancar**

Rebuke and Ridicule by Neighbours is most feared…

"Though I am normal yet the neighbours have a suspicion even about my state, they do not speak with me." **Sister in law of Lata Tope**

"I do not want to inform others about my son and daughter in law to anybody or else people will not talk. Also my grand daughter is negative and we cannot let her parents' status affect her marriage when she grows up." **Mother in law of Lata Tope**

"Me and my wife are not allowed to enter shops and are laughed at. " **Husband of Jumana**

"My relatives are not good towards me and my family." **Husband of Malti**

Moral support is all the family has left at times to give…

"I have spent so much money on my brother's treatment that now have a huge loan on my head, Now though I cannot support them economically I do provide them moral support because we have no parents. I think that a person can live longer if his family supports him at least morally." **Brother in law of Jaya Bedekar**

"My brother visits us occasionally and provides moral support." **Husband of Jaya Bedekar**

"I have not informed any other relatives as I fear that they will cut all relations with my family, I cannot support them economically but always provide them the courage to fight and be practical, they should not feel neglected." **Brother of Jaya Bedekar**

Most victims resist telling their family members about their status for fear of social ostracism. Some family members of HIV-positive persons shun them because of social ostracism – such as their sons/daughters may not find matrimonial matches. There is an in built fear about sharing food, visiting, allowing access in public places

and also ridicule faced by the WLHA at the hands of her family – it may be present in some cases while in some cases there is a tolerance.

6.11.1 Enacted Stigma Indicators

- Family ties are cut off by in-laws family because of fear that a family member may not get a good matrimonial match.
- Access to family support only till husbands live.
- Lack of moral/emotional support of the family.
- Financial status of the HIV+ person – the poor suffers more ostracism and discrimination.
- Lost respect/standing within the family and/or community.
- Given poor health services
- Teased or sworn at
- Visited no longer or visited less

SECTION 6.12: STIGMA INDICATORS FOR THE FAMILY

Interviews with the family members of the WLHA have provided sufficient evidence about the discrimination against her. She definitely does not get support from her marital home after her husband dies. Even when he is alive the sole reason for the support is to keep the fact about the disease within the family and to take care of her husband. The family definitely behaves differently when it comes to supporting the male members as opposed to the WLHA. In all the three locations there were differences which existed.

PARAMETERS	AURANGABAD	KANPUR	UDUPI
	Males are bad, going to other women but family is supportive as they are obsessive about a son Sex determination tests are done regularly as daughters are not preferred Women are not supported after death of husband Till he is alive she is expected to take care of her husband after which her natal family should support her or she can live alone No stigma is practiced towards the males, their waywardness and sickness is acceptable	Both males and females are discriminated Males are not looked after even by their mothers The community also ridicules and shuns both males as well as females	Males and females are both accommodated Not asked to leave house but taken care of by family though enacted stigma of separate utensils and clothes exists Families do not throw out their daughters as they have a legal right on the father's property

The natal family is also generally is a bit guarded about supporting her and would keep her at a distance after her husband dies. Her status is a closely guarded secret as it will have an adverse impact on the social standing of the family. She may also be blamed for the condition of her spouse if she has brought insufficient dowry or is involved in any other domestic problems with her in-laws.

Whatever their motives for providing support, the WLHA seems to be thankful for whatever little support she gets. Wherever the family support has been neutral – not expecting anything from her – the WLHA is able to lead a normal life as possible. Expectations from her husband are also minimal as long as she can stay with him till the end.

The least a family can do for her is to understand her minimum requirements and grant her just a piece of these to let her live the rest of her life peacefully as a normal human being – surely that is not a tall order for the family where she has grown up and has her bonding and also for the family for whom she has toiled hard to give them peace.

Section 7

Stigma & Discrimination: The WLHA Side

SECTION 7.1: STIGMA AND DISCRIMINATION - THE WLHA SIDE

The plight of the Indian woman is at the best of times far from enviable. Both in her natal and marital homes, gender plays a crucial role in determining one's status within the family. In most middle and lower middle class homes in India, girls are considered to be a burden on their parents, and are at best tolerated till they are married off, or at worse, discriminated against. In their marital homes, women are expected to look after not just her husband but his entire family and often here too, she is at the receiving end of ill-treatment from her in-laws. The already unequal status of women gets worse when she is diagnosed as being HIV-positive. Almost instantly, she loses her rights, she is segregated and even more discriminated against. Worse still, she is often blamed for bringing "bad luck" and for infecting her husband, when the reverse is often the case. Though she is expected to look after her HIV positive husband, she herself cannot expect any treatment or even empathy from her members of her marital home. Even in her natal home, HIV positive women cannot be sure of getting emotional and financial support. It is not surprising then that many HIV positive women have low self-esteem and curse their fate for their plight.

SECTION 7.2: METHOD OF CONTACT WITH WLHA

WLHAs were recruited by the positive networks whom the research team had contacted at the three locations. They were cooperative and eager to tell their side of the story. Discussions with each WLHA were held separately in a closed room. Permission to audio tape the interviews was sought from her before hand. In many cases the WLHA also got her children along with her for the interviews. They were found to be possessive and indulgent towards their children. Their children seemed like their only reason for existence. The WLHA were made at ease about the purpose of the research and requested to answer only those questions which did not pose any problem for them.

SECTION 7.3: WLHAs MET WITH (all names have been kept confidential)

Aurangabad:

- Jaya Bedekar
- Sapna Marathe
- Punam Shelke
- Bharti Nayak
- Lata Tope
- S Salgaocar
- Meenakshi Thakur
- Jyotsna
- Amrita

Kanpur:

- Savitri Sahoo
- Kalavati
- Julekha
- Sabri (tested HIV –ve but husband is positive)

Udupi:

- Rajeshwaree (Widow)
- Pramila (Widow)
- Laxmi (Widow)
- Malti
- Caroline
- Savitree
- Vijaya

In Udupi it was also considered to be useful to conduct an FGD as the society was open to discuss about AIDS – HIV + women were also forthcoming to participate in the discussion.

SECTION 7.4: AWARENESS OF CAUSES

She is generally caught unaware... does not even know what HIV stands for…

"We did not know anything about the disease. We found out when my daughter fell ill and she had to be given blood. My husband's blood tested positive. That's when the doctor told us about the disease…that untested blood should not be used; if my husband has the disease we should not have sexual relations and if we do, we should use condoms." - **Sabri, HIV-negative woman whose spouse is HIV-positive, Kanpur**

*"I came to know about HIV after my husband tested positive, he had continuous fever" - **Jyotsna, HIV-positive woman, Aurangabad***

"**I was diagnosed positive at the time of my pregnancy after which my husband was also declared positive" **Jaya Bedekar, HIV-positive woman, Aurangabad

*"I came to know that 2 yrs back. My husband died 2 yrs back. After his death I came to know about this. We were good and happy. He was not very ill. He only had malaria but within 2-3 days he died. Doctor said that we have to do the blood test. After that he got to know that he has HIV. But I am not aware what HIV is. Then my father took me to the hospital and there they conducted my test also. There I came to now that I am also HIV +ve. Honestly speaking I really don't know what HIV is all about. Today when I meet everybody and hear everybody talking about this then we came to know that we don't have to say this to everybody". **Mala. HIV –Positive woman, Udupi (FGD)***

"I came to know about this one year back. My husband's doctors were saying that he has T.B. when he died. 2 yrs back I thought I have T.B. all cough and fever. Then I went to doctor, he said that you got pneumonia and cough and he has given me the medicine and I got well. But after one month again I got cough and fever. The doctor told me that I will have to go for blood test and X-ray and then he came to know that I

have T.B. when I was taking medicines for T.B. I was getting weak day by day and then after that my brother had gone to the doctor and said what has happened to her. She has got bedridden and is not able to get up. Then doctor said that don't tell her but do one HIV test for her. Then they took me for the test and they came to know that I have HIV. Doctors gave me the medicines for 6 months and I was getting alright and after that they told me". ***Parul, HIV –Positive woman, Udupi (FGD)***

"I do not know what HIV is and when my husband got ill then only I came to know about this." ***Leela, HIV –Positive woman, Udupi (FGD)***

"Its been 8 years I came to know that I am HIV +ve. My husband was ill and he had q hernia problem. Then we had to go for test where we got to know that he is HIV +ve and I have gone for my test after 1 years and I have found myself HIV +ve too." ***Prem, HIV –Positive woman, Udupi (FGD)***

"I was not aware of HIV and all and that's why I was not afraid. My husband was crying and after seeing him I also got scared. Its been 7 yrs I know this from one test during my delivery. My husband died 2 years back." ***Sunita,, HIV –Positive woman, Udupi (FGD)***

"I was 17 yrs old when I got married. When I was pregnant I got to know this, not me actually my family members got to know this". ***Bharti,, HIV –Positive woman, Udupi (FGD)***

Most women were totally clueless about HIV when they or their spouses were first diagnosed as being HIV-positive. They would keep falling ill and keep going to the doctor until some doctor advised them to get tests done. Awareness however does not always lead to prevention. Take the case of Sabri, whose husband is HIV-positive, and who is now aware of the causes of infection. However, she has not got herself tested properly, even though she admits that she often gets a fever.

In cases of Bharti and Sunita in Udupi, they came to know even about their husband's positive state only when they themselves were tested during their pregnancy. In case of Parul she came to know about the disease only after her husband died – she now presumes that he probably had the same disease.

Positive women today who have been carrying the virus even for as recent as last two years were totally unaware of what HIV was when they were diagnosed with it – they assumed it to be just like any other disease – they did not have even inkling about the consequences of the disease.

The low awareness may be due to low interest, as women feel that the disease can happen only to those indulging in immoral behaviour. They are almost never aware of the wayward ways of their husbands and even if they are, negotiation of sex or insistence on use of condom does not come easily to them. As a result the disease never enters into their mindset until it reaches a stage when the symptoms become more discernible – when the doctor diagnoses either of them with the disease and on testing finds that the other spouse also has it.

The awareness indicator of the causes of transmission:

"Percent of community aware of the causes of transmission" should be tested for the females in the community v/s the awareness level of WLHA at present to evaluate whether there is a positive or negative difference in the awareness level.

SECTION 7.5: FEAR

Fear expressed by community and family takes its toll on her... she in turn does the same to her children and also in the society..

"I sleep on the same bed with my daughter. I don't think she will get the infection from me due to that….But I don't eat with my children. I am scared that they might get the infection. I don't let my daughters wear my clothes and I have not breast-fed my small child." **- Kalavati, HIV-positive, Kanpur**

"I go to functions as nobody knows about this so I go. I go to the functions but if at all if we have to cut some thing or to make something. I don't do that". **Sunita, HIV-positive woman, Udupi (FGD)**

Family members do not allow her inside their house…or even speak with her…

"People are afraid of getting the disease from me even if they speak with me" – **Bharti Nayak, HIV-positive woman, Aurangabad**

"In our colony 3-4 persons have died of HIV AIDS, since then everyone is scared to come near me but since my daughter is negative they allow her to play with them..my brother does not allow me to visit his place as I might infect his family." – **Punam Shelke , HIV-positive woman, Aurangabad**

"My brother doesn't eat anything made by me, they make the food and give it to me.. they keep my utensils separate." **Sheela , HIV-positive woman, Udupi (FGD)**

"My child is –ve but still other children don't play with him. Their parents don't allow them to play with my child. So whatever my child demands I get that thing for him so that they will not have to go to other's house to play." **Leela, HIV-positive woman, Udupi (FGD)**

"They don't talk also. They will not get infected by talking but still they don't talk. They don't even touch. My mother in law use to say don't give your food to your child, keep everything separate." **Bharti , HIV-positive woman, Udupi (FGD)**

"My in laws say make your (-ve) children stay with us otherwise they will also get infected. They tried a lot in separating me and my children. My mother in law says don't give your food, don't make them eat with your utensils. Keep his clothes separate and wash his clothes separately, My brother has small kids. Earlier they used to come to me, eat with me and sleep with me. But when they came to know about this they stopped doing all this."- **Sheena , HIV-positive woman, Udupi (FGD)**

Very few support her but from a distance…

"People around me who had HIV, they have not lived much. They died very soon. Then my family members said that if you have got this nobody can do anything. Just live your life like earlier. We are with you". – **Parul , HIV-positive woman, Udupi (FGD)**

Fear looms large in the community and family – HIV positive people are shunned totally – they are neither spoken with nor allowed to visit the house of the near and

dear ones. The disease carries this kind of stigma probably because it is incurable and also sex related.

In most cases women find themselves shelter less after the death of their husband. If they move out and stay in their parents' house they do not want to be a burden on their brother family or cause any harm to them – they feel that separate utensils, separate food, washing clothes are a small price they have to pay in return for the roof over their head.

Even when they stay separately with their child, the feeling of self detest and being balked at has permeated into the minds of the WLHAs so much that though they are now well aware about the routes of transmission they still take precautions like segregating their utensils and washing and cleaning their clothes and utensils separately. Though they know that contact alone cannot lead to transmission of the disease, in the case of their children, they feel 'scared' and therefore make it a point to not share their bed, food and clothes with their children lest they infect them.

However, they are hurt most if their child is taken away from them – they are denied being a mother to their child – they want to keep their child with them at any cost – if the children are negative – they may send them for studies far away from them or even if they stay with her she would indulge in precautions – but she is not willing to be separated from her child under any circumstances, they want to fulfil all the wishes of their child.

7.5.1 Fear Indicators

- Infecting family members by talking, eating, sleeping and staying with them
- Attending social functions lest they cause some harm
- Sleeping and eating with own child
- Sharing clothes with own daughter
- Allowing HIV negative child of WLHA to play with other children
- Child being taken away by in laws if he/she is negative

SECTION 7.6: BLAME

The health workers are the starting point in the blame game..

"When I was hospitalized doctors used to say you have done wrong things now you bear the results. My mother and brothers support me but my grandmother always misbehaves, she put a cloth in front of her mouth when she speaks with me. I have also not told any other relatives about my status. .When I have not done anything, why are these people torturing me?" – **Bharti Nayak, HIV-positive woman, Aurangabad**

The Mother in law is waiting for an opportunity to belittle her and throw her out as early as possible…also take away her property right forcefully… even her jewellery is not spared..she is left with no emotional or financial security into the streets at the mercy of her natal family who may or may not have her back…

"My husband used to be sick all the time… and my mother in law would say 'from the time she has come to this house, everything has gone wrong in this house'. Before his illness, she didn't have a problem with me, she would treat me like a daughter. I don't know how she changed so much." - **Savitri, HIV-positive woman, Kanpur**

"After she (mother-in-law) came to know about the infection, she would say 'you will not be able to live for more than 6 months. You will die. You are reaping what you have sowed". **Savitri, HIV-positive woman, Kanpur**

"When they had their son till that time there was no problem - but when their son had gone, they started scolding me, my mother in law and my sister in law. After 2 days of my husband's death they started all this. Even my son says don't go there, they scold you and you will die. When my husband was bed ridden and was unconscious my mother in law, with one lawyer's evidence made my husband sign a paper where it was written that I am ill and my wife is also not well so my mother will take care of my son and all my property belongs to my mother". **Bharti , HIV-positive woman, Udupi (FGD)**

"My mother in law said that my son has not done anything. She used to tell everybody that I roamed all around the village and she has given this disease to my son. Then my husband said that I have got this disease. Don't say all this. You have said this for the first time and this should be the last time also. Then my brother said that believe in god and just come in front of god and say, if my sister is like this she must die. He said when my sister got married she was too young. She cant do all this but still if you think she is like this then god should take her back. Now she don't say anything in front of me but she says this to others. They say that why don't you die. You have got such a major disease and still you don't die. If there would have been some other girl she must have died till now." **Bharti , HIV-positive woman, Udupi (FGD)**

"My in laws have taken all my gold ornaments and are saying that we have spent everything on your husband's treatment but the reality is there were no expenses." **Bharti , HIV-positive woman, Udupi (FGD)**

Mother and natal family are not too supportive either:

"Earlier I had all the rights, I had the right to live there and had all the responsibilities but now I don't have any right and I want rights in my husband's house. They don't allow us to live in his house. I am living with my mother now. Even in my mother's house they don't allow us to do anything, they behave very bad with me. If I would be earning at that time would they have done anything like this? I want rights and respect in my husband's house." **Sheela , HIV-positive woman, Udupi (FGD)**

Least of all the community also does not spare her…

"People say that we have sinned and therefore we have got this disease…they look at us as if we have sinned. But if we had money they wouldn't treat us like that." - **Kalavati, HIV-positive woman, Kanpur**

"I stay alone so if I get bored and go to somebody's place then people say that she goes in night even my brother says that she goes in night. Sometimes when I come late at night after work then my family members and neighbours say that you have killed your husband and how many more people you want to kill? They say these things loud enough so that I can also hear that. : No body. No matter how much

happy we are but whenever we are alone we cry a lot. A woman can tolerate anything but she cant tolerate if anyone will question her character. I think if I didn't have kids I would have died. I have to tolerate everything for my kids." **Sheena , HIV-positive woman, Udupi (FGD)**

Do women who have contracted the disease from their husbands blame them for their condition? Some do and others curse their own 'fate' or 'bad luck'.

"I don't hold anyone responsible for my condition. It was in my fate. So it happened. What's the point in blaming anybody?" **Savitri, HIV-positive woman, Kanpur**

"My husband did not give me anything except this disease."-**Kalavati, HIV-positive woman, Kanpur**

"These men (who go to sex workers) are not bad, usually their wives are demanding …bring this ...bring that…so they often get fed up and go to other women…. I have nothing to complain about my husband…he has been truthful to me…I feel sad for myself but I still have dreams. I have my own strength." - **Jyotsna, HIV-positive woman, Aurangabad**

"I take care of my husband but nobody takes care of me." – **Punam Shelke , HIV-positive woman, Aurangabad**

"I am not angry with him. I love him a lot but he should be healthy, do something and we also want to live a normal life." – **Sunita , HIV-positive woman, Udupi (FGD)**

"Our culture is like this only, our husband is our God." **Sheena , HIV-positive woman, Udupi (FGD)**

A woman is born with the blame stigma – if anything goes wrong anywhere in her natal family or marital family the blame falls squarely on her – she is the culprit who has brought ill luck to the family. Despite being a known fact that the woman must have contracted the virus from her husband she is blamed by all and sundry – starting from the health workers who refuse to treat her to the mother in law who blames her for "misdeeds' for making her son ill. Even the community perceives the WLHA to be a sinner.

The WLHA remains unagitated even in the face of all the blame – she cares for the ill condition of her husband, does not deny him sex and embraces the disease as her fate. In retrospect after the husband dies she does have a feeling of being left alone to combat her fate and sometimes blames him for her condition.

But worse is the constant barrage against her character – even if she is working hard for her livelihood to support herself and her child she is rebuked by her own family who accuses her of being of loose character. The inlaws and neighbours consider her to be a bad influence in the society. Even in her own maternal home she is denied the basic rights of eating and sleeping. She is cursed for being alive.

The issues which hurt WLHAs most are denial of their right to live, denial of any rights in parents and in laws house (after husband's death) and pointing fingers at her character.

7.6.1 Blame Indicators

- WLHA is responsible for bringing ill luck to the family
- WLHA is responsible for bringing illness to her husband
- WLHA is a fallen woman
- WLHA is a dirty woman
- WLHA is paying the price for her sins
- The husband of the WLHA is not responsible for her condition
- WLHA should comply with the sexual needs of her husband when he is positive and before she tests positive
- WLHA should care for her husband when he is sick
- WLHA should die once her husband dies
- WLHA is a burden on her parents
- WLHA does not have any right to the property left by her husband she should leave it for the in laws

SECTION 7.7: SHAME

There is disgust with ones own self for bringing shame to the family..

"I feel ashamed of myself, I feel guilty" – **Punam Shelke , HIV-positive woman, Aurangabad**

"I felt that by contracting this disease I had brought shame on my family….I was scared that my family, my neighbours, would think wrong things about me. I have not visited my natal home for one and a half years." - **Julekha, HIV-positive woman, Kanpur**

"After my daughter was born, there was a newspaper story. After that people came to know about it. I can't show my face to anyone." - ***Julekha, HIV-positive woman, Kanpur***

Nobody knows in my neighbourhood. Its only me and my 3 brothers who know about this, neither my mother nor my maternal and paternal aunts know about this. My mother will get mad at me. I have not told this to my sister in laws also. My brothers are very good, they know but their wives doesn't know about this. They say neither we will tell nor you will tell this to anybody.

Prema, HIV-positive woman, Udupi (FGD)

This also results in self-hatred and internal stigma…

"Others perceive me to be 'dirty'. They say that I must have had some illicit relations that's why I have got this infection. When I hear things like this about me, I feel dirty." **Savitri, HIV-positive woman, Kanpur**

"I felt more insulted than angry when people don't even talk to me. I feel lonely… the hatred..is the worst thing, I have to live for my daughter. Even I have a feeling of hatred for myself, feel disgusted..I feel I will infect my daughter also..I am scared to

even touch her..the only feeling I have now is hatred for myself…nothing else…" - **Jyotsna, HIV-positive woman, Aurangabad**

The stigma carries on in the future and may have an effect on the future of her child.

"My in laws says that you should not get your child married, but I say why will he not get married, he is –ve." **Bharti, HIV-positive woman, Udupi (FGD)**

The stigma attached to the infection consequently gives rise to shame and self hatred among WLHA. She withdraws from her family completely – stops contact with her natal home – which is a means of succour for her when she feels low. Her character is doubted. She develops an aloofness even from her own children as she feels unclean to touch them. The self hatred turns their life into a mere existence for the sake of their children. But she feels that maybe eventually the future of her children may also get bleak because of her own positive status.

7.7.1 Shame Indicators

- WLHA feels ashamed of herself
- WLHA feels guilty
- WLHA feels people think wrong things about her
- WLHA stops visiting her natal home
- WLHA feels self hatred
- WLHA feels dirty
- WLHA refrains from touching her own children
- WLHA cannot disclose her status which starts weighing upon her
- WLHA feels her shame may have an effect on the future of her child

SECTION 7.8: JUDGEMENT

Prefer to battle it alone as they are afraid of further disruption in their already scattered lives…

"*If people come to know about my infection, who will marry my daughter? She is 17 now. Nobody will come to my house, nobody will speak to us*." - **Kalavati, HIV+, Kanpur**

"*What is the use of telling anybody*." **Kanta, HIV-positive, Aurangabad**

"Please do not publish any of this in a newspaper."- **A family member whose relative is HIV-positive, Aurangabad, making an appeal to the interviewer.**

"*I have not told my mother-in-law about my illness, because it will cause tension, my husband cannot work so I make my living by stitching blouses, I also feel very tired, I don't want to even tell my mother and cause her any pain."* **Jyotsna, HIV-positive woman, Aurangabad**

The child is her only reason to live...and she wants to live and earn for her child and herself…

"My name is Lalita. I don't want to die , it's a very small life. I have a small daughter, that's why I want to live my life happily." **Leela, HIV-positive woman, Udupi (FGD)**

"I see my child and get happy for him. We get happy by seeing our children and forget all our sorrows." **Bharti, HIV-positive woman, Udupi (FGD)**

"Everybody is earning for themselves, I along with my son don't want to be burden on anyone and if at all we will become a burden on anybody then they will behave very bad". **Bharti, HIV-positive woman, Udupi (FGD)**

On finding out about their HIV-positive status, the tendency is to hide this fact from their family and neighbours. Disclosure is a real problem with most women. Fear of social ostracism forces many to hide their HIV status from family members in their natal as well as marital homes. For instance Kalavati who has 3 daughters and 1 son has not told even the eldest daughter about her infection.

Most of the women feel socially ostracised within the community and also within the family. The only solution out of this condition is to have economic freedom – with their limited energy resources they try to earn enough so that they may be able to feed themselves and their child and also give him a good future – their child is the only reason to live .

7.8.1 Judgement Indicators

- Telling anyone about the disease will not help WLHA in any way
- Making her illness public would jeopardize the future of her children
- Disclosing the disease to her marital family would only bring her more trouble
- Livelihood means is the best solution to all the problems

SECTION 7.9: ENACTED STIGMA

Clearly, judgement, fear and the blame game all lead to HIV-positive people experiencing stigma and discrimination from their family members as well as neighbours and other members of their community.

Almost all women feel the need for emotional support and sympathy from their family members. A few words of kindness and humane treatment is all that most women expect and this too is not granted to them. In terms of financial support from their families, apart from shelter and food, they get little else.

Made to work endlessly even though she needs rest…

" I get up in the morning at 5.30 AM, do not rest in the afternoon because my mother in law gives me lot of work to do, I sleep at 10.30 PM." – **S. Salgaoncar, HIV-positive woman, Aurangabad**

Lack of care for human beings…

"My mother in law does not allow me to touch the vessels, drinking water for me is kept separately, I am never invited for any social functions, people stare at me when I go out … this is very hurtful. I have not even told my parents else they will get very worried and maybe will not even be able to bear the news…my younger brother is aware but he does not allow me to visit his place… I am very lonely… whatever I earn is spent on medicines for my husband… where will I go after he dies?" – **Sapna Marathe , HIV-positive woman, Aurangabad**

"When my husband was ill for 6 months, I was there at his home. He was bedridden and nobody was there to look after and help us. I was the only one who had to take care of him. He wanted tea, food many times in a day and I had to do all this. They expelled me from that house and now I am living in my mother's house. Here everybody is not good but my father supports me."- **Sheela, HIV-positive woman, Udupi**

Deprived of even social communication ….

"My devrani (husband's brother's wife) has stopped talking to me after she came to know that I am infected." **- Julekha, HIV-positive woman, Kanpur**

"After the family came to know about my husband's infection, they raised a wall in the house."

Sabri, HIV-negative woman whose spouse is HIV-positive

"Everyone on my husband's side knows, they do not want me to come to their place, they would feel insulted if it is known." - **Jyotsna, HIV-positive woman, Aurangabad**

"Nobody plays with my children…..When people come to our house, they don't eat the food that I cook. So we order food from restaurants and serve it."- **Julekha, HIV-positive woman, Kanpur**

Humiliated publicly…

"I feel very depressed when my neighbours tease me when I go out" – **Punam Shelke , HIV-positive woman, Aurangabad**

"I have not done anything wrong and yet I have got this infection. But still I have to suffer the taunts and comments of people. That's what hurts the most…." - **Savitri, HIV-positive woman, Kanpur**

"When I go to attend phone calls at the village booth, the villagers will wipe the instrument after I have used the phone. They say that 'why does she come here…isn't there any body in her house who can attend the phone; why does she come?.' As a result I have stopped going out and talking to anybody." **Savitri, HIV-positive woman, Kanpur**

Moral Support provided by some families makes them brave the odds..

"My only expectation is that my brother should speak with me and inquire about my health, feel proud that I am braving such odds and give me moral support, I attend all social functions as I have not informed the relatives about my state..if they will come

to know they will stop speaking with my family." – **Punam Shelke , HIV-positive woman, Aurangabad**

"I am happy about moral support provided by my brother in law and brother but I need economic support, I do not like my brother in law's wife avoiding me, I want to fight and survive." – **Jaya** B**edekar , HIV-positive woman, Aurangabad**

"I earn money by making silver belts at home. Papa helps me when I need money desperately. Earlier my brother would give me money. But my sisters have stopped him from giving me money." – **Rajeshwaree, HIV-positive woman, Udupi**

"Courage comes, when you know food has to be procured by you, you cannot depend that husband will get it. But you have to do it…Whatever I want, I will do it slowly but it will get done." **- Jyotsna, HIV-positive woman, Aurangabad**

"I don't know whether my brother knows about my infection. I haven't told him anything….It would be nice if he could stand by my side. I don't even expect any financial help from him. I just wish he would treat me with love and kindness."- **Julekha, HIV-positive woman, Kanpur**

"I am like that only which I was few years back when I didn't have anything like this. My family members support me. Nobody has behaved differently that I am not like them. I have not felt any kind of difference. When they cry I also cry with them. I don't feel any difference." **Bharti, HIV-positive woman, Udupi**

Self inflicted isolation

"People stay away from us. Nobody call us, nobody even talks to us. They sit at a distance. Some like my 'nandoi' (sister-in-law's husband) who knows about this, calls us but we don't go." **Julekha, HIV-positive woman, Kanpur**

"I wish people wouldn't hate us. All I need is some sympathy, I feel so lonely. I just want to look after my children." - **Kalavati, HIV-positive woman, Kanpur**

On the flip side, HIV-positive persons also point out that people's reactions have changed when they have found work. Many feel that if you have money, nobody would dare to ill-treat you. In a few cases, PLHAs have reported that not everybody discriminates against them.

"Ever since I have started working things have begun to change. Some people talk to me nicely. They ask me how I am and ask about my work. I find it really strange that how the same people who used to shun me have now begun to be nice to me." - **Savitri, HIV-positive woman, Kanpur**

Loss of rights is experienced by most HIV-positive women, particularly in their marital homes. Almost none of the women have been able to live on in their marital homes after the death of their HIV-positive husbands. Though most find shelter in their natal homes – except in some cases – here too life is not discrimination-free for HIV-positive women.

"In our society, we have rights in our natal homes, not in our marital homes…" **Rajeshwaree, HIV-positive woman, Udupi.**

"I am not allowed to cook in my natal home. I have three children but my family members do not treat them well. My sister refuses to talk to me. We have to keep our things separately. The only reason they tolerate me is because of my father who supports me. The day he dies, I am sure they will throw me out." - **Pramila, HIV-positive woman, Udupi**

Enacted stigma at the hands of the in-law family, the natal family and the community is almost always a way of life. In most cases they are discriminated against by their marital home family members and neglected by their natal homes. While bad treatment from in-laws is accepted by most as being a fact of life, the ill treatment by their birth home family members causes pain and hurt. WLHAs are not looking at financial support but more at emotional support.

In cases where they have been provided even moral support by their family members they have managed to brave the odds and are looking ahead with optimism despite all the hardships.

7.9.1 Enacted Stigma Indicators

- WLHA made to work from morning to night without any rest'
- Eats and cooks with separate utensils
- Drinking water separated
- Not invited to social functions
- Stared at
- Stopped from visiting her relatives and family house
- Feeling of loneliness
- Brother stops speaking to her
- Family sits at a distance
- Family does not eat food cooked by her
- No one plays with her children
- Stops going out for fear of being ridiculed
- Ostracised socially no one visits their house
- Break down of communication within the family
- Used and thrown out of marital home when not required (after death of husband)

SECTION 7.10: A COMPARISON OF THE THREE LOCATIONS: MIND STATES OF WLHAS

In terms of HIV+ persons' expectations from family members, this differs in all three locations. In Aurangabad, WLHAs expect nothing from their in-laws and most meekly accept that once their husband dies, they will not have any rights in their marital homes and will be thrown out. Here, most WLHAs conceal their status from their own parents as they do not want to cause them more anxiety in their old age. Women here do feel that empathy from their brothers, a little understanding and some financial support from them would go a long way in helping them face their grim situation. They are happy if they are allowed to attend social functions in their marital

homes. Their expectations from their husband is also minimal while the WLHA is willing to take care of her husband and support him till the very end.

In Kanpur, WLHAs have no expectations from their relatives in their marital and natal homes. They feel that this situation is their 'destiny' and they cannot turn to anybody and must wait for death. Shunned by both families, she only expects economic support from her husband.

In Udupi, WLHAs expect that their natal homes will look after them and provide them with food and shelter. Since daughters have a right to the property they are confident that their share cannot be denied. They expect their brothers to be non-discriminating, financially supportive and treat them as normal people. WLHAs expect to attend all family functions in their natal and marital homes. Their expectation from husband is in terms of both financial and emotional support and they are willing to separate if necessary.

However barring in a few cases these rights are even denied in Udupi – she suffers a similar plight – in fact she is also tormented as being of bad character, her property is taken away from her forcibly, she is humiliated by her own family – yet she compromises her "non existent" status for the sake of her children.

In Udupi, during the in –depth interview stage most WLHA were protective about their families for fear of word getting out and losing their only shelter. However in the group situation they gathered the courage to speak, they could also not deny certain facts as their condition was known to other members – this brought out the reality in Udupi – it is as grim as in the other locations.

Section

8

Conclusion

8.1 Interplay between HIV, Gender and Stigma

Stigma and discrimination against HIV-positive persons, and particularly WLHAs, emanates from a combination of factors. Fear, Blame, Shame, Judgement and Enacted Stigma are not just individual elements in the Stigma/Discrimination dynamic but are also part of a continuum. All these factors are at play at three levels – the community level, the family level and the PLHA/WLHA level. Any intervention that is designed to address stigma and discrimination will have to be targeted at each of these levels in order to achieve the desired results.

We have seen in our interactions with the community, family and the WLHA herself – at the core of all the stigma and discrimination towards the WLHA is a simple fact – She is a woman! She is destined to bear the brunt of the sins of her husband and she can be thrown in and out of houses, can be robbed off all her possessions and left in a state of destitution for all the family or community cares. She has come to face the wrath of HIV at a very young age when she is entering a new married life full of dreams – but soon her dreams are shattered when she finds herself positive. She then is cursed for bringing bad luck to the family though the positive son may be well cared for. She nurses her husband till his last days and is happy that she could discharge her responsibilities as a wife but she does not want to get married all over again to an HIV person for the sake of companionship and she recoils even at the mention. She cannot bring herself to nurse another person once more – it has been living hell for her – she would rather embrace loneliness than seek such companionship.

8.2 The Loner

And there lies the crux – she is now a loner – being HIV positive - all because she was an innocent victim to her husband's misdeeds. She has been blamed, rebuked, denied property, jewellery and even basic human rights like food and shelter and also motherhood in some cases. However good she may be she is only good till such time as the husband and the family need her. She is made to pay a heavy price for her husbands philandering ways – and for that too she is blamed. Like one woman in Kanpur said probably she has been a demanding wife troubling her husband for getting her things and he in his frustration had to visit the prostitute to take his mind off so ultimately she has failed in her duty as a wife and deserves to be thrown out anyways.

Till such time the community and the family view all her actions in a prejudiced manner. Stigma and discrimination against her is not likely to abate.

Based on the findings of the study we have developed a Desired-Perception-Matrix at each level – for the community, the family and the WLHA. Interventions should be developed with the aim of achieving these 'desired perceptions' to ensure that there is the desired change in behaviour which will ultimately lead to reducing stigma and discrimination.

SECTION 8.2: COMBATING STIGMA AT THE COMMUNITY LEVEL

The community has a pre-eminent position in the Indian way of life. Whether an individual is stigmatised or not depends on the perceptions of the 'community' (often also referred to as 'society') . Bringing about a change in the perceptions of the community is critical to fighting stigma and discrimination of PLHAs.

Current Perception	Building awareness to create the following Perception	Desired Behaviour
Fear of contracting the disease	Clearly emphasising how the disease spreads. There needs to be more information about how it doesn't spread – e.g. By talking, sharing food, clothes, etc.	Allowing HIV-positive children to play in the community area; stopping the isolation and segregation of PLHAs.
Infection is a result of bad/dirty/immoral behaviour. Hence a feeling of disgust towards the HIV-positive person.	It is an infection. It can happen to anybody. Proper care and treatment are critical issues.	Reforming the 'us vs. them' mentality. HIV-persons are not abnormal or bad. They are not deserving of 'disgust' and suspicion.
Isolation is necessary – and their utensils and clothes should be kept separately. They are deserving of our ridicule.	There is no danger in sharing food, utensils and clothes with HIV-positive persons. Extending support in small ways and accepting them as a part of the community is critical to the well being of PLHAs.	HIV-positive persons deserve our support, not ridicule.
Women cause the spread of this disease and they are deserving of contempt.	Emphasising the role of women as caregivers and as the anchors of family. Treating women with respect and granting them their rights is essential to the welfare of any society.	Equality and respect of women. When a woman is ill, she needs as much care and treatment as men.

SECTION 8.3: COMBATING STIGMA AT THE FAMILY LEVEL

The significance that every Indian places on the family need not be emphasised. Despite the disintegration of the joint family system in urban India, there is no denying that the emotional bonding with the extended family has not lost its significance. In times of distress, it is the family that one turns to. For married women, the marital home is not just her physical abode, but traditionally, the home where all her loyalties lie. The natal home plays second fiddle as the traditional Indian belief is that a daughter is *"paraya dhan"* (the wealth of another). She fulfils many roles in the marital home: most importantly, that of a caregiver. However as has been evident from the interviews in this study, most married women face the threat of being rendered homeless when they contract the disease. Worse, they often find little to no support in their natal homes. Sometimes, they may be given shelter but are otherwise treated like outcastes, where they are not allowed to cook or participate in routine things and often their sisters and brothers do not even speak to them. Any

intervention that aims at reducing stigma and discrimination will have to address the issue of women's status in both the marital home and natal home.

8.3.1 Marital Home:

Current Perception	Building awareness to create the following Perception	Desired Behaviour
WLHA must look after her husband till he is alive at the expense of her own health	Women suffering from HIV deserve of care and treatment themselves. And need rest so that they can fulfil their duties.	Supporting women to help them face the challenges of life.
After the death of her husband, the natal family should be responsible for her. Or she should take care of herself	After marriage she is an important member of our family and has a right to maintenance and support of our family.	Support her even after the death of our son.
It's her duty to the family to take care of its members	It's her right to get medical care, rest and nutrition.	Family ensures that she is not overburdened with work.
When the husband is too ill to earn a living, it's her duty to find work and earn.	She has a right to shelter and maintenance.	Family ensures that she is not deprived economically.
She is the cause of all our family's problems. She has infected our son.	She is as much a victim as our son. It's not her fault that she contracted the disease.	Family treats her as a respectable person and not as a social pariah.
She is dirty and invokes fear and disgust. She should stay in her room, and not come in contact with anyone else.	She is suffering from a disease and needs our support and proper care. There is no harm in eating meals cooked by her.	She is part of our family and is involved in all our daily routines – like preparing food, etc. – and actively participates in our family functions.
She may infect her children and she needs to be separated from them. She should be left alone to deal with her problems.	She needs our support to ensure that her children are taken care of.	She needs our moral and emotional support to think positive and lead a better life.
If she is earning and bringing home money, she will be tolerated.	She needs not just financial support but also emotional and moral support.	Her financial independence gives her the self-confidence to lead a better life. And she will always have our support no matter what.

8.3.2 Natal Home:

Current Perception	Building awareness to create the following Perception	Desired Behaviour
She is no longer a part of our family	She is our daughter and will always be a part of our family.	She has equal rights to property.
She has married a wayward person and has to pay for her sins. Or, this is her 'destiny'/karma.	She has not done anything to be ashamed of and all she needs is encouragement and support to carry on.	Her parents and brothers should instil in her the courage and will to live.
We do not have the economic means to support her. We have our own families to look after.	She is only asking for some sympathy and an assurance that 'we will always be there for you'.	Visiting her and being around for her to help her when she needs.
She should be there for family events but not disclose her status to everybody.	As a family member she is entitled to participate in family events.	As a family member it's her right to be involved in family events.
If she has nowhere to go, we will take her in but she can't expect anything more than that.	Treating her like an outcaste in her own parent's house is adding insult to injury.	As a family member, she can participate in all activities and events in our household.

SECTION 8.4: COMBATING STIGMA AT THE INDIVIDUAL LEVEL

Ultimately it is the person who has been infected who has to face the brunt of the disease. The perceptions and attitudes of the community and the family towards PLHA shape the individual's own perceptions and attitudes. Often when the community perceives HIV-positive persons to be of loose character, self-stigma sets in. Self worth and self esteem are severely degraded and this results in a fatalistic view of life. Moreover, for women who have been raised to believe that they are the second sex, that suffering is in their 'karma', and have always received discrimination at their natal and marital homes, the HIV-stigma only adds to this burden. There is therefore an urgent need to empower women and create an awareness about their fundamental rights in general. Only with this awareness, will women be able to take on the challenge of combating HIV. Access to employment opportunities and avenues for self-growth will give a boost to their morale and give them the self-confidence to battle HIV/AIDS.

Current Perception	Building awareness to create the following Perception	Desired Behaviour
I am dirty, I shouldn't even touch my children as I may infect them.	The infection hasn't made me a lesser person.	I have not done anything wrong and I will live my life with dignity and self-esteem.
I don't want my children to suffer; I will remove myself willingly from the family	By withdrawing from the family and children, I am neither helping them nor	By keeping the communication channels open, I will convince them

	doing any good to myself.	that HIV is not infectious.
I don't want to trouble anybody but I do need empathy from my brother and father.	It is my right to get the support of my marital and natal family members.	By keeping the communication channels open, I will convince them that HIV is not infectious
I have stopped dressing up or feeling feminine as all my desires have died. I am just living for the moment when I die.	It is possible to lead a normal life – a healthy, fulfilling life for many years.	I am confident that I can make the best of my situation and I can face the challenges with confidence and dignity.
I don't blame my husband for my condition but the least he can do is empathise with me.	Access to good healthcare, nutrition is my right.	I look after my husband and children but don't neglect my own health either.
I want to earn my living and support myself and my children.	I deserve employment that suits my needs.	I am economically independent and can support myself and my children.

Many of the transitions from current perceptions to desired behaviour can only happen when education and awareness about HIV/AIDS is supplemented with programmes intended to raise the status of women in India. No society that treats its women as second class citizens and denies them access to nutrition, healthcare, education and employment can ever be able to completely put the genie of stigma and discrimination back into the bottle.

SECTION 8.5: STIGMA INDICATORS IDENTIFIED AT THE COMMUNITY, FAMILY AND WLHA LEVEL

Community Interventions at the community, family and WLHA level would be monitored and evaluated if there is a change in the attitude towards the WLHA. Indicators identified from the qualitative research would be measured using appropriate scales at the base line and end line levels. A summary list of indicators which have been identified are:

AWARENESS INDICATOR

Awareness about modes of transmission of HIV AIDS (% of people in community, family and WLHA aware)

COMMUNITY LEVEL INDICATORS (written in font colour Dark Red) **A**

FAMILY LEVEL INDICATORS (written in font colour Dark Yellow) **A**

WLHA LEVEL INDICATORS (written in font colour Dark Green) **A**

COMMUNITY LEVEL INDICATORS

FEAR

- Talk to a person with HIV AIDS
- Stay in the same house with a person who has HIV AIDS
- Sit next to someone who is showing signs of AIDS
- Touch a person living with HIV or AIDS
- Eat food prepared by a person living with HIV or AIDS
- Care for a person living with HIV or AIDS
- Child playing with child who has HIV or AIDS
- Cutting of hand while cooking food
- An HIV positive child biting another child
- Sneezing by an HIV positive person
- Sleep in same room as someone who has HIV or AIDS
- Share toilet with a person living with HIV or AIDS
- Share eating utensils with PLHA
- Sleep in same bed with someone who has HIV or AIDS
- Wash clothes with those of PLHA
- A PLHA would be able to live longer if given shelter and support by family
- Saliva
- Sweat
- Mosquito Bite
- Use of common soap and shampoo

BLAME

- The HIV positive person has himself to blame as they have indulged in a wrong act
- Women who are positive are innocent victims their husbands are to be blamed
- I don't blame the HIV positive persons I feel sorry for their condition
- People with HIV are promiscuous

- Percent of people who blame persons living with HIV/AIDS for their illness.

SHAME

- Percent of people who would feel shame if they associate with a PLHA
- I would be ashamed if someone in my family had HIV/AIDS
- People with HIV should be ashamed of themselves
- People with HIV deserve sympathy
- % of people who are aware of anyone who has the infection
- People with HIV/AIDS should be allowed to fully participate in social events in our community.
- If the communication messages emphasise transmission through blood rather than through sex and multiple partner route feeling of shame associated with an AIDS infected person would decline.
- If the AIDS person continues to discharge his responsibility towards his family and society properly feeling of shame associated with an AIDS infected person would decline.

JUDGEMENT

- PLHA are dirty
- PLHA has dirty thoughts
- No one should have relations with HIV infected persons
- An HIV infected person is an object of ridicule
- An HIV infected person should be asked to stay away from his family and society
- An HIV infected person should be abandoned even by his spouse
- If a woman gets infected by her husband she should not abandon him but take care of him
- HIV is a disease of poor people.
- An HIV positive person deserves no respect in society

DISCLOSURE

- If you personally found out that you were HIV positive would you tell anyone? If No or Don't know, why not?
- If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret or should this information be available to the community?
- If a member of your family contracted HIV/AIDS, would you want it to remain a secret?

- If a member of your family got infected with HIV and was not showing signs of AIDS, would you advise them to disclose their status in the community?
- An HIV person should keep the information of being infected to himself else he would be ill-treated by his family. (% agreement)
- An HIV infected person should share the information of his infection immediately with his family so that he may be provided with good care. (% agreement)
- An HIV infected person should wait till the last stages when the body becomes weak and it is obvious that he is suffering to tell his family. (% agreement)

ENACTED STIGMA

- Lost customers to buy his/her produce/goods or lost job.
- Abandoned by spouse/partner.
- Abandoned by family/sent away to the village.
- Lost respect/standing within the family and/or community.
- Given poor health services
- Teased or sworn at
- Visited less or no longer
- Family support provided to the infected person enabled him/her to lead a better life (% cases known)
- A person with earning capacity or with a responsible role in the family is not stigmatized (% agreement)

FAMILY LEVEL INDICATORS

FEAR

- Fear of talking
- Fear of mixing
- Fear of visiting home of infected person or letting infected person visit them
- Fear of children getting infected by mixing with HIV children of sister/brother
- Fear of handling food or taking food prepared by infected person
- Fear of disease being incurable

BLAME

- HIV can happen only to immoral persons
- HIV infected persons are dirty
- WLHA is responsible for the condition of her spouse
- WLHA has brought shame to the family
- WLHA has the right to refuse sex to her husband who is positive
- WLHA has the right to take some rest and not expected to take care of her husband
- WLHA has the right to property after her husband dies
- WLHA has right to shelter after her husband dies
- WLHA should be provided shelter at least in her natal home

SHAME

- Percent of people who would feel shame if they associated with a WLHA
- I would be ashamed if someone in my family had HIV/AIDS
- People with HIV should be ashamed of themselves
- People with HIV deserve sympathy
- % of people who are aware of anyone who has the infection
- People with HIV/AIDS should be allowed to fully participate in social events in our community.
- HIV persons in the family impact the social standing of a family

JUDGEMENT

- Non-disclosure of status to extended family
- An HIV infected person should be asked to stay away from his family and society
- Children of the WLHA should be cared for
- If a WLHA is being given support by the family she should try and pay them back in some way either by working outside or by working at home.

ENACTED STIGMA

- Family ties are cut off by inlaws family because of fear that a family member may not get a good matrimonial match.
- Access to family support only while husband is alive.
- Lack of moral/emotional support of the family.
- Financial status of the HIV+ person – the poor suffers more ostracism and discrimination.
- Lost respect/standing within the family and/or community.
- Given poor health services
- Teased or sworn at
- Visited less or no longer

WLHA LEVEL INDICATORS

FEAR

- Infecting family members by talking, eating, sleeping and staying with them
- Attending social functions lest they cause some harm
- Sleeping and eating with own child
- Sharing clothes with own daughter
- Allowing HIV negative child of WLHA to play with other children
- Child being taken away by in laws if he/she is negative

BLAME

- WLHA is responsible for bringing ill luck to the family
- WLHA is responsible for bringing illness to her husband
- WLHA is a fallen woman
- WLHA is a dirty woman
- WLHA is paying the price for her sins
- The husband of the WLHA is not responsible for her condition
- WLHA should comply with the sexual needs of her husband when he is positive and before she tests positive
- WLHA should care for her husband when he is sick
- WLHA should die once her husband dies
- WLHA is a burden on her parents
- WLHA does not have any right to the property left by her husband she should leave it for the in laws

SHAME

- WLHA feels ashamed of herself
- WLHA feels guilty
- WLHA feels people think wrong things about her
- WLHA stops visiting her natal home
- WLHA feels self hatred

- WLHA feels dirty
- WLHA refrains from touching her own children
- WLHA cannot disclose her status which starts weighing upon her
- WLHA feels her shame may have an effect on the future of her child

JUDGEMENT

- Telling anyone about the disease will not help WLHA in any way
- Making her illness public would jeopardize the future of her children
- Disclosing the disease to her marital family would only bring her more trouble
- Livelihood means is the best solution to the problems

ENACTED STIGMA

- WLHA made to work from morning to night without any rest
- Eats and cooks with separate utensils
- Drinking water separated
- Not invited to social functions
- Stared at
- Stopped from visiting her relatives and family house
- Feeling of loneliness
- Brother stops speaking to her
- Family sits at a distance
- Family does not eat food cooked by her
- No one plays with her children
- Stops going out for fear of being ridiculed
- Ostracised socially - no one visits their house
- Break down of communication within the family
- Used and thrown out of marital home when not required (after death of husband)

ANNEXURES

ANNEXURE I: SEC CLASSIFICATION

SEC Classification

OCCUPATION	ILLITE-RATE	SCHOOL UP TO 4 YRS/ LITERATE BUT NO FORMAL EDUCATION	SCHOOL 5-9 YRS	SSC/ HSC	SOME COLLEGE BUT NOT GRADUATE	GRADUATE/POSTGRADUATE GEN.	GRADUATE/ POSTGRADUATE PROFF.
UNSKILLED WORKER	E2	E2	E1	D	D	D	D
SKILLED WORKER	E2	E1	D	C	C	B2	B2
PETTY TRADER	E2	D	D	C	C	B2	B2
SHOP OWNER	D	D	C	B2	B1	A2	A2
BUSINESSMEN/INDUSTRIALIST WITH NO. OF EMPLOYEE-NONE	D	C	B2	B1	A2	A2	A1
BUSINESSMEN/INDUSTRIALIST WITH NO. OF EMPLOYEE 1-9	C	B2	B2	B1	A2	A1	A1
BUSINESSMEN/INDUSTRIALIST WITH NO. OF EMPLOYEE 10+	B1	B1	A2	A2	A1	A1	A1
SELF EMPLOYED PROFESSIONAL	D	D	D	B2	B1	A2	A1
CLERICAL/SALESMAN	D	D	D	C	B2	B1	B1
SUPERVISORY LEVEL	D	D	C	C	B2	B1	A2
OFFICERS/EXECUTIVE JUNIOR	C	C	C	B2	B1	A2	A2
OFFICERS/EXECUTIVE MIDDLE OR SENIOR	B1	B1	B1	B1	A2	A1	A1

ANNEXURE II: Framework for Assessment of Stigma and Discrimination

What is Stigma and Discrimination?

Stigma is a complex social phenomenon involving an interplay between social and economic factors in the environment and psychosocial issues of affected individuals. [9]

Stigma is "an attribute that is deeply discrediting" and results in the reduction of a person or group "from a whole and usual person to a tainted, discounted one" (Goffman, 1963). Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatised through discriminatory actions.[10]

Link and Phelan describe stigma as a dynamic process occurring within the context of power (2001). This process has four distinct steps. The first three steps seek to divide the "tainted" from the "usual" people by distinguishing and labelling differences, associating negative attributes with those differences, and separating "us" from "them." Gilmore and Sommerville describe these three steps in the process as allowing the others ("them") to be perceived as non-persons (1994). This allows the "us" to distance themselves from the negative attributes of the "others" to justify treating the "others" in negative ways that would be unacceptable if they were one of "us" and to prevent "us" from being treated in the same negative manner. These steps culminate in the fourth and final step in Link and Phelan's process—status loss and discrimination for the stigmatized. Thus the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatised through discriminatory actions. [11]

Discrimination (or enacted stigma) are the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatised. [12]

Types of Stigma

There are three types of stigma:

- "abominations of the body," or stigma related to physical deformities
- stigma related to "blemishes of individual character," such as people who are considered to be weak-willed, to have unnatural passions, or to be dishonest
- "tribal stigma," or stigma relating to race, nation or religion, or membership of a despised social group. Because one typically inherits membership to this last group, tribal stigma can equally adhere to and affect all members of a family.

[9] ICRW, 2005
[10] USAID, 2006
[11] MEASURING HIV STIGMA: RESULTS OF A FIELD TEST IN TANZANIA, USAID,2005
[12] MEASURING HIV STIGMA: RESULTS OF A FIELD TEST IN TANZANIA, USAID,2005

Stigma related to medical conditions is greatest when the condition is associated with deviant behaviour or when the cause of the condition is viewed as the individual's responsibility. This becomes particularly strong when the illness is associated with religious beliefs and thought to be contracted through morally sanctionable behaviour.

Stigma is hard to define and measure, making it difficult to design and implement interventions. Stigma is too cultural, too context-specific and too sensitive to be addressed fully.

HIV and AIDS have all of the characteristics associated with heavily stigmatised medical conditions. HIV/AIDS-related stigma is important because it frequently shatters the infected persons' identity and self-confidence, significantly decreasing their ability to manage the disease successfully.[13] Stigma can act as a barrier to care and treatment and can be more painful than the disease itself.

HIV-Related Stigma

HIV/AIDS-related stigma can be described as a "process of devaluation" of people either living with or associated with HIV and AIDS. This stigma often stems from the underlying stigmatisation of sex and intravenous drug use—two of the primary routes of HIV infection. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group.

HIV-related stigma is further accentuated on account of gender, age, sexual orientation, class, race or ethnicity.

Classification of HIV Related Stigma

Stigma can be categorised into four broad groups: physical, social, verbal and institutional. The measurement of such stigma has been formulated by USAID suggesting a framework for categorising stigma as follows:

- Fear of casual transmission and refusal of casual contact with people living with HIV/AIDS (PLHA)
- Values: shame, blame, and judgment
- Enacted stigma (discrimination)

[13] USAID, Stigma and HIV AIDS, A Pervasive Issue

- Disclosure

The types of stigma and stigmatising behaviour that leads to the stigma need to be matched in order to arrive at indicators that can be measured.

Since each of the above areas would have a separate impact on the control of stigmatising behaviour, a separate indicator is required rather than a composite measure. This requires development of detailed indicators. However, it is necessary to know the prevailing social conditions in different societies, as one set of detailed indicators might not hold true for all the social conditions. The present research has been formulated to understand the existing framework for stigma indicators and developing new indicators as relevant for Indian conditions.

Physical	Social	Language/Verbal	Institutional
Isolation	***Isolation***	***Gossip***	***Loss of livelihood/future***
▸ Separating sleeping quarters	▸ Reduction of daily interactions with family and community	▸ Speculation on how person acquired virus	▸ Loss of employment
▸ Marking and separating eating utensils	▸ Exclusion from and shunning at family and community events	▸ Spreading rumors	▸ Loss of customers/business
▸ Separating clothing and bed linens	▸ Loss of social networks	▸ Whispering behind back	▸ Denial of loans, scholarships, visas
▸ No longer allowing person to eat meals with family	▸ Decreased visits from neighbors	***Taunting***	***Loss of housing***
▸ Confinement to certain rooms of house	***Voyeurism***	▸ Insults	▸ Denied housing
▸ No longer allowing person to participate in housework (e.g. cooking food)	▸ Increased visits from neighbors, not out of concern but to mock individual or report back to community	▸ Mocking	▸ Eviction by landlord
▸ Public rejection (refuse to sit next to person on bus, bench, at church, tea shops or in bars)	***Loss of identity/role***	▸ Finger-pointing	***Differential treatment in schools***
▸ Separation from children	▸ Viewed and treated by community as having no future	▸ Threats	▸ Teachers supporting the idea of separating children of HIV+ people to "protect" other students
▸ Abandonment by family	▸ No longer considered productive member of society	***Expressions of blame and shame***	***Differential treatment in health care settings***
Violence	▸ Automatically associated with "social evils" (e.g., drug use, sex work)	▸ Scolding (e.g., blamed for not listening to elders)	▸ Excessive and unnecessary precautions by health care staff
▸ Beatings	▸ Expected to adopt new role of teaching others about HIV and disclosing status	▸ Blamed for bringing "bad luck" to whole family	▸ Shuffled between providers to avoid caring for HIV+ patient
▸ Being kicked	▸ Loss of power, respect, and standing in community	***Labeling and use of derogatory words to describe people living with HIV or AIDS***	▸ Denial of health services
▸ Throwing stones	▸ Loss of right to make decisions about own life	▸ In Africa:"moving skeleton,""walking corpse,""keys to the mortuary"	▸ Provision of substandard treatment
▸ Arrests	▸ Loss of marriage and childbearing opportunities	▸ In Vietnam:"they are social evils,""scum of society,""deserves to die"	▸ Use of separate medical tools for people with HIV or AIDS
			▸ Place patients with HIV in separate rooms
			Differential treatment in public spaces
			▸ Refusal of services (e.g., will not be served food by vendors, or not served in shared containers)
			Media and public health messages and campaigns
			▸ Posters and news stories emphasizing negative images of people with HIV and AIDS and employing fear tactics to warn about HIV and AIDS
			▸ Posters and news stories presenting factual information about HIV and AIDS with a moral and judgmental tone
			▸ Inflammatory news stories about HIV-positive individuals purposefully infecting others

Understanding of Existing Framework (

Secondary stigma occurs when the family and children of the HIV-infected person are stigmatised. The children of people living with HIV and AIDS may sometimes be denied a place in school or be taunted, teased, and rejected by peers.

Measurement of Stigma

USAID has developed indicators at the community level and individual level for measuring the different forms of stigma faced by HIV-infected persons. (The health provider has not been considered as a focus of this study).

Physical Stigma - Community level

Fear of casual transmission and refusal of casual contact with people living with HIV/AIDS (PLHA)

Percent of people aware of the routes of transmission of the infection.

Percent of people expressing fear of contracting HIV from non-invasive contact with PLHA.Percent of people who would refuse casual contact with a PLHA who:

- Was not exhibiting signs of AIDS. (E.g. children of HIV-infected individuals)
- Was exhibiting signs of AIDS.

The first level indicator captures the actual fears that individuals hold about transmission of HIV through non-invasive routes (i.e. no exchange of body fluids). The second level indicator measures the behaviour of refusing contact with a person living with HIV/AIDS. Indicators developed by USAID for first and second level are:

01. Sit next to someone who is showing signs of AIDS
02. Sleep in same room as someone who has HIV or AIDS
03. Touch a person living with HIV or AIDS
04. Share toilet with a person living with HIV or AIDS
05. Eat food prepared by a person living with HIV or AIDS
06. Share eating utensils with PLHA
07. Sleep in same bed with someone who has HIV or AIDS
08. Care for a person living with HIV or AIDS
09. Child play with child who has HIV or AIDS
10. Be exposed to sweat
11. Be exposed to saliva
12. Be exposed to excreta

The above indicators may differ in different settings from community to community depending upon the kind of non-invasive contact that can occur. For e.g., other than saliva, sweat and excreta which are considered common fluids which an individual is exposed to, it can even include just talking to or standing in close proximity of a HIV-positive person.

All the above could result in “Enacted Stigma of the Physical Kind” described in Column One of the table above.

Social, Verbal and Institutional Stigma - Values: Shame, Blame, Judgment, and Enacted Stigma (Discrimination)

Social stigma is a result of the attitude towards the HIV infected persons. It takes place in three domains – shame, blame and judgement.

Community level *Percent of people who judge or blame persons living with HIV/AIDS for their illness.*

- HIV is a punishment from God.
- HIV/AIDS is a punishment for bad behaviour.
- It is women or prostitutes who spread HIV in the community.
- People with HIV are promiscuous.
- HIV/AIDS spreads due to immoral behaviour.

Percent of people who would feel shame if they associated with a PLHA.

- I would be ashamed if I were infected with HIV.
- I would be ashamed if someone in my family had HIV/AIDS.
- People with HIV should be ashamed of themselves.

Attitudinal statements relating to shame, blame and judgement

- People with HIV/AIDS deserve sympathy.
- I would attend a social event with someone know to have HIV.
- People with HIV/AIDS should be treated the same as people without HIV/AIDS
- People with HIV/AIDS should be allowed to fully participate in social events in our community
- I would invite a person with HIV/AIDS to a social event.

Percent of people who personally know someone who has experienced enacted stigma in the past year because he or she was known or suspected to have HIV or AIDS.

Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS?

- Excluded from a social gathering.
- Lost customers to buy his/her produce/goods or lost a job.
- Had property taken away.
- Abandoned by spouse/partner.
- Abandoned by family/sent away to the village.

- Teased or sworn at.
- Lost respect/standing within the family and/or community.
- Gossiped about.
- No longer visited, or visited less frequently by family and friends.
- Visitors increased to “check them out.”
- Isolated within the household.

PLHA level: *Percent of PLHA who experienced enacted stigma in last year.*

- Been excluded from a social gathering.
- Been abandoned by your spouse/partner.
- Been isolated in your household.

Don’t touch me.

Don’t eat with me.

Don’t sit with me.

Hide me so no one knows I have HIV.

- Been isolated by friends and family – they no longer visit or do so less frequently.
- Been teased, insulted or sworn at.
- Lost customers to buy produce/goods or lost a job.
- Lost housing or not been able to rent housing.
- Been denied religious rites/services.
- Had property taken away.
- Been gossiped about.
- Lost respect/standing within the family and/or community.
- Been threatened with violence.
- Been given poorer quality health services.
- Been physically assaulted.
- Been denied promotion/further training.
- Had an increase of visitors to “check out” how doing.
- Been abandoned by your family/sent away to the village.
- I feel physically ill knowing I have HIV.
- Having HIV makes me feel dirty.

The above indicators do not sufficiently cover all social, verbal and institutional stigma that have been identified. New indicators need to be developed in the context of the social settings.

Impact of Stigma - Disclosure

- Stigma creates an obstacle to prevention as individuals do not perceive themselves to indulge in the high-risk behaviour which is considered to be the cause of the infection. They are therefore not inclined towards prevention.
- HIV and AIDS-related stigma also prevents people from coming forward for testing, or when they do get tested, from returning for their test results. Many people avoid going to clinics known as HIV testing sites for fear of being seen there by others and thus suspected as having HIV. Another fear is that test results will not be kept confidential.

People with infection also refrain from disclosing their HIV status to others for fear of discrimination. Indicators have been suggested for the Impact of Stigma on Disclosure.

Community-level Percent of people who have had someone they personally know disclose their HIV-positive status to them.

Percent of persons tested for HIV who have disclosed their status beyond a trusted few individuals.

Percent of persons tested for HIV in relationship specific people who have disclosed their status to their primary sexual partner and who have disclosed within 6 months of learning their status.

Percent of persons reporting that self-disclosure by PLHA is a primary way that people in the community find out about a person's HIV status.

- The infected person discloses his/her status.
- From general rumours/gossip.
- From the HIV-positive person's family.
- From the HIV-positive person's employer.
- From the HIV-positive person's friends/neighbours.
- From the health centre/health care worker where the person got tested.
- The person looks ill and has lost a lot of weight.

PLHA-level: Percent of PLHA who have disclosed their status beyond a few trusted individuals and who have disclosed within 6 months of learning his/her status.

Percent of PLHA who have disclosed their HIV sero-status to their primary sexual partner.

Percent of PLHA whose HIV status has been disclosed without their consent.

Development of New Indicators – The Family Level, Internal Stigma

The framework suggested by USAID and ICRW encompasses physical, social, verbal and institutional stigma. These would be adequate in coverage of most kinds of stigma though they would also be required to be developed in the context of the social setting and also in the context of the HIV- infected woman.

Family level

A gap area that has been observed in the framework suggested is the availability of indicators for the community and PLHA levels only. In the Indian context the family level is a critical indicator since the family is the first tier of care and support for the PLHA. PLHAs would be able to increase their will for survival if stigma at the family level is curtailed.

Internal Stigma

New set of indicators combining the rights and different stigma as described above can be arrived at and examined in the Indian context. These indicators are yet short of covering the internal stigma experienced by the HIV-infected person. A USAID study - Stigma and HIV/AIDS— A Pervasive Issue examined the impact of internal stigma.

According to this study, stigma is a complex social phenomenon or process that results in a powerful and discrediting social label and/or radically changes the way individuals view themselves and are viewed by others. Stigma can be experienced internally (self-stigma) or externally (as in discrimination). Internal stigma can lead to a person's unwillingness to seek help or to access resources.

Measurement of internalised stigma focuses on how external stigma leads to internal stigma in the form of negative self-image. Stigmatised individuals or groups may accept that they "deserve" to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult. This phenomenon is often termed "internalised stigma" (also sometimes termed "self-stigma"). Research shows that this internal stigma manifests in many ways, including self-hatred, self-isolation, and shame.[14]

[14] MEASURING HIV STIGMA: RESULTS OF A FIELD TEST IN TANZANIA, USAID,2005

ANNEXURE III: INSTRUMENTS FOR EXPLORATORY RESEARCH

DISCUSSION GUIDELINE FOR MLHA

Section I – Knowing About HIV AIDS

Q1. You have just found out you are HIV positive. What were your immediate feelings then? *Probe: Shame, Anger, Guilt, Fear, Sadness and Depression*

Q2. How have you started to "live" with HIV AIDS since then? What is it that you were doing earlier but now cannot do it? Who has helped and supported you? How? What is it that you found most helpful, Why?

Q3. Whom did you share the information about being positive?

- mother or father
- partner
- children
- close friends
- colleagues at work
- religious or spiritual guide
- people from your place of worship
- support groups or HIV organisations
- political organisations
- class mates in school or college
- teachers.

(Probe why was it shared with some and not shared with others, what was their fear?)

Q4. Have the views of some people who were against your HIV AIDS status earlier now changed? Have they become more accepting? Why do you think they have changed?

Q5. Do you regret having told some people that you have HIV? Why?

Section II – Impact of Peoples Attitude towards HIV

Q1. Are there some people's attitudes about HIV which make you feel worse about yourself? What is it about you that these people find most unacceptable and intolerable?

Q1. What kind of battle are you fighting against ignorance, fear, indifference and hardships and heartbreak in your personal lives? Can you describe it for us?

Q1a. What kind of ridicule, insult or harassment have you faced because of your HIV status. Who indulges in these activities?

Q1b. Were people angry with you? Who were they? How did they express their anger?

Q1c. Were people disgusted with you? Who were they? How did they express their disgust?

Q1d. Did people avoid contact with you? Who were they? How did you feel that they were avoiding you?

Q1e. Did some people also laugh at you? When?

Q1f. Did people not allow you to buy things from their shops? Why? What did they Say?

Q1g. What about other community places like temples and parks? Are you free to go there?

Q1h. What about your children, do the neighbours allow them to play with their children? What do they say?

Q1g. Have you been excluded from any social functions? By whom? Describe the functions?

Q1h. Do people make you feel that you are “dirty”? Do you feel “unclean”?

Q1i. Do you think people also see you as an immoral or “bad” person?

Q1j. Do people tell you that HIV is what you deserve for how you lived your life? When people learn you have HIV, do they look for flaws in your character? What kind?

Section III – Attitude and Behaviour of Immediate family

Q2. What are the usual activities you are excluded from by family members such as cooking, sharing food or eating implements or sleeping in the same room as other family members?

Q2a. Have you also lost financial support from family members due to HIV? Is it that the family finds it a good excuse to throw you out and take away your shares?

Q2b. Have you been forced to change residence because of HIV status?

Q2c. Have you been threatened by physical violence or been physically assaulted due to HIV status?

Q2d. Does your family provide you with sufficient food and rest? Do you know that these two are very important for your survival? Do you know that these two are very important for your survival and will also prolong your life? Are you able to take more rest and eat better after you discovered your HIV AIDS status? In case you are denied food or rest do you think it is because of your positive status?

Q2e. What about rights to property and expenditure on your treatment? How has it changed since your positive status? Have you been denied any property or financial

rights which you had enjoyed earlier? Which are those? Why do you think you are being denied these rights? Is there some ulterior motive or simply disgust for you?

Section IV – Attitude and Behaviour of Spouse and close friends

Q3. What has been the support extended by your partner because of HIV status? Do you feel it her duty to take care of you?

Q4. Have your friends also discrimination you because of HIV status? How? Can you describe any instance for the same?

INSTRUMENTS FOR EXPLORATORY RESEARCH CONTD.

TRANSECT WALKS IN COMMUNITY

Transect Walks are walks through a community or location to identify different places, people and activities regarding HIV AIDS and the community.

For the area chosen for transect walks:

I. Key locations in the area – market, health services, schools, places of worship etc.

Market
Health Services
Schools
Places of worship
Parks
Other places of interest

II. Identify what people do and where they do it- for example places where people meet work and relax.

III. Observe the environment – cleanliness, food sold in open, drainage system, power shortage, water shortage, public hygiene, availability of medicines, condoms etc.

Cleanliness
Food Sold in Open
Drainage System
Power, Water Supply
Public Hygiene Facilities
Availability of Medicines/Condoms, ARV centres, VCTC centres etc.

IV. Identify whether there are groups of Street children, unemployed youth gatherings, people playing cards etc.

Street Children
Unemployed Youth.
Informal Gatherings of people.

V. Community organizations and their activities – what good acts have they promoted in the community? Types of non-governmental organisations or religious organisations in the community

VI. Housing Conditions in Area

VII Observe how people interact with each other at different places- friendly, business like, indifferent to few people.
Interactions between men and women observe whether restricted or free/with respect.

Community Interviews in Transect Area

General Community Knowledge and Attitude towards HIV AIDS

The interviews given below should be conducted with the respondents in the 5-6 areas which have been identified. Ideally area chosen should if possible be in the middle of the city-neither close to bus or railway station nor close to the main business area.

- Petty Shopkeeper-1 (Pan shop/Mobile shop/Barber shop)
- Vegetable Vendor -1
- Auto driver/rickshaw puller-1
- Maid servants/labour class -1
- Temple priest/Other religious person
- Hotel restaurant owner
- Car Mechanic
- Health Clinics
- Any civic authority of the ward-1
- Youth – College Students- group of 2-3

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DISCUSSION GUIDELINE FOR GENERAL COMMUNITY

Dear Sir, we are doing a small opinion survey about health and community issues in some small cities. We will ask you your opinion about certain issues. Please describe your views freely.

Important Places in Community

Q1. Which places and people are important in the community where you stay?

Q2. What are your concerns about the community where you stay, what would you like to change?

Q3. Which are the people most helpful in your community, which of them create a nuisance value?

Q4. Can you describe how you would like your community area to look in the future? Do you feel that you would be more comfortable if some people in the community go and stay else where, if so who? Why? Do some people in the community avoid meeting a specific section of the people? Which are these? Why are they avoided?

Q5. Are there different key groups into which the population can be divided? Where do the majority of the population in your community work? What other places do they visit in the city?

Common facilities in the community

Q6. What are the common facilities which all the members of the community use? – Market, health services, schools, religious places?

Q7. Can all the people use the resources and services available to them or there are some restrictions? What are these? What about women, can they use all the common services or there are restrictions?

Q8. How do you think the situation can be improved? You mentioned that there are certain categories of persons the community at large does not associate with and also there are certain restrictions on these people to use common facilities. Does this also happen to general people who have contacted HIV AIDS?

Awareness and Opinion towards HIV AIDS

Q9. What is HIV AIDS? How does it occur? Who do you think is responsible for the spread of the disease – is it the male or the female? Why do you think so? If a housewife gets the disease who do you think is responsible, she or her husband? Why?

Note: Out of the five stated possibilities of HIV AIDS transmission, how many do they state correctly.

Q10. People have many different feelings when they think about people who have AIDS. As I read each of the following feelings, please tell me how you personally feel:

- Angry at them (person with AIDS)? Blame
- Afraid of person with AIDS? Fear
- Disgusted by the person with AIDS? Shame
- Sorry for the person with AIDS? Empathy

Q11. HIV AIDS is a punishment of God, and serves the person right since he or she has indulged in immoral act, do you agree?

- Do you think that many people who get HIV through sex have only themselves to blame? Blame
- People with HIV/AIDS should be ashamed of themselves. Do you agree? Why? Shame
- The family of the person with HIV/AIDS is also to blame. Do you agree? Why? Blame
- Women get HIV because they are prostitutes. Do you agree? Why? Blame
- People who have AIDS are dirty. Do you agree? Shame

Q12. In your community, what is the primary way people know if someone has HIV?

Q13. If a person learns he/she is infected with the virus that causes AIDS, should the person be allowed to keep this fact private or should this information be available to the community? Do you agree? Why? Fear, Blame, Shame

Q13. Would you prefer to know who has HIV/AIDS in your community so that you can be careful not to get infected by him/her? The names of people with AIDS should be made public so others can avoid contact with them. Do you agree? Why? Enacted Stigma

Q12. The HIV AIDS person is likely to spread the disease to others in the community, they should be kept separately and not allowed to use any community facilities, All AIDS patients should have to live in a special village. Do you agree? Why? Fear

- A man who has HIV/AIDS would be abandoned by his partner Do you agree? Why? Enacted Stigma
- A woman who has HIV/AIDS would be abandoned by her partner, Do you agree? Why? Enacted Stigma

Q13. Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS? Enacted Stigma

- Excluded from a social gathering.
- Lost customers to buy his/her produce/goods or lost a job.
- Had property taken away.
- Abandoned by spouse/partner.
- Abandoned by family/sent away to the village.
- Teased or sworn at.
- Lost respect/standing within the family and/or community.
- Gossiped about.
- No longer visited, or visited less frequently by family and friends.

Q14. People with HIV/AIDS should be required to carry a special identity card. Do you agree? Why? Fear, Blame, Shame

Q15. If a female relative of yours became sick with the virus that causes AIDS, would you be willing to care for her in your household? Fear, Blame, Shame

Q16. If you learned that a friend of your had AIDS, you would stop being his/her friend. Do you agree? Why? Fear, Blame, Shame

Q17. A person who has AIDS should not be allowed to make food to sell. Do you agree? Why? Fear, Blame, Shame

Q18. Should persons with the AIDS virus who work with other persons such as in a shop, office, or farm be allowed to continue their work, or not? Do you agree? Why? Fear, Blame, Shame

Q19. People who have AIDS should not be allowed to work at all. Do you agree? Why? Fear, Blame, Shame

INSTRUMENTS FOR EXPLORATORY RESEARCH CONTD.

DISCUSSION GUIDELINE FOR WLHA

Section I – Knowing About HIV AIDS

Q1. You have just found out you are HIV positive. What were your immediate feelings then? Probe: Shame, Anger, Guilt, Fear, Sadness and Depression

Q2. What is it that you were doing earlier but now cannot do it? How have you started to "live" with HIV AIDS since then? Who has helped and supported you? How? What is it that you found most helpful, Why?

Q3. Whom did you share the information about being positive?

- mother or father
- partner
- children
- close friends
- colleagues at work
- religious or spiritual guide
- people from your place of worship
- support groups or HIV organisations
- political organisations
- class mates in school or college
- teachers.

(Probe why was it shared with some and not shared with others, what was their fear?)

Q4. Have the views of some people who were against your HIV AIDS status earlier now changed? Have they become more accepting? Why do you think they have changed?

Q5. Do you regret having told some people that you have HIV? Why?

Section II – Impact of Peoples Attitude towards HIV

Q1. Are there some people's attitudes about HIV which make you feel worse about yourself? What is it about you that these people find most unacceptable and intolerable? What is it that affects you the most?

Q1. What kind of battle are you fighting against ignorance, fear, indifference and hardships and heartbreak in your personal lives? Can you describe it for us?

Q1a. What kind of ridicule, insult or harassment are you facing because of your HIV status. Who indulges in these activities? How much does this affect you?

Q1b. Are people angry with you? Who are they? How do they express their anger? How much does this affect you?

Q1c. Are people disgusted with you? Who are they? How do they express their disgust? How much does this affect you?

Q1d. Do people avoid contact with you? Who are they? How do you feel that they were avoiding you? How much does this affect you?

Q1e. Do some people also laugh at you? When? How much does this affect you?

Q1f. Do people not allow you to buy things from their shops? Why? What do they Say? How much does this affect you?

Q1g. What about other community places like temples and parks? Are you free to go there? How much does this affect you?

Q1h. What about your children, do the neighbours allow them to play with their children? What do they say? How much does this affect you?

Q1g. Have you been excluded from any social functions? By whom? Describe the functions? How much does this affect you?

Q1h. Do people make you feel that you are “dirty”? Do you feel “unclean”? How much does this affect you?

Q1i. Do you think people also see you as an immoral or “bad” person? How much does this affect you?

Q1j. Do people tell you that HIV is what you deserve for how you lived your life? When people learn you have HIV, do they look for flaws in your character? What kind? How much does this affect you?

Section III – Attitude and Behaviour of Immediate family (Parents, Parents-in-law and relatives)

Q2.What powers did you enjoy in your household before testing positive? What kind of discrimination you had faced then being a woman? How have these powers been taken away since then? How do you feel about the loss of power? Which right do you feel deprived of the most – a mother, a wife, a daughter or a wife? Do you feel you are being subject to this treatment more because you are a woman?

Q2a. What are the usual activities you are excluded from by family (natal and in –laws) members such as cooking, sharing food or eating implements or sleeping in the same room as other family members?

Q2b. Have you also lost financial support from family (natal and in –laws) members due to HIV? What about rights to property and expenditure on your treatment? How has it changed since your positive status? Have you been denied any property or financial rights which you had enjoyed earlier? Is it that the family (natal and in –laws) finds it a good excuse to throw you out and take away your shares? Which are those? Why do you think you are being denied these rights? Is there some ulterior motive or simply disgust for you?

Q2c. Have you been forced to change residence because of HIV status? By whom?

Q2d. Have you been threatened by physical violence or been physically assaulted due to HIV status? By whom?

Q2e. Does your family (natal and in –laws) provide you with sufficient food and rest? Do you know that these two are very important for your survival and will also prolong your life? Are you able to take more rest and eat better after you discovered your HIV AIDS status? In case you are denied food or rest do you think it is because of your positive status?

Q2f. Does your family expect you to look after your husband if he is positive but would be willing to abandon you if you tested positive, is this true?

Q2g. Who among all the family members is most considerate towards you and who does not understand you at all and is responsible for the treatment towards you?

Section IV – Attitude and Behaviour of Spouse and close friends

Q3. What has been the support extended by your partner because of HIV status?

Q4. Have your friends also discrimination you because of HIV status? Can you describe any instance for the same?

INSTRUMENTS FOR EXPLORATORY RESEARCH CONTD.

DISCUSSION GUIDELINE FOR FAMILY AND RELATIVES

Section – I Awareness about AIDS

Q1. Are you aware of HIV AIDS? What is HIV AIDS? How does it occur? What are the cures of HIV AIDS you are aware of?

Note: Out of the five stated possibilities of HIV AIDS transmission, how many do they state correctly.

Q2. People have many different feelings when they think about people who have AIDS. As I read each of the following feelings, please tell me how you personally feel:

- Angry at them (person with AIDS)? Blame
- Afraid of person with AIDS? Fear
- Disgusted by the person with AIDS? Shame
- Sorry for the person with AIDS? Empathy

Q3. How would you describe the HIV AIDS disease?

Q3a. What are the stories you have heard about HIV AIDS? From whom? How much do you believe these stories?

Q3b. Can this disease happen to any one?

Q3c. Do you think that those who are not truck drivers, sex workers, bar girls, drug users etc. are safe from the disease?

Q4. HIV AIDS is a punishment of God, and serves the person right since he or she has indulged in immoral act, do you agree?

- Do you think that many people who get HIV through sex have only themselves to blame? Blame
- People with HIV/AIDS should be ashamed of themselves. Do you agree? Why? Shame
- The family of the person with HIV/AIDS is also to blame. Do you agree? Why? Blame
- Women get HIV because they are prostitutes. Do you agree? Why? Blame
- People who have AIDS are dirty. Do you agree? Shame

Q5. You have just found out that your daughter/daughter in law is HIV positive. What were your immediate feelings then? Which concern came up first? Probe: Shame, Anger, Guilt, Fear, Sadness and Depression

Q5a. What is it that she was doing earlier but now cannot do it? How has she started to "live" with HIV AIDS since then? Who has helped and supported her? How? What are the constraints you have in helping her?

Q6a. So in your opinion who is responsible for the disease when it happens in normal families? Is there a culture of secrecy when it comes to HIV AIDS? Why do you think families like to keep it a secret? (Probe difference between males and females – does it exist?)

Q6b. Does an HIV person have a right to work and earn a living? If the HIV positive person is earning and contributing to the family would you allow her to stay but is she id a dependent would you send her away?

Q7. Is HIV AIDS infectious? Do you agree whether touching and HIV person or staying with HIV person is infectious? Can the virus spread by sharing the same toilet or mosquito bites? (Probe difference between males and females – does it exist?)

Q7a.HIV AIDS patients should be put in special areas in health care centres as it is infectious. Do you agree? (Probe difference between males and females – does it exist?)

Q7b. Do you think they have the right to live in the same house? Why? What is your fear? Will they spread infection? Or is it shameful t be staying with them? (Probe difference between males and females – does it exist?)

Q8. If a person learns he/she is infected with the virus that causes AIDS, should the person be allowed to keep this fact private or should this information be available to the family? Do you agree? Why? Fear, Blame, Shame (Probe difference between males and females – does it exist?)

Q8a. What is the kind of care and support an HIV AIDS person can expect from his family? What are the positive contributions a family can make in the lives of positive people? If the family does not support an AIDS person in the house, what is it which would be denied to the AIDS person? (Probe: Health care, emotional support, food, rest) (Probe difference between males and females – does it exist?)

Q8b. Can you give me an example of how the caring and support of family has helped and HIV AIDS person, what measures did that family take? Did the family also face opposition from the community? (Probe difference between males and females – does it exist?)

Q8c. Was the family black listed for supporting the HIV AIDS person? (Probe difference between males and females – does it exist?)

- like not allowed to attend social functions

- lost customers to buy his/her produce/goods
- teased or sworn at.
- lost respect/standing within the community.
- gossiped about.
- no longer visited, or visited less frequently by other family and friends.

Q8d. How on the other hand an uncaring family has made life miserable for an HIV AIDS person? Please give an example you know about. (Probe: Right to take care and live with children) What made the family behave in such a manner – was it fear of infection or disgust for the person or shame for the family which brought about such a reaction? Do you think these families feel that the HIV AIDS person has any right to live or is it that they feel it is better that she dies?

Q8e. How do you think such uncaring families should be made aware of their responsibility? What is it that they need to know so that they may respect the woman suffering from HIV AIDS in their household?

Q9. Read the following statements and ask how each one should be made to understand that he is wrong. What message should we give him so that he will stop thinking like this?

"She has a right to work and earn so that she can look after herself and others who depend on her. You cannot take that right from her"

"…how can we urge families to help her claim her right."

Spouse

"She must have got it from somewhere…Surely, I'm not at fault…I can't be responsible!"

Parents-in-law

"She must have got it from somewhere. Surely our son is not at fault. Because of her he's got it too! Let her die!"

"I know I can't get infected with just casual contact. But what if…The danger is always there."

"She must be a loose person. Why else would she have HIV/AIDS? She deserves what she gets. Why waste time on her."

Parents

"How could this happen? How could she do this to us? Now what will everyone think of us? She has brought shame to all of us!"

"Why spend all that money on her treatment. She's going to die anyway"

"She's the responsibility of her husband/in-laws after marriage. Why should we support her?"

INSTRUMENTS FOR EXPLORATORY RESEARCH CONTD.

DISCUSSION GUIDELINE FOR COMMUNITY GROUPS

Stage I: Putting at ease

Introduction of team

Welcome the FGD participants and thank them for coming.

Ask the name and Age and occupation of each participant *(Write it down on a piece of paper, for addressing them by name in future)*

Purpose: The purpose of the study is to know and understand the health related issues, want to know more about your health problems in this part of Kanpur/Aurangabad/Udupi city, what kind of diseases are common and how you becomes aware of these diseases, how you get treatment, and what will be a best social message for the people like you to tackle these issues.

Explains the rules of a FG discussion

Everybody has the same right to speak, each person will be given time to speak and communicate their views

There are no right or wrong ideas. Al opinions are equally important to us. Listen to each other; respect each other, if possible, only one person should speak at one time

Make them feel at ease in expressing themselves by making them talk one by one and in a few words about their job, family, kids and daily routines of life. The moderator should start by talking about himself

Stage II: Health Problems

What kind of health problems are coming up now a days in the society?

Which of these are the serious problems & why?

You may have seen many ads which provide awareness and small tips for preventing the diseases, Which Ads you are aware of and recently seen and remember it right now?

Tell me whether these Ads are helpful in any way?

Which Ad you like most, what do you like in the Ad? *Probe also on the celebrity. The discussion may provide the hints to start discussion about HIV/AIDS, if not ask:*

Stage III: Awareness about HIV AIDS

Have you heard about HIV/AIDS? What are your views about it? Why do you have such a view?

What are your sources of information on HIV/AIDS (Probe for Ads in TVs, Papers, posters, health worker, banners etc)

If you need information on HIV/ADIS where would you get it from (probe for source doctor, friend etc)

Stage III: Digging deeper HIV/AIDS

… Method of Transmission you are aware of (Check how many routes they are aware of)

Can you tell of other ways of transmission? *(Probe on the perception also, whether mosquito bite, by talking, kissing, sexual transmission etc.)*

… Symptoms

… Protection

… What should a person do if he gets the disease? (HIV)

… Do you know any person who has HIV/AIDS? What happened to him? *Ask about his story*

… What do you feel about him or a person who have HIV/AIDS?

Stage IV: Test the Stigma and Reason for Stigma

…Do you experience any fear from an HIV infected person? What kind of fear is it? Why do you fear him?

…Do you think an HIV infected person is a shameful person? In what way?

…Do you blame the HIV infected person? In what way?

…..What is the treatment an HIV person should get from the society and his family? Why?

…Do you believe that a PLHA can live longer if supported by the family?

Stage V: Check and probe if the following stigma exist for fear (probe further beyond the following indicators)

- Talk to a person with HIV AIDS
- Stay in the same house with a person having HIV AIDS
- Sit next to someone who is showing signs of AIDS \
- Touch a person living with HIV or AIDS
- Eat food prepared by a person living with HIV or AIDS
- Care for a person living with HIV or AIDS
- Child playing with child who has HIV or AIDS
- Cutting of hand while cooking food
- An HIV positive child biting another child
- Sneezing by an HIV positive person
- Sleep in same room as someone who has HIV or AIDS

- Share toilet with a person living with HIV or AIDS
- Share eating utensils with PLHA
- Sleep in same bed with someone who has HIV or AIDS
- Wash clothes with those of PLHA
- Any other fears
- If we have to remove the existing fear of HIV/AIDS what has to be done (Probe for what is required for loosing fear like do they need more knowledge, more access to information, etc)
- What is it that is preventing them to get the above mentioned aspects required for loosing fear (probe for specific barriers in accessing information, problems with the present communication / media material, cultural and belief patterns, etc)
- Who do you think should take up the initiative to do the above mentioned things and at what level (Family, community, government, NGOs etc)

Stage VI: Check and probe if the following stigma exists for shame, blame and judgement. (Probe further beyond the following indicators)

Shame, Blame and Judgement Indicators

- HIV is a punishment from God.
- HIV/AIDS is a punishment for bad behaviour.
- It is women or prostitutes who spread HIV in the community.
- People with HIV are promiscuous.
- HIV/AIDS spreads due to immoral behaviour.
- I would be ashamed if someone in my family had HIV/AIDS
- People with HIV should be ashamed of themselves
- People with HIV deserve sympathy
- % of people who are aware of any one who has the infection
- People with HIV/AIDS should be allowed to fully participate in social events in our community.
- Any other reactions towards HIV/AIDS
- If we have to remove the feeling of shame/blame/judgement regarding HIV/AIDS what has to be done (Probe for what is required for removing it like the need for discussing issues of sex and sexuality openly etc)
- What is it that is preventing them from removing the shame/blame/judgement related to HIV/AIDS (probe for specifics regarding familial, cultural and belief patterns.

- Who do you think should take up the initiative to remove it and at what levels (Family, community, government, NGOs etc)

Stage VII: Check and probe if the following enacted stigma indicators exist (probe further beyond the following indicators)

- Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS?
- Lost customers to buy his/her produce/goods or lost a job.
- Abandoned by spouse/partner.
- Abandoned by family/sent away to the village.
- Lost respect/standing within the family and/or community
- Given poor health services
- Teased or sworn at
- Visited no longer or visited less
- Any other happenings
- If we have to remove the discrimination (enacted stigma) regarding HIV/AIDS what has to be done (Probe for what is required for removing it like do they need more knowledge etc)
- What is it that is preventing them from removing the discrimination (enacted stigma) related to HIV/AIDS (probe for specifics regarding familial, cultural and belief patterns.
- Who do you think should take up the initiative to remove the discrimination (enacted stigma) and at what levels (Family, community, government etc)

Stage VIII: Disclosure Indicators (probe further beyond the following indicators)

- If a person learns that he/she is infected with the virus that causes AIDS, should this information remain this person's secret or should this information be available to the community?
- If a person you know contracted HIV/AIDS, would you want it to remain a secret?
- If a person you know is infected with HIV and was not showing signs of AIDS, would you advise them to disclose their status in the community?
- Any other matters of disclosure
- How can disclosure of HIV/AIDS status by a person infected, made easier for him and the community (Probe for what needs to be done so that a person confidently discloses his HIV status)

- What is it that is preventing HIV positive people form disclosing their status (probe for specifics regarding familial factors, community denial / factors etc)
- Who do you think should take up the initiative to facilitate easy and confident disclosure of HIV status?

Stage IX – Media Exposure

ASK about TV, TV Channels, Commercials/AD,.

Newspaper, Magazine

Radio

The best media according to them, which has greater coverage and greater impact in their mind. (Probe for the barriers in communication / message transmission)

Ask about the message, how it should be provided? What should we say?

RESPONDENT PROFILES KANPUR

Annexure IV- Respondent Profiles for Kanpur Community Groups

Sno	City	SEC	Name	Age	CWE Education	Occupation	MHI	Resident	Gender
1	Kanpur	D	Nand Kishore	33	5th Standard	Tea Shop	2500	Transport Nagar	Male
2	Kanpur	D	Rajesh K Baoudh	34	8th Standard	Electrician	2500	Transport Nagar	Male
3	Kanpur	D	Vikash Singh	28	9th Standard	Carpainter	3000	Transport Nagar	Male
4	Kanpur	D	Arun Kumar	32	9th Standard	Painter	2800	Transport Nagar	Male
5	Kanpur	D	Rinku	25	9th Standard	Salesman	2500	Transport Nagar	Male
6	Kanpur	D	Narayan Vora	35	8th Standard	Kabadi Wala	4000	Transport Nagar	Male
7	Kanpur	D	Mukesh Kumar	26	5th Standard	Mochi	2000	Transport Nagar	Male
8	Kanpur	D	Rajendra K Verma	30	8th Standard	Painter	2500	Transport Nagar	Male
9	Kanpur	C	Vishal Srivastava	24	12th Standard	Clerk	6000	Transport Nagar	Male
10	Kanpur	C	Dhruv Narayan	34	10th Standard	Shop	4000	Transport Nagar	Male
11	Kanpur	C	Santosh Kumar	29	9th Standard	tea Shop	4000	Transport Nagar	Male
12	Kanpur	C	Sanjai harti	24	10th Standard	Supervisor	6000	Transport Nagar	Male
13	Kanpur	C	Lav Kush	25	12th Standard	Electrician	3500	Transport Nagar	Male
14	Kanpur	C	Dinesh	30	10th Standard	Petty Trader	3000	Transport Nagar	Male
15	Kanpur	C	Jitendra Gupta	34	12th Standard	Salesman	2000	Transport Nagar	Male
16	Kanpur	C	Abdul Khan	26	10th Standard		2000	Transport Nagar	Male
17	Kanpur	B	Pankaj Pandey	34	B.S.c	Sales Executive	5000	Transport Nagar	Male
18	Kanpur	B	Ram Babu Tiwari	34	12th Standard	Electric Equipm	4000	Transport Nagar	Male
19	Kanpur	B	Dinesh K Gupta	34	B.Com	Bank Clerk	10000	Transport Nagar	Male
20	Kanpur	B	Tej Pal Singh	34	B.Com	Teacher	6000	Transport Nagar	Male
21	Kanpur	B	Gaurav Ganguly	25	B.S.c	Teacher	10000	Transport Nagar	Male
22	Kanpur	B	Deepak Singh Rajpoo	26	12th Standard	Salesman	10000	Transport Nagar	Male
23	Kanpur	B	R. Tiwari	26	B.A	Shop Owner	4000	Transport Nagar	Male
24	Kanpur	B	Govind Bajpai	25	B.A	Railway Clerk	10000	Transport Nagar	Male
25	Kanpur	C	Radha	28	12th Standard	Salesman	1200	Transport Nagar	Female
26	Kanpur	C	Monika	25	10th Standard	Petty Trader	2000	Transport Nagar	Female
27	Kanpur	C	Ashima Jaiswal	34	10th Standard	Sales Executive	4000	Transport Nagar	Female
28	Kanpur	C	Sunita	34	B.A	Petty Trader	4000	Transport Nagar	Female
29	Kanpur	C	Neeta Gupta	28	12th Standard	Clerk	5000	Transport Nagar	Female
30	Kanpur	C	Poonam Gupta	35	10th Standard	Supervisor	6000	Transport Nagar	Female
31	Kanpur	C	Urmila Singh	30	10th Standard	Salesman	2500	Transport Nagar	Female
32	Kanpur	C	Savita	25	12th Standard	Supervisor	3000	Transport Nagar	Female
33	Kanpur	D	Manju Verma	35	8th Standard	Petty Trader	2000	Transport Nagar	Female
34	Kanpur	D	Sudha Srivastava	30	8th Standard	Sales Represen	1500	Transport Nagar	Female
35	Kanpur	D	Rajeshwari	34	8th Standard	Mechanic	2500	Transport Nagar	Female
36	Kanpur	D	Laxmi dvi	26	8th Standard	Petty Trader	3000	Transport Nagar	Female
37	Kanpur	D	Sita Gupta	24	9th Standard	Petty Trader	1800	Transport Nagar	Female
38	Kanpur	D	Anita	27	9th Standard	Halwai	3000	Transport Nagar	Female
39	Kanpur	D	Bina Devi	34	5th Standard	Worker	2000	Transport Nagar	Female
40	Kanpur	D	Baby Soniya	34	9th Standard	Skilled Worker (	2500	Transport Nagar	Female
41	Kanpur	B	Munni Devi	30	B.A	Tailor	3000	Transport Nagar	Female
42	Kanpur	B	Gudia	28	12th Standard	Florist	3000	Transport Nagar	Female
43	Kanpur	B	Alka Pandey	34	B.S.c	Sales Represen	5000	Transport Nagar	Female
44	Kanpur	B	Sarita Sharma	33	M.A	Clerk	5000	Transport Nagar	Female
45	Kanpur	B	Bina Singh	28	B.A	Clerk	4000	Transport Nagar	Female
46	Kanpur	B	Arti Gupta	26	M.Com	Teacher	5000	Transport Nagar	Female
47	Kanpur	B	Sulekha	29	B.A	Sales Executive	6000	Transport Nagar	Female
48	Kanpur	B	Sushma Gupta	34	B.S.c	Clerk	7000	Transport Nagar	Female

RESPONDENT PROFILES UDUPI

Annexure IV- Respondent Profiles for Udupi Community Groups

Sno	City	SEC	Name	Age	CWE Education	Occupation	MHI	Resident	Gender
49	Udupi	B	Sthyawati	34	B.Com	PA	3000	Kundapur	Female
50	Udupi	B	Prema	30	B.A	Shop Owner	4000	Kundapur	Female
51	Udupi	B	Shrilatha	28	B.A	Workshop	3000	Kundapur	Female
52	Udupi	B	Jyothi	33	9th Standard	Barber	3000	Kundapur	Female
53	Udupi	B	Ashalatha	30	10th Standard	Shop Owner	3000	Kundapur	Female
54	Udupi	B	Radha	33	12th Standard	Trader	3000	Kundapur	Female
55	Udupi	B	Savitha	30	10th Standard	Business	4000	Kundapur	Female
56	Udupi	D	Malathi	30	10th Standard	Unskilled Worker	2000	Kundeshwara	Female
57	Udupi	D	Nagavani	29	10th Standard	Beedi Factory Wor	3000	Kundapur	Female
58	Udupi	D	Lakshami	34	10th Standard	Industrial Worker	2000	Kundapur	Female
59	Udupi	D	Saku	32	5th Standard	Industrial Worker	2000	Kundapur	Female
60	Udupi	D	Gowri	29	5th Standard	Industrial Worker	3000	Kundapur	Female
61	Udupi	D	Shobha	34	8th Standard	Petty Trader	5000	Kundapur	Female
62	Udupi	D	Sujatha	26	7th Standard	Worker	2500	Kundapur	Female
63	Udupi	C	Srimathi	24	12th Standard	Petty Trader	4000	Balapoojary	Female
64	Udupi	C	Bharthi	25	12th Standard	Driver	4000	Kundapur	Female
65	Udupi	C	Saritha	24	12th Standard	Tailor	6000	Kundapur	Female
66	Udupi	C	Shoba	26	12th Standard	Teacher	5000	Kundapur	Female
67	Udupi	C	Yashodha	34	12th Standard	Petty Trader	4500	Kundapur	Female
68	Udupi	C	Suguna	34	12th Standard	LIC Agent	6500	Kundapur	Female
69	Udupi	C	Savithri	32	10th Standard	Tailor	4000	Kundapur	Female
70	Udupi	C	Rafiq	24	12th Standard	Salesman	4000	Kundapur	Male
71	Udupi	C	Ganesh	26	12th Standard	Mechanic	6000	Kundapur	Male
72	Udupi	C	Ashraf	25	12th Standard	Salesman	4200	Kundapur	Male
73	Udupi	C	Hamid	26	12th Standard	Salesman	2800	Kundapur	Male
74	Udupi	C	Umesh	29	12th Standard	Pan Shop	4000	Kundapur	Male
75	Udupi	C	Prakash	33	8th Standard	Farmer	5000	Kundapur	Male
76	Udupi	C	Alfrad D Souza	26	10th Standard	Shop Owner	3000	Kundapur	Male
77	Udupi	D	Dinesh	27	10th Standard	Worker	3000	Kundapur	Male
78	Udupi	D	Ganesh	34	10th Standard	Farmer	3000	Kundapur	Male
79	Udupi	D	Vishwanath	29	8th Standard	Fisherman	4000	Fish Market Road	Male
80	Udupi	D	Gourge	33	8th Standard	Shop Owner	6000	Kundapur	Male
81	Udupi	D	Sandeep	25	8th Standard	Fisherman	2000	Kundapur	Male
82	Udupi	D	Raghvendra	24	9th Standard	Petty Trader	2500	Kundapur	Male
83	Udupi	D	Vijay	28	9th Standard	Clerk	4400	Kundapur	Male
84	Udupi	D	Ashif	24	9th Standard	Petty Trader	7000	Kundapur	Male
85	Udupi	B	Devan	33	B.A	Clerk	4800	Kundapur	Male
86	Udupi	B	Shankar	32	12th Standard	Petty Trader	2400	Kundapur	Male
87	Udupi	B	Raghuvendra	26	12th Standard	Shopkeeper	2000	Kundapur	Male
88	Udupi	B	S Dube	26	12th Standard	Clerk	2500	Kundapur	Male
89	Udupi	B	Sudhakar	28	12th Standard	Carpainter	4500	Kundapur	Male
90	Udupi	B	Gangadhar	25	10th Standard	Shop Owner	2800	Kundapur	Male

RESPONDENT PROFILES AURANGABAD

Annexure IV- Respondent Profiles for Aurangabad Community Groups

Sno	City	SEC	Name	Age	CWE Education	Occupation	MHI	Gender
91	Aurangabad	D	Vishal Malhotra	26	10th Standard	Helper	3400	Male
92	Aurangabad	D	Dalletry A ture	34	8th Standard	Auto Driver	3000	Male
93	Aurangabad	D	Sanjay G	34	7th Standard	Tea Shop	3500	Male
94	Aurangabad	D	Bahulal	31	8th Standard	Auto Driver	4000	Male
95	Aurangabad	D	Kiran Bourode	26	9th Standard	Electrician	3000	Male
96	Aurangabad	D	nilesh	27	9th Standard	Helper	3500	Male
97	Aurangabad	D	Satish	28	10th Standard	Helper	3000	Male
98	Aurangabad	C	Rajkumar	34	12th Standard	Clerk	7000	Male
99	Aurangabad	C	Millind	29	12th Standard	Shop Owner	8000	Male
100	Aurangabad	C	Bhumirao	30	12th Standard	Shop Owner	7000	Male
101	Aurangabad	C	Anil	25	B.A	Mechanic	8000	Male
102	Aurangabad	C	Arvind	25	12th Standard	Electrician	7500	Male
103	Aurangabad	C	Vijay Kumble	28	10th Standard	Auto Driver	6000	Male
104	Aurangabad	C	Sanjay Rao	30	12th Standard	Technician	8000	Male
105	Aurangabad	B	nitin	27	B.A	Clerk	14000	Male
106	Aurangabad	B	Arjun	28	12th Standard	Shop Owner	10000	Male
107	Aurangabad	B	Vinod	27	12th Standard	Shop Owner	13000	Male
108	Aurangabad	B	altab	27	12th Standard	Shop Owner	14000	Male
109	Aurangabad	B	Yashwant	34	M.A	Teacher	15000	Male
110	Aurangabad	B	Manoj	25	B.A	Shop Owner	12500	Male
111	Aurangabad	B	Rajkumar	26	B.A	Mechanic	12000	Male
112	Aurangabad	B	Sanjay	28	B.Com	Accountant	11000	Male
113	Aurangabad	B	Ashmita Desai	33	B.Ed	Teacher	15000	Female
114	Aurangabad	B	Geeta patel	30	12th Standard	Shop Owner	14500	Female
115	Aurangabad	B	Kanta Pathak	32	12th Standard	Shop Owner	14500	Female
116	Aurangabad	B	Valiben Patel	34	12th Standard	Businesss	15000	Female
117	Aurangabad	B	Chaya	34	B.A	LIC Clerk	15000	Female
118	Aurangabad	B	Sushila Gaikwa	28	12th Standard	Clerk	12500	Female
119	Aurangabad	B	Seema Gaikwa	33	12th Standard	Clerk	12000	Female
120	Aurangabad	B	Nalini	30	B.A	Hotel Clerk	13500	Female
121	Aurangabad	C	Chaya Srivasta	29	10th Standard	Driver	5000	Female
122	Aurangabad	C	Pratibha	32	12th Standard	Constable	7000	Female
123	Aurangabad	C	Meena Chauha	34	10th Standard	Constable	7000	Female
124	Aurangabad	C	Sarita Sahi	25	10th Standard	Mechanic	6000	Female
125	Aurangabad	C	Alka Gaikwad	30	7th Standard	Shop Owner	6500	Female
126	Aurangabad	C	Savita	24	12th Standard	Courier	5500	Female
127	Aurangabad	C	Lata Gaikwad	30	12th Standard	Technician	5500	Female
128	Aurangabad	D	Beena Dhewaa	28	5th Standard	Weaver	3000	Female
129	Aurangabad	D	Suman	34	9th Standard	Constable	4000	Female
130	Aurangabad	D	Ujjawala	24	10th Standard	Peon	3500	Female
131	Aurangabad	D	Mangala	25	7th Standard	Auto Driver	3000	Female
132	Aurangabad	D	Shobha	30	7th Standard	Auto Driver	3500	Female
133	Aurangabad	D	Indusen	32	10th Standard	Watchman	2500	Female
134	Aurangabad	D	Chitra	26	9th Standard	Policeman	4000	Female
135	Aurangabad	D	Hina chauhan	30	9th Standard	Constable	4500	Female