

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 in 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 cases 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 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 companionship 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 husband's 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.