Understanding Stigma Together
Workshop with Sex Workers on HIV-related Stigma and Discrimination
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Executive Summary

Positive sex workers (PSWs) experience multiple forms of stigma. HIV-related stigma and discrimination add to the stigma associated with their work along with stigma attached to social class, gender and poverty. A study exploring this stigma in the Indian context formed part of an initial assessment for a new project to reduce stigma against HIV-positive sex workers in Belgaum District, Karnataka State, South India.

In order to understand the forms, contexts and consequences of stigma related to sex work as a profession and HIV status among female sex workers, data was collected during a three-day residential workshop in June 2012. A total of 24 female sex workers were selected from targeted interventions led by either non-governmental or community-based organisations through a purposive sampling based on geography (rural/urban), typology and age. The group of sex workers was divided into three peer groups: young sex workers, home-based sex workers and street-based sex workers. Using participatory tools, the sex worker groups depicted pictorially the manifestations of stigma within the family and the community, the causes and effects of stigma, experiences of HIV-related stigma and discrimination, coping and resilience strategies and strategies to address stigma from family, community and self.

Positive sex workers experienced HIV-related stigma and discrimination from family and community, and within institutional settings. Within the household, stigma manifested itself in the form of isolation, neglect, teasing, blaming, and de-recognition of the PSW’s position. PSWs were given separate, clothes, bed linens and utensils to eat with; were disallowed from doing household chores such as cooking or cleaning; were excluded from decision making and family events; and were denied emotional support. In extreme cases, they were thrown out of the house and separated from their children. Factors driving the adverse reactions of the family members (termed “actionable drivers and facilitators”) included the fear of contracting HIV, a sense of impurity associated with the infected person, fear of losing reputation in the community, and the loss of productivity of the woman once she falls ill. Within the community, PSWs were often told that they deserved their condition and were blamed for being vectors of the disease and for bringing shame to the village. They were abandoned by friends and co-workers and subjected to constant gossip about how they acquired the virus. They were no longer invited to community events, and people refused to sit near them in public transport. Significantly, PSWs reported being stigmatised by other sex workers who feared a loss of clientele due to association with an infected person. People closely associated with a positive sex worker, especially children, too faced the negative consequences of stigma.

HIV-related stigma and discrimination have debilitating effects on an individual’s self-esteem and quality of life. They undermine the effectiveness of HIV prevention and treatment programmes. Interventions to reduce stigma, while addressing the fears of the infected persons, must also sensitize family and friends to gather them as sources of support in the fight against stigma based discrimination.
1. Background

Stigma is a part of life for most people living with HIV, but for women in sex work who are already facing stigma due to their work the added stigma of being HIV positive can be devastating. In India, stigma and discrimination against female sex workers (FSWs) are validated and gain legitimacy as they operate in a socio-cultural context where sex work is considered as an immoral, non-normative female behaviour. This is further aggravated by FSWs being viewed as the vectors of the HIV epidemic to the general population. The HIV prevalence among FSWs stands at 4.9% while the prevalence in the general population is only 0.31% in 2009. Positive sex workers (PSWs) experience dual stigma as HIV-related stigma and discrimination further marginalise vulnerable groups and ‘build on pre-existing forms of stigma and discrimination associated with sexuality, gender, race, and poverty’. HIV stigma tends to ‘heighten pre-existing prejudices, undermine prevention, deter or delay testing and disclosure’. It reduces the quality of care, delays treatment and lowers the chances of survival, and hinders adherence to medication. It can lead to ‘job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support’.

Positive sex workers face abandonment by their families and friends, desertion by their partners and lovers, separation from their children, differential treatment in health care settings, segregation in public places and exclusion from the community. Studies elsewhere have found that stigma undermines the agency and status of FSWs, thus increasing their vulnerability. Internalisation of stigmatising attitudes and behaviours from their environment results in low self-esteem among FSWs, which adversely influences their condom use and care seeking behaviour. Similar findings have been reported in Karnataka State. Sex workers with low self-esteem and who fear stigma and discrimination are less likely to adopt preventive strategies such as seeking treatment for sexually transmitted infections, getting counselled/tested or returning for results, accessing health care professionals for treatment, disclosing their HIV status and adhering to treatment. HIV prevalence rates are very high among FSWs in North Karnataka, 22.30% in Belgaum, for instance, (IBBA 2010), home to an estimated 3147 positive sex workers.

Recognising stigma as a barrier that blocks access to prevention, treatment, care and support services, it was decided to do an initial assessment in this...
area in Belgaum district in Karnataka, to understand the forms of stigma and discrimination against HIV positive sex workers. To this end, a three-day residential workshop was conducted as part of a project, funded by International Center for Research on Women (ICRW) and the United Nations Development Program (UNDP), to reduce stigma against HIV-positive sex workers in Belgaum.

2. Objectives
The main objective of the workshop was to understand the forms of stigma related to sex work as a profession and HIV status among female sex workers.

The specific objectives of the workshop were as follows:
1. To map out contexts where HIV positive women in sex work face stigma with special focus on the family.
2. To understand the causes and effects of stigma on self and the family.
3. To understand various forms of stigma that exists for HIV positive women in sex work.

3. Methods and Sampling
Female sex workers were mobilised irrespective of their HIV status, to participate in the three-day residential workshop. Twelve FSWs were chosen from Sankeshwar and Savadatti TIs led by the NGO BIRDS, eight FSWs from Raibag and Ugar TIs in Belgaum district led by the CBO Shakthi AIDS Tadegattuva Mahila Sangha, and the remaining four FSWs from Mudhol and Jamkhandi TIs in Bagalkot district led by the CBO Chaitanya AIDS Tadegattuva Mahila Sangha in Bagalkot. The workshop provided a platform for the community and the organisations to together further their understanding about HIV-related stigma and discrimination.

Inclusion Criteria
Participants were screened for potential inclusion in the study using the following criteria: being a practicing female sex worker i.e. she has traded sex for money in the last month.

Participatory learning and action tools (see Annexe 1) were used for a qualitative assessment of HIV-related stigma and discrimination during the workshop. A total of seven tools were used to identify the forms, contexts and consequences of stigma. The large group of sex workers was divided into three peer groups of young sex workers, home based sex workers and street based sex workers. Each of these peer groups was given a name and a number chosen by the group members. The group members also chose the facilitators whom they wanted to work with for the next three days. The group composition and the facilitator assigned to assist them remained the same throughout the workshop.

Within the overall number of subjects who would fit the inclusion criterion mentioned above, a purposive sampling was done and 24 female sex workers were selected, from both NGO and CBO led TI. The participant sample was chosen based on geography (rural/urban), typology and age (see table below):

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8 The workshop was held from 11th to 13th June 2012 in GyanNiketan, Belgaum district, Karnataka, India.
Twelve female sex workers each from rural and urban sites

Eighteen street based and six home based female sex workers

Seven young female sex workers (18-25 years of age), twelve female sex workers between 25 to 35 years of age and five female sex workers of 35 years and above.

<table>
<thead>
<tr>
<th>NGO led</th>
<th></th>
<th>CBO led</th>
<th></th>
<th>% of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>TI name</td>
<td>Sankeshwar</td>
<td>Savadatti</td>
<td>Raibag</td>
<td>Ugar</td>
</tr>
<tr>
<td>Geography</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Rural</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Typology</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Street based</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Home based</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–25 years</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>25–35 years</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>35 and above</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>

3.1. Data processing and analysis

At the end of each session, each peer group explained the illustrated diagrams with the texts. These were transcribed into English on site. The peer groups presented their diagrams to the rest of the participants and this was followed by discussions of which notes were taken down on-site. The presentations and the transcribes of the discussions were translated. Manual thematic analysis was conducted. Analyses by theme were conducted for each of the peer groups (home based, street based and young female sex workers) and were also compared across the three groups.

4. Understanding Stigma Together

The workshop started with a brainstorming session to capture the varied understandings of stigma. A total of seven sessions were held over three days where the community and the staff worked together to understand the forms, experiences and causes of stigma. Using different participatory tools, the sex worker groups depicted pictorially the manifestations of stigma within the family and the community, the causes and effects of stigma, experiences of HIV-related stigma and discrimination, the coping and resilience strategies and strategies to address stigma from family, community and self.
4.1. Mapping of Stigma

The first session on ‘Mapping of Stigma’ set the ground for wider and in-depth discussions on stigma and resultant discrimination for the next two days of the workshop. It was a large group discussion which started with participants brainstorming on the meaning of stigma. The participants were encouraged to recount their lived experiences of stigma and discrimination based on their sex worker identity or as a result of perceived or actual HIV-positive serostatus. They described different processes (refer to Figure 1) which manifested stigmatising behaviour in their interpersonal relationships (family, friends and lovers/partners) and at the level of community and health service systems.

The sex workers reported being ‘devalued’ by the community for practicing sex work and being incorrectly blamed (‘stereotyping’) for spreading HIV in the community. They described facing sex-work related stigma, where the community ostracised them as they were considered immoral and as having HIV. They spoke about false assumptions (‘suspicion’) by the community and ‘gossip’ about their HIV status negatively influencing their relationship with the family. As a sex worker reported, “if we work very hard in a day and in the evening we have body pain or fever, then the community starts saying that she has HIV; this discussion will reach home and because of such talk in the community, I am today staying separately with my son.”

The sex workers described more severe outcomes resulting from a combination of sex work and HIV-related stigma. They narrated experiences of being ostracised, avoided and deserted by their family and friends if found to be HIV positive. They reported losing their freedom to move out of their homes, as the family believed them to be dangerous for the larger community: “don’t go outside of home, you will create problems for everyone in the village”. They also explained how stigma due to HIV intersected with gender discrimination to result in differential care for a female sex worker as compared to her male partner: “if the partner is HIV positive, the family or

Figure 1: Meaning of stigma as defined by FSWs in ‘Stigma Mapping Exercise,’ on 11 June 2012, in Belgaum district, Karnataka, India.
Community mapping is a participatory stigma mapping tool used to ‘provide a non-threatening way to start a discussion about sensitive subjects including sex, HIV/AIDS, drug use and so on’.

**4.2. Community Mapping**

The peer groups were then introduced to the concept of ‘Community Mapping’. Each group was asked to draw a map of the community on a chart paper identifying places where stigma occurs in the community. The groups drew a social map of their village, indicating places where stigma occurs, the agents of stigma in these contexts and the forms of stigma. The participants were encouraged to think about and mention how these experiences varied for a sex worker as compared to a positive sex worker. However, the contexts, the drivers and forms of stigma identified did not differ much on the basis of the HIV status of a sex worker. The identification was based on both personal experiences of the participants and those of others that they knew or had heard about in their village.

The participants reported many different contexts in which stigma occurs – bus station, streets, village well or hand pump, school, clinic, workplace, marketplace, bars, temples, during open defecation in the fields and other public places. They were stigmatised by their neighbours, friends, clients, village elders, police, local doctors and the clinical staff, and other women in the community. The contexts and forms of stigma did not vary significantly across peer groups. In all these contexts, stigma took similar forms, which included insulting, isolation, shaming, stereotyping and name-calling. For instance, the group of young sex workers explained being denied entry into the village.

<table>
<thead>
<tr>
<th>Context</th>
<th>Agents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bus station</td>
<td>clients, neighbouring women, friends of clients, co-travellers</td>
</tr>
<tr>
<td>Social gatherings</td>
<td>neighbours and relatives</td>
</tr>
<tr>
<td>Local clinic or hospital</td>
<td>doctors and other staff</td>
</tr>
<tr>
<td>Death procession</td>
<td>community members</td>
</tr>
</tbody>
</table>

*Figure 2: Examples of contexts, agents and experiences of stigma, identified by female sex workers – Community Mapping exercise, on 11 June 2012, in Belagum district, Karnataka, India.*
temple and treated like an untouchable, where the village priest took care to not touch her hand while giving her the deity’s offering: “She is a Devadasi. Don’t allow her inside the temple.” They reported being discriminated against in self-help groups, where the community women showed differential treatment to sex workers and positive sex workers. They narrated other experiences of stigma such as being driven away from public places by the police, spoken to disrespectfully at the village local government office, and targeted with comments based on wrong assumptions: “If we bring good thick pieces of firewood, then other women will say, she might have gone with some man, had sex with him and then got the firewood with his help.”

The impact of HIV-related stigma and discrimination was reported to be much stronger. The stigma directed at HIV positive sex workers included them being perceived as immoral and being subject to isolation, separation, and social rejection among others. The participants reported HIV positive sex workers being the target of such treatment by friends, co-workers, healthcare providers, employers and others. For instance, they narrated experiences of positive sex worker(s) being isolated by her colleagues: “Don’t go near her. Protect your husband from her.” Most times, they will not sit with her during meal times. They reported being chased away from their rented accommodation: “If the owner came to know about her status, they won’t allow her to live there.” In the bus stations, co-passengers refused to sit near positive sex workers. The positive sex workers often faced name-calling and condemnation from village elders: “She was a prostitute. She was earning a lot from sex work. Look at her now. She is infected.” Other women from the community showed their prejudice by physically distancing themselves from the positive person: “At the village well, if a positive woman comes to fetch water, then all others will go away and come later after she is gone.” Their children are insulted and discriminated against in schools by other children: “Her mother was a sex worker and is HIV positive. Don’t touch her.”
Community map drawn by street based sex workers in India showing public places and agents of stigma where sex workers and HIV+ sex workers face discrimination

Reference: Adapted from a diagram by FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
Significantly, sex workers reported stigmatising other sex workers who are HIV positive. The admissions by the participants reflected lack of adequate knowledge among themselves about the routes of HIV transmission: "If we mingle too much, we may also get HIV." However, a much more predominant concern was about associated stigma and loss of business resulting from an affiliation with the positive sex worker: "In some cases, I am having sex with one person. He may be visiting the positive sex worker. So, I want to keep her away. The positive woman is already stigmatised. If the same man comes to me, others will stigmatisate me too." They feared that they would lose clients if they continued to be friends with a HIV positive sex worker.

4.3. Household Mapping

The second day of the workshop started with a session on ‘Household Mapping’ to help the participants understand HIV/AIDS related stigma within their homes. Each of the peer groups were asked to make a drawing of a typical house in their community. The participants were asked to demarcate spaces within the household where an HIV positive sex worker were stigmatised and isolated within a home. The groups then explained the ways in which they experienced stigma in these spaces including the changed nature of interactions and relationships with their family members once a sex worker was identified as HIV positive. The participants reported that there was no space within the household which was stigma-neutral. Kitchen, pooja room, bedroom, bathroom and verandah were marked by all three groups as spaces within the house where a HIV positive sex worker experienced stigma.

The fear of infection resulted in family members restricting the infected person’s access to the kitchen, prayer room and the bathroom. The immediate outcome was to no longer have any common household implements, not share food items and avoid any physical contact. The infected person was given a separate set of utensils, toiletries, and bed and mattress. For instance, once infected, she was no longer allowed to enter the kitchen to fetch water or eat: “Once she is infected, she is not allowed to take food from the kitchen. She is given leftover food after everyone else has eaten, and is served grudgingly (eat and die!) and from a distance so that the spoons don’t touch the plate that she is eating from. She is told that no one will eat at home if she cooks. Even if they offer to help her get water or food, it is because they don’t want her to touch anything in the kitchen.” They were prevented from assisting the family with daily chores such as washing clothes or utensils and cooking. The participants also recounted instances where the infected woman was thrown out of the house to live in a corner of the cattle shed for the rest of her life: “She is given a place in the cattle shed. Her plate, bowl, glass and clothes are kept there. Her food is served there. She is asked to clean the shed as it is considered demeaning for others to do it. They ask her to do it because she is infected and so she can do work that is not considered good.”

The stigma extended even to the children of the positive sex workers, with instances where they were denied entry into the kitchen once their mother was infected. Similarly, the participants reported that an HIV positive woman was denied permission to go to the toilet situated outside the house which is a usual practice for women in the villages: “If an

11 Household mapping is a participatory stigma mapping tool which, ‘helps to explore places in the home where people fear contact with people living with HIV or AIDS. It can also show where people living with HIV or AIDS may be stigmatized or isolated within the home’. Tools Together Now! 100 participatory tools to mobilise communities for HIV/AIDS. International HIV/AIDS Alliance. May 2006.
Map identifying possible points of HIV/AIDS-related stigma and discrimination in the household

Reference: Adapted from a diagram by FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
infected woman goes to the toilet near her house, the neighbours complain to the family saying that their kids also use the same space, so she should go somewhere else. Her own family will not allow it saying that the children play around the house. They tell the children not to go near the place where she is bathing as they believe it is not safe to cross the stream of water flowing from where she has bathed.” Infected women also experienced separation from their children which included them not being allowed to care for their children and show affection: “Children are no longer allowed to sleep with their mother. She cannot eat with them and if she gives some of her food to the children, it is immediately taken out of their plate. Even if the child is crying, she cannot go inside the kitchen to pick up and pacify the child. Sometimes, they are not allowed to touch or kiss their children.”

Untouchability and notions of impurity surfaced strongly with respect to the use of the prayer room. An infected woman was not allowed to enter the prayer room, clean it or touch the deities or the materials used for worshipping them: “She is not allowed to pluck flowers for the puja (worship) because they think the plant or the tree will die if she did that. Even if she brought the flowers, they are not used as it is considered impure.” The positive persons were mocked by the family members during prayers: “Why are you praying? You already have it. What is the point? What are you asking for?” Over time, she starts staying away from prayers as she begins to believe these messages and loses faith in god.

Positive sex workers also experienced stigma and discrimination as the family feared a loss of social standing in the community. Within the household, these reflected in infected persons being asked to stay away from social ceremonies and functions at home or hide when there were visitors at home. The family was anxious about the negative local attitudes towards the family and hence did not want to expose her to the larger community: “If there is a ceremony in the house, she is asked to not come out of her room. Sometimes, they put curtains in the windows and doors facing the living room so that she is not seen by others. She is also not allowed to sit on the porch as they feel the neighbours will stigmatise the house because of her association with it.” Other family members would also not sit with her on the porch while she is resting.

The participants explained that once the woman was found to be HIV positive, she often lost her position and power in the family. Prior to being infected, she was the primary earning member. Once infected, she loses her ability to earn and as a result the family begins to consider her useless and as a burden on the family: “Earlier, she used to be the decision maker for the entire family. Once she is ill, she is not made part of any decision making process or consulted for her opinions especially on matters such as the marriage of her daughter or son.”

4.4. Cause and Effect Diagram

Once the participants had defined stigma and discussed its forms and locations within the community and the household, they were engaged in a session to identify the causes and effects of stigma. The ‘Cause and Effect diagram’ was used to encourage the participants to discuss the causes of stigma related to HIV/AIDS and the immediate effects of this problem. Stigma about HIV/AIDS was the problem chosen to be discussed. The three peer groups drew pictures with illustrations that depicted the causes of stigma and its resultant effect on the stigmatised sex worker.

The causes of stigma identified by the participants included:

- **Moral judgements about how people became infected with HIV:** Being infected with HIV was linked to transgression of accepted sexual

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12 Cause and effect diagram is a participatory tool used to analyse the causes and effects of a problem relating to HIV/AIDS. Tools Together Now! 100 participatory tools to mobilise communities for HIV/AIDS. International HIV/AIDS Alliance. May 2006.
behaviour. The women were perceived as having made personal choices to engage in immoral and promiscuous behaviours such as illicit relationships outside of the marriage or engaging in sex for money. They were considered guilty and as a disgrace to the village community. Most often non-Devadasi sex workers practice sex work without the knowledge of the family. When she becomes infected, the family blames her for engaging in an activity believed to be a social evil that undermines the reputation of the family: “Those who are infected with HIV have committed a sin. By keeping them away, it is a lesson for others to not commit that sin.”

**Fears about causal transmission of HIV:** Poor knowledge about the routes of HIV transmission due to low levels of education causes people to believe in a lot of misconceptions about the disease. This generates fear about contracting HIV through casual contact or sharing of the same space, utensils, and other household artefacts. Children of infected women may have to discontinue their education and face social exclusion in school as the school authorities fear transmission of the disease to other kids. As a result, infected persons are isolated and rejected: “If someone visits my home, I will serve food to eat. They will not eat because they think they will get infected if they eat it.”

**Fear of perceived stigma:** Often stigma is also experienced by people closely associated with those living with HIV/AIDS such as family and friends. They fear being discriminated against as a result of being associated with an infected person. As a result, the HIV positive person is abandoned by family and friends and separated from their children: “If you mingle with HIV+ people, others will think that you are also infected, so those who don’t have HIV will not mingle with those who are positive.”
+ **Loss of income coupled with increased cost of care:** The sudden loss of financial independence of the sex worker and her inability to earn, provide for and support the needs of the family is another reason for stigma. For a poor family, a sex worker is often the primary source of income. The costs involved in caring for someone with HIV and AIDS makes the infected person a burden and leads to her being stigmatised and neglected: “When she is HIV +, she is economically dependent and so people start stigmatising her. Earlier, she had the money, she was the decision maker and therefore an authority figure. Now, after HIV, she is not earning, her health is deteriorating and she is not involved in decision making because she has no power.”

+ **Competition, professional rivalry or jealousy:** Within the sex workers’ community, a sex worker being infected is at times seen as an opportunity to get more business for those who are not infected. Hence, fellow sex workers use stigma as a means to oust her from the village: “Within the sex worker community, other FSWs are jealous and talk bad about that person to spread rumours to get her to leave the village. So they will get more clients and it will improve their business.” Participants also said that stigma is sometimes used as a means by family members to grab a share of the infected person’s property.

The effects of stigma included:

+ **Being overcome by guilt, dejection, depression, worry, and stress:** Positive sex workers suffer from feelings of intense anxiety and hopelessness as they have concerns about being socially rejected and this sometimes leads to extreme reactions such as suicidal ideation: “She will feel bad about the consequences that she has to face as a HIV+ person. She will go in search of wells in the fields to commit suicide.”
Discrimination by family, and friends: PSWs experience physical and emotional exclusion from the family, which is often the primary care giver for the infected person: “Once the family members know about her status, discrimination will start. They will start separating her, neglecting her, keeping separate utensils and she also feels bad and gradually, she will become bedridden and nobody will be there to take care of her.”

Separation from her children: HIV-related stigma also affected the children of the positive sex workers as it forced their separation from their primary care giver (mother), thereby denying them her love and affection: “HIV+ woman sends her own child away from her to somewhere outside the village to grow up because she fears that her child will also face stigma if she stays with her in the village. Because of this, child will lose the mother's love and care.”

Loss of self-worth and low self-esteem: PSWs begin to look down upon themselves as they are overcome with feelings of worthlessness especially as the disease takes a toll on their physical appearance. They also tend to feel useless as they are no longer able to support their dependants: “Once she is HIV+, she is like a plant full of thorns and no one will touch her. Earlier she was like a beautiful tree, attracting and supporting everyone like a big tree with full of flowers and fruits.”

Self-isolation and lack of willingness to seek treatment: Self-isolation used by PSWs as a means of self-preservation against stigma takes a toll on them in time physically and emotionally. Lack of support for care combined with depression lead to PSWs neglecting their health and not accessing treatment: “Psychologically, they feel low. They start avoiding food and hospital visits and then they will become physically weak as a result.”

cause and effect of stigma on sex workers living with HIV/AIDS.
Reference: Adapted from a diagram by FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
Migration and resultant increase in poverty: Fear of social reactions to her HIV positive status forces the PSW to migrate to a new place thereby jeopardising the existing support systems. In the process, she loses her livelihood and has to struggle to start anew in an unfamiliar place. This puts enormous strain on her already limited financial resources, thereby deepening her poverty: “She leaves her town and goes to some unknown place because of stigma. She faces more problems there. She loses her money and property also. So she is driven further into poverty.”

Reference: Adapted from a diagram by FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
4.5. Story with a gap

The tool ‘Story with a gap’\textsuperscript{13} was used to enable female sex workers to share experiences of HIV-related stigma and discrimination. The participants for this exercise were purposively chosen for being sex workers and not based on their HIV positive status. Hence, the group was asked to think about a typical life story of an HIV positive sex worker from the time she goes for testing and map out the various situations through which her life progresses once the status is revealed. All three groups of sex workers described the reactions of the family, community and self that involved both a devaluing of self and discrimination from others.

On analysis of the narratives of the three groups of sex workers, family, friends and partners emerge as the main drivers of stigma. None of the groups reported facing stigma from care centres or hospitals. The sex workers’ own and immediate response to their HIV+ status was that of disbelief, denial and dejection. In an effort to hide their status from their family, the sex workers refuse to access treatment from authorised government ART centres and to seek counselling. Self-stigmatisation outcomes include attempting to commit suicide, alcoholism, resorting to unsafe sex, abstaining from food and feeling intense guilt. Desertion, blaming and shaming and a refusal to care for the diseased are the common stigmatising reactions from the family, partners and friends. Children stigmatise their mother, but are also the recipients of negative outcomes of stigma at school, such as being taunted, teased and excluded by teachers, fellow students and their parents. Intense guilt, depression and isolation are very common outcomes. Deteriorating health coupled with lack of access to care inevitably leads to her death. The stigma continues even after the death of the HIV+ sex worker, where all her belongings and clothes are burned in a religious ritual.

“When you were younger, you earned and enjoyed your life a lot. Now that you are diseased, even your partner is not taking care of you. We dedicated you to a life as Devadasi, which did not mean you had to do sex work. You could take on other roles such as singing or asking for alms in the name of Yellamma. Now, you are infected and we are not responsible for this.”

- Response of brothers to a HIV+ female sex worker

\textsuperscript{13} Story with a gap is a participatory tool used to involve community members to tell a story about HIV/AIDS through pictures to highlight the issues involved. \textit{Tools Together Now! 100 participatory tools to mobilise communities for HIV/AIDS}. International HIV/AIDS Alliance. May 2006.
Picture story discussing the life of a young female sex worker once she is diagnosed with HIV

Reference: Adapted from a diagram by young FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
Picture story discussing the life of a home based female sex worker once she is diagnosed with HIV

Reference: Adapted from a diagram by home based FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
Picture story discussing the life of a street based female sex worker once she is diagnosed with HIV.

Reference: Adapted from a diagram by street based FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
4.6. Coping and Resilience Mechanisms

Having explored forms, causes and effects of stigma, the participants were then asked to think about and depict ways in which they would cope with stigma related discrimination. The peer groups discussed amongst themselves and listed down various mechanisms that they would adopt to avoid stigma. This session clearly surfaced the differences between the preparedness of young sex workers and older sex workers (home and street based) to cope with the stresses related to HIV related stigma. The older sex workers predominantly spoke about positive ways of handling stigma. These included actions such as:

- disclosing their status and reaching out to friends, peers and counsellor for support
- undergoing periodic CD4 testing
- seeking ART treatment
- eating nutritious food to maintain good health
- regularly using condoms to prevent further deterioration of health
- creating a network of people who will understand her status and support her
- taking good care of her children so that they take care of her in the future
- distancing herself from those who stigmatise her
- helping other infected people through groups and organisations
- maintaining a positive attitude towards life

Few of the other responses also involved hiding their status or using two condoms or making a pact with God so that she is taken care of.

In contrast to the above responses, the resilience mechanisms listed out by the young female sex workers were largely negative and driven by fear of stigma. These included:
+ denying or hiding their status
+ isolating themselves from the community and not attending social functions or sangha meetings
+ not going for repeated testing and refusing to access ART treatment for fear of their HIV positive status being disclosed
+ seeking ART from private hospitals or those in other talukas to avoid being identified
+ drinking alcohol
+ taking Ayurvedic medicines to put on weight so as to avoid suspicion from others
+ citing witchcraft or financial problems in the family as reasons for looking weak
+ permanently migrating from the village once others know about her status

The positive responses involved accepting their status, being open about it, and staying fully engaged with work or spending time with friends to avoid unnecessary worry about the status.

4.7. Addressing Stigma

The final session of the workshop asked participants to discuss strategies to address self-stigmatisation and stigma from the family and community. Each of the groups was asked to come up with strategies to deal with stigma from a different stakeholder. Home based sex workers were to give suggestions on handling stigma within the family, street based sex workers on stigma from the community and young sex workers on ways to address self-stigmatisation.

Strategy to address stigma against a HIV/AIDS infected female sex worker

Reference: Adapted from a diagram by FSWs during the PSW workshop on Stigma and Discrimination, Belgaum district, Karnataka, India, June 2012.
5. Discussion

Positive sex workers (PSW) experienced HIV-related stigma and discrimination from family and community, and within institutional settings. They experienced social, physical, verbal, and institutional stigma\(^\text{14}\) and these did not vary according to typology of the sex workers. Within the household, stigma manifested itself in the form of isolation, neglect, teasing, blaming, and de-recognition of her position. PSWs were given separate eating utensils, clothes and bed linens; forbidden to do household chores such as cooking or cleaning; excluded from decision making and family events; and denied emotional support. In extreme cases, they were thrown out of the house and separated from their children.

\(^{14}\) "The forms of physical stigma can be grouped into isolation and violence, with the former being widespread and the latter less common. The manifestations of social stigma can be grouped into social isolation, loss of identity and role, and voyeurism. A third form of stigma is verbal. This can be direct (pointing fingers, insulting, taunting, or blaming), or more indirect (gossip and rumors). Institutional stigma refers here to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV.” Ogden J. and NybladeL. CommonAt its Core: HIV-Related Stigma Across Contexts. International Center for Research on Women (ICRW). 2005.
Actionable drivers and facilitators of the adverse reactions of the family members were the fear of contracting HIV, a sense of impurity associated with the infected person, fear of losing reputation in the community, and the loss of productivity of the person once she is ill. Within the community, PSWs were often told that they were deserving of their condition and blamed for being vectors of the disease and for bringing shame to the village. They were abandoned by their friends and co-workers, and subjected to constant gossip about how they acquired the virus. They were no longer invited to community events, and people refused to sit near them in public transport. Significantly, PSWs reported being stigmatised by other sex workers who feared a loss of clientele due to association with an infected person. People closely associated with a positive sex worker, especially children, also faced the negative consequences of stigma. They were denied access to spaces within the house such as kitchen or prayer room, separated from their mother, and isolated and insulted at school by their peers and teachers.

The manifestations and outcomes of HIV-related stigma were wide ranging and similar across peer groups. **Perceived stigma** prevented PSWs from seeking treatment and other psycho-social support such as counselling, visiting public hospitals, or reaching out to their family and friends for support. They feared that the disclosure of their HIV status would result in a potential loss of status for self and family and desertion by lovers and partners. It also prevented them from seeking treatment from public hospitals and isolating themselves from family and friends. **Experienced stigma** manifested itself in outcomes such as loss of livelihood, segregation by family, friends and community and low self-esteem. PSWs ability to earn a living was immediately affected as they were thrown out of brothels by the owners or due to a decrease in the client base or because families no longer permitted them to continue in sex work. This increased their dependence for care on families, who often turned hostile after the disclosure of the PSW's HIV status thus greatly affecting the quality of care they received. Isolation by family, friends and community was another of the most common manifestations which resulted from their poor awareness and knowledge about the routes of HIV transmission, such as acquiring HIV through everyday contact. This also arose from the fear of being socially ostracised due to their association with a positive person. Further, entrenched cultural values linking sex work to immorality led to PSWs being subject to dual stigma of being a sex worker and being HIV positive. PSWs often tended to internalise the negative responses from their surroundings. **Internalised stigma** led to feelings of insecurity and guilt, depression, withdrawal and low self-worth among PSWs and to suicidal feelings. This affected condom use and treatment access by the PSWs, as they failed to appreciate the value of practising safe sex or being treated once they were infected.

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15 ‘Perceived stigma is the fear of how others would stigmatise oneself, the expected reactions of their surroundings.’ Talja M. Stigmatisation and discrimination of people living with HIV/AIDS in Maputo, Mozambique. A Minor Field Study in Human Rights. Göteborg University, Centre for the Study of Human Rights. April-October 2005.


Figure 1: A framework for understanding stigma and programme implementation with FSWs

Reducing HIV Stigma & Discrimination: A Framework for Understanding Stigma and Programme Implementation with Female Sex Workers

Actionable Drivers

Fear of HIV Infection
- Lack of knowledge
- Irrational fears

Fear of social ramifications/ loss of reputation
- Own family
- Community
- Clients
- Lovers
- Children

Economic loss coupled with burden of care
- Of Illness and death
- Of loss of livelihood

Social Judgment/ Morality
Prejudice & stereotypes regarding:
- HIV status
- Sexual behaviour
- Sex work
- Gender
- Age

Actionable Facilitators

Institutional
- Laws, policies, policy environments
- Institutions (family, schools, health care, religious, media)

Individual & Community
- Power
- Social support
- Social assertiveness
- Resilience

Cultural
- Gender culture
- Sexual culture
- Health beliefs
- Ethics & morality

Intervention Points

General Community
HIV positive Key Populations
Peers and Family

Stigma ‘Marking’

Stigma Manifestations (Domains)

Perceived Stigma
Internalized Stigma
Experienced Stigma

Resilience
Discrimination
(isolation, neglect, teasing, gossip, blaming, exclusion from decision making, derecognition of position, exclusion from family events, thrown out of homes, desertion by family and lovers)

Stigma Outcomes

Low condom use
Low uptake of HIV service, disclosure, adherence
Low uptake of psychosocial support
High mobility and migration

Quality of Life
HIV Incidence
HIV Prevalence
Morbidity
Mortality

A significant difference was noted in the coping strategies narrated by older home-based and street-based sex workers as compared to young female sex workers. The older sex workers narrated positive strategies such as disclosure of their status to access support and care, undergoing proper treatment, eating well, practicing safe sex, creating a support group, helping others to cope with the disease, being positive about life, and self-isolation from those who stigmatize. In contrast, the strategies of the younger sex workers mostly centred on ways to avoid disclosure of their positive status, ranging from self-isolation to permanent migration from the village. Older sex workers stated a ‘problem-focused, active coping styles’ found to be more effective in dealing with stigma as compared to ‘emotion-focused, passive coping styles such as avoidance’ in younger sex workers. Further, friends and family emerged as the two key groups to be sensitised about the effects of stigmatisation on infected persons. A more sensitive attitude from these groups will help the PSWs to overcome the fear of rejection and reach out for their support to cope with HIV.

In short, HIV-related stigma and discrimination has debilitating effects on the individual’s self-esteem and quality of life. It undermines the effectiveness of HIV prevention and treatment programmes. Interventions to reduce stigma, while addressing the fears of the infected persons, must also sensitise family and friends to gather them as sources of support in the fight against stigma-based discrimination.

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### Annexure 1: Participatory tools for qualitative study on HIV-related stigma against sex workers

<table>
<thead>
<tr>
<th>Tools</th>
<th>Objectives</th>
<th>Process and Methodology</th>
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<tbody>
<tr>
<td><strong>Stigma mapping</strong></td>
<td>✦ To identify the places/contexts where stigma occurs</td>
<td>1. Discuss what stigma is with the participants</td>
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<td></td>
<td>✦ Explore how stigma manifests in different context</td>
<td>2. Discuss what type of stigma to explore – stigma of being a FSW and Stigma of being HIV positive sex worker</td>
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<td>✦ Explore the reasons for stigma in different contexts</td>
<td>3. In pairs the participants talk about where stigma occurs in their community</td>
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<td>4. Draw a map of the community and identify locations where stigma occurs for a sex worker and a HIV positive sex worker</td>
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<td>5. Discuss how stigma manifests in different contexts</td>
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<td></td>
<td>6. Explore the reasons for stigma in different contexts</td>
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<tr>
<td><strong>Household Mapping</strong></td>
<td>✦ Identify participants fears about living with and caring for people living with HIV or AIDS</td>
<td>1. Explain the purpose of household mapping to participants</td>
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<td></td>
<td>✦ Understand the reasons for people’s fears about caring for PLHIV</td>
<td>2. Ask them to make a drawing or a model of a typical house in the community</td>
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<td></td>
<td>✦ Explore the impact of these fears on PLHIV</td>
<td>3. Ask them to show places where people might be scared of getting HIV through non sexual contact with PLHIV</td>
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<td></td>
<td>✦ Identify strategies for reducing fears about caring for PLHIV</td>
<td>4. Discuss why such fears exist</td>
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<td>5. Discuss the effect of such fears on the family members</td>
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<td></td>
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<td>6. Discuss the effects of such fears on PLHIV</td>
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<td>7. Discuss strategies for reducing fears about caring for persons living with HIV</td>
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</tbody>
</table>
### Cause and effect diagram

- Provide a non-threatening way to talk openly about stigma relating to HIV and AIDS and identify root causes
- Raise awareness of and concern about effects of a problem
- Explore relationship between causes and effects of a problem
- Begin to identify ways to address a problem

1. Select the problem “Stigma again HIV positive FSWs”. Write or draw the problem in the middle of the diagram
2. Encourage the participants to discuss immediate causes of the problem. Draw or write each of the causes underneath the problem. Use arrows to show how one thing causes another
3. Encourage participants to identify the causes behind each immediate cause. Keep asking: but why does this happen?
4. Encourage the participants to now identify immediate effects of the problem. Draw or write each of the effects above the problem. Keep asking: but why does this happen? Use arrows to show how one thing causes another
5. Discuss what the diagram shows. Discuss which cause is most important and which effect is more severe
6. Ask participants what can be done to address the causes and lessen the effects

### Story with a gap

- Provide a visual and non-threatening way to explore sensitive situation related to PLHIV and their families
- Identify the life course of a FSW living with HIV after she discloses her status
- Identify what choices PLHIV have and the factors that affect those choices

1. Select a situation related to the community like a “sex worker has found that she is HIV positive”
2. Ask the participants to draw that picture and label it as number 1 and as beginning of the story
3. Then ask the participants to think about real events after that and draw pictures to complete the story and conclude
4. Starting from picture 1 encourage the participants to identify the choices that were available to the person at each stage of the story. Identify the factors that led the person to move on to the next stage in the story. Ask them to write the factors below the picture
5. Repeat the process for all the pictures
6. Encourage the participants to discuss what the story shows. Ask if the story depicts reality in the community. Why is the situation bad or good for the HIV positive sex worker? How can the situation change or improve?
