HIV-positive sex workers are a highly marginalized group in India because of their HIV status and because their work is considered immoral and illegal. As a result, they experience intersecting stigmas that impede their health and livelihood options. Using a community-based participatory approach, this project aimed to improve the quality of life of HIV-positive female sex workers (FSWs) by addressing the stigma and discrimination they face. The initiative was conducted in Bagalkot and Belgaum districts in north Karnataka and was part of a larger effort to adapt and pilot test a global stigma reduction framework to the Indian context.

Understanding the problem

The project began with a three-day participatory workshop with 24 FSWs. The workshop revealed that participants and their peers experience internalized, anticipated and intersecting stigma. A mapping exercise (see Figure 1) illustrated the many places in the community where sex workers, including those who are or are presumed to be HIV-positive, experience stigma, including in the home by family members.

The team also conducted a baseline survey with 240 FSWs and in-depth interviews with five FSWs and five family members. The data showed high levels of HIV-related stigma among respondents and confirmed social judgement, lack of awareness of stigma and fear of infection through casual contact as its key drivers. For example, nearly two-thirds (64%) of FSWs surveyed thought that people with HIV should be isolated and 67% felt that families of people with HIV should be ashamed. Respondents held many misconceptions about how HIV is transmitted, such as through mosquitoes, sharing utensils, sweat and shaking hands. Additionally, the data highlighted the stigma around sex work (e.g. 64% have not disclosed their profession to anyone) and stigmatizing and discriminatory behaviour experienced by respondents in the health care setting including being given less care and attention than other patients, having to wait longer for care, receiving unnecessary referrals and being denied services. Overall, the findings point to the need to work at multiple levels with sex workers and family members.

Project highlights

- High levels of discriminatory attitudes and social judgment were observed among female sex workers.
- It is feasible and acceptable to integrate a multiple-level approach focusing on intersecting stigmas into existing targeted interventions.
- Intensive counselling of HIV-positive female sex workers helped women overcome internalized stigma and foster resilience.
- Strengthening the capacity of targeted interventions in stigma reduction enhances the sustainability of such efforts.

Implementation

Building capacity of targeted intervention staff

The project was integrated into five targeted interventions (TIs), covering 75 villages. Using ICRW stigma-reduction toolkit exercises that were adapted to this particular context, the project team trained TI staff, including programme managers, outreach workers and counsellors to understand issues around stigma and discrimination, and on methods of conducting facilitated discussions with community stakeholders, family members and HIV positive sex workers. In addition, the training strengthened counselors’ skills, especially in the area of rapport, empathy and reflective listening. It also helped them to recognize and challenge their own values and attitudes towards HIV positive sex workers and develop strategies for working with FSWs in a more positive way.

Group sessions with FSWs and family members

The trained TI outreach workers and counsellors used group sessions to engage sex workers and family members in discussions around HIV stigma. Held over a period of three to four months, the

sessions consisted of role playing, sharing personal stories, drawing pictures, analyzing case studies and having interactive discussions. The sessions’ themes included forms and causes of stigma, stigma and gender, misconceptions about HIV transmission, stigma in the family and community, the rights of HIV-positive people and seeking treatment. Altogether, 22 group sessions with approximately 348 FSWs and three sessions with 123 family members were conducted.

Counselling
A total of 157 HIV-positive sex workers received individual, intensive counselling, covering such topics as coping mechanisms, building self-esteem, effective ways of disclosing one’s HIV status to family, the rights and responsibilities of people with HIV, assertiveness and death and dying. As many sex workers are anxious about their children, some sessions focused on how to plan for the future for themselves and their children. In addition, 23 family members also received counselling.

I am regularly attending the group sessions. What I have learnt … is that we should not look at the HIV-positive people differently. If we stigmatize them it will hurt them badly. Personally I have made lot of changes. Before, I was scared to talk, touch or sit close to them. I was afraid of getting infected. But now I know that all these are false. Now I have the courage to confront these fears and whenever I come across anybody doing similar things I go and educate them. Whatever knowledge I got I have shared with my daughters”

MAHADEVI, HIV-NEGATIVE FEMALE SEX WORKER

Presently I am on ART and I regularly go to get medicines. I was counseled seven or eight times by the counsellor who gave me moral and mental support to cope. When I shared my life story for the first time, she is the one who gave me all the courage, knowledge and psychological support. Now I am confident and realize that by sharing I get relief and some peace of mind. Now I eat well and never worry about my HIV status

KHATIZA, HIV-POSITIVE FEMALE SEX WORKER

Lessons learned
Reducing stigma towards HIV-positive FSWs requires a multi-level approach consisting of concurrent interventions with individuals (FSWs) and families. The family and FSW group sessions provided an opportunity to tackle the drivers of HIV stigma in a participatory manner. The individual counselling sessions helped women overcome internalized stigma and build resilience. Together, the multi-level approach contributed to improvements in relationships, including increased support to HIV-positive FSWs from family members.

To be effective, activities and tools are needed to address intersecting stigmas. In this case, stigma associated with sex work intersected with HIV-related stigma.

TI programmes are a feasible and appropriate platform for integrating stigma-reduction efforts. However, getting the support of TI programmes for training and engaging staff takes time, as stigma is not the main focus of TI programmes. However, once staff are trained and mobilized, integration into TI programmes offers a pathway to sustainability for stigma reduction programming.

Mobilizing FSWs for group and family sessions in urban areas is a challenge. Sex workers are often mobile and come from different places, making their participation and that of family members in multiple sessions problematic. The model developed for this pilot study was more easily applied in less urban settings.

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