# HIV/AIDS AND ILLNESSES IN RED-LIGHT AREA



Match and Mismatch of Health Services



#### The Context

Prerana firmly believes that sex trafficking and commercial sexual exploitation can be effectively fought through a broad based social movement based on networking, partnering and collaborations. It is for this reason collaborations, partnerships, research, and dissemination of on-ground experiences and observations, etc have always been pivotal to Prerana's strategic fight against trafficking. Each year, many research scholars from across the globe visit Prerana for carrying out their research work at the grassroots level. The exchange is not unidirectional as it helps us document our own learnings. In May 2019, Claire Viscione from George Washington University, USA visited Prerana to study the perceptions of health and access to health services among the red-light area based women victims of commercial sexual exploitation who are now rehabilitated.

We, at Prerana, took that as an opportunity to update ourselves on how the formerly sex trafficked and prostituted, but now rehabilitated, women perceived health and health services. Prerana also tried to understand the magnitude to which their health is affected because of their being in the sex trade in the past, and the far-reaching repercussions thereof. Seven women, between the age of 29 and 57 years, mostly HIV positive, were interviewed in the course of the research.

#### **Being Healthy: The Perception of Prostituted Women**

The seven women were requested to share what "being healthy" meant to them. Initially they were a little lost for words. As the researchers explained the concept of health to them, one of the women concluded that a healthy person would be someone without any ailment, leading a stress-free life and in good physical shape. Another woman shared that a healthy person eats well.

One of the interviewees said that, she had never actually given health much thought since her childhood, until she started falling ill because of being trafficked in the sex trade. After testing positive for HIV, she has now become regular with her health check-ups. Interestingly, she remembered her important life events by chronicling them with the important political events in the country e.g. she recalled that she was trafficked into the sex trade in the year when India's Prime Minister (Mrs.) 'Indira Gandhi was assassinated (i.e. the year 1984)'. At the time she was barely 16, condoms were not freely available then, nor was there any discussion on the importance of using condoms, she recalled. In her memory it was the year when India's Prime Minister (Mr.) 'Rajiv Gandhi was assassinated (1991)', that she got to know that she was HIV positive.

Another woman said that, "It is needless to think about health, as it is natural for people to fall sick." She said that even if she thought about it, that there was not much she could do about it.

In Prerana's experience of working with the women in the red light area women in the sex trade are unable to take care of their health or prioritise it as they lack support systems in the red-light area, especially to protect their health. Most of the work around health done so far by various organisations has been preventive, with a focus limited to

HIV prevention and not on the holistic health. The work on health in the decade after 1990 was limited in its focus and coverage namely condom distribution, condom negotiation and condom usage.

Prior to the spread of HIV related scare, the outsiders spoke to us of nothing else but Gupta-rog (sexually transmitted diseases). Its only recently that people have started speaking to us about menstrual health, nutrition, family planning, immunisation of our children, tuberculosis, and cancer etc.



Signboards of doctors in Kamathipura

#### Mental Health of the Prostituted Women

As different from their perception of physical health, the women had an understanding of what amounted to stress in their day-to-day life. One of the women shared that she felt it was more important to be healthy mentally than physically, as she felt that something that can affect a person's mental health would have an adverse effect on their physical well-being too.

The women do look for avenues to placate the mental distress they go through. One woman said that she would take rest and look for someone who could listen to her to calm herself and feel better.

Another woman shared that when she felt anxious or stressed she visited places of worship, be it a temple or a mosque, to calm herself. On being asked what was it about religious places that helped her calm down, she said that it was the rituals, prayers and meditation and the feeling of being connected to the Creator that helped her calm down.

One woman said that she got assistance from Prerana's staff who listened to what she had to say. The women, per se, do not visit a therapist or a counsellor. However, they did give credit to the civil society organizations, like Prerana, for having counsellors, who

who they could talk to. The women said that mental health interventions by Prerana like counselling have helped them work on anger, keeping calm and manage stress. "It has also helped us analyse and act on our addictions to tobacco and alcohol" said one of the women.

Despite this, given an option between talking to a family member and a counsellor, one of the women shared that she would choose the former when she is stressed.



A corner for peace in one of the brothels at Kamapthipura

Women also revealed that their financial condition was a perennial source of stress for them. "My father had mortgaged his land and I had to do away with whatever I had earned to get the land back. I couldn't save anything for my children," said a woman pointing out what actually caused her stress. She shared that talking to her children helped her feel better.

When it came to their *aadmis* (fancyman), there was a mixed response. While some touted their fancyman as the one providing them emotional support, others said the exploitation by their *aadmi* had been a cause of distress for them.



During the conversation, the women said they visualize a stress-free life as one in which their children are safe with a good education, where the women do not have any financial issues and when they are free of any ailment or disease. One of the women said how her aadmi was distressing her by forcing her back into the sex trade. None of the women talked about "being happy" while they were in the sex trade.

#### Their Sexual Health

As far as the understanding of "yaun swasthya" or "sexual health" was concerned, the women did have a fair understanding of "safe sex as sex by using condom". However, they did not understand the broader meaning of "sexual health". Their understanding of sexual health too was limited to using condoms for safe sex.

The women said that their first sign of not being sexually healthy manifested when they were into the sex trade. They did complain of having frequent stomach aches, body pain and boils near and on their sexual organs which they called "private areas", white discharge, *Nagin* (herpes) when they were into the trade, the result of which they continued to suffer even now in form of some or the other ailment.

One of the women shared that "In the early 1990's the brothels did not provide girls and women with condoms. Women in the sex trade do not have any control on the sexual transaction and cannot insist upon safe sex, even if the woman tells the customer about using condoms, some simply refuse to use condoms. Even today, you find women in the sex trade testing positive for HIV, of course not as many as we saw 10 and 15 years back." She herself contracted HIV from a customer. However, she did not have access to any testing or treatment facility back then and continued to have unprotected sex with many customers. She said men would reject them if they insisted on using condoms. "They thought the fact that we insisted on condom usage means we were HIV positive. Today, I work for an NGO. I receive treatment along with counselling. I talk to the women here about safe sex, HIV testing and ART" she shared.

Yet another woman said "Being in the sex trade, we are unable to make choices including about our sexual activity. We are expected to conform to the customers' demands."

Up until 2010 in government hospitals the treatment of stigma and discrimination against women from the red-light area was very rampant. It restricted their access to health care said one woman who is currently working with a civil society organization.

One of the women who was middle aged said that, "There was no condom" when she was deeply engaged thoroughly exploited in the sex trade. Once she was out of it, due to the interventions by the NGOs, she got information on the free availability of condoms, gained awareness about health, the spread of HIV and precautions to be taken. They also attributed the increase in awareness to the work by the NGOs such as SAI, who also provide basic medical help and medicines. Unfortunately, many tested positive before they became aware.

An interviewee said that even today some women suffer from a sexually-transmitted diseases, but don't actually know what to do, as they are hesitant to talk to anybody about it. "People become judgmental and so women refrain from discussing their sexual health." said one woman

## Falling ill and the Treatment

Despite increased awareness after leaving the sex trade, a mixed response came from the women regarding their approach to their own health. Most of them said that when they fall sick, they resort to self-medication, or go to a local chemist and take the medicines suggested by them.

"We have to die anyway," said one of the interviewees, overlooking the need to visit qualified medical practitioners and legitimate healthcare facilities for medical care.

It's only when they feel that their own medicines do no work, they visit the doctors. "Some women also go to godmen and take treatment from them. In the recent years, women who are closely associated with an NGO, visit a qualified doctor for health care and have stopped accessing godmen and quacks" said one woman.

One of Prerana workers also shared her experience about healthcare in the red-light area. She stated that when she began to work in the area, almost all women would go to quacks but would also go to qualified doctors when accompanied by Prerana's staff. She further said that things were changing lately. "There is a greater awareness among women. They not only access qualified medical practitioners and government hospitals, but also appreciate the importance of completing treatment and not giving it up once they begin to feel better" she said.

The HIV positive women among the interviewees said they rushed to a hospital if they had the slightest of the ailment. One of the women said that in the five years since she had started her ART (Antiretroviral Therapy), she hadn't fallen sick.

However, the general scepticism about visiting a doctor stems from the fact that sometimes, doctors in private clinics in the red-light area do not administer proper medicines.

#### **Medical Assistance**

Women, especially those infected with HIV/AIDS, in the red-light area of Falkland Road and Kamathipura in Mumbai rely on two government hospitals — JJ Hospital and Nair Hospital. Those infected with HIV have their ART (Antiretroviral therapy) card, which helps them avail free medicines. In case of emergency, they are admitted. As of today the treatment is hassle-free in both the hospitals.

However, one woman said that it had been difficult to get an ART card for her as the government hospital sought her residential proof. While procuring an identity document is a tough task for these women, it was only after she approached the hospital with a letter from Prerana, introducing her and acknowledging that they know her, she was issued an ART card.

Financially, these women often have to struggle to make ends meet. "There are expenses we can't manage. I have two daughters. One of them stays in a suburban area of Mumbai and has to pay a monthly rent of Rs 5,000/-. So much of money goes in just paying rent." said a woman.

One of the interviewed women, who was not HIV positive, said that from these hospitals she gets free check-up but not free medicines. The women also said that in private hospitals the facilities are quick and they also do not have to produce too many documents as compared to the government ones.

# Place of Medical Services – Private Hospitals Vs. Private Clinics Vs. Govt. Hospitals

The women, their HIV status notwithstanding, said that they preferred going to government hospitals as compared to the private ones in case of severe illness, but

prefer private clinics over government hospitals in case the ailment is minor. But, for most of them, their first step towards treatment is mostly self-medication or reliance on local pharmacists.

The women prefer government hospitals near to where they stay, as they incur less expenses on traveling. An interviewee, from Kamathipura, mentioned how her ART treatment from Nair Hospital was shifted to Gaurabai Hospital due to the proximity of the latter to the place where she lived. The arrangement turned out to be convenient for her as she did not have to stand in the long queues at 5 in the morning.

Some women in the sex trade still prefer to go back to their village for treatment as they find it economical.



Private clinics on Falkland Road

#### **Interaction with the Frontline Personnel in Health Services**

The women shared mixed experiences and responses about the medical staff in their visits to private hospitals, government hospitals and private clinics.

"While I was admitted to the JJ Hospital once, a nurse used to scorn at me for being HIV positive," said a woman adding that although she was satisfied with the medical treatment, the discrimination was severe.

One of them, who was HIV positive, said that over the years she has seen a lot of improvement in the behaviour of medical practitioners. She said initially, when her CD4 count (white blood cells that fight infection), was down, the nurses used to feel scared to talk to her. But now no matter how low the CD4 count is, the doctors give care, proper treatment and coordinate. "It's because the doctors cooperate, I too cooperate and take the medicines properly," she added.

Through the course of the interview, the women were also asked if they had been open

about their HIV status with doctors, "It depends on the kind of doctor we go to. If it is a doctor who administers ART to me then I don't feel nervous," said one of the interviewees.

The women previously also preferred to not disclose about being in the sex trade. It is only when they are asked, they open up about it.

The women said at hospitals, where they take regular treatment, doctors understand their problems. "The doctors do rant if we skip the date of medication," a woman taking ART said.

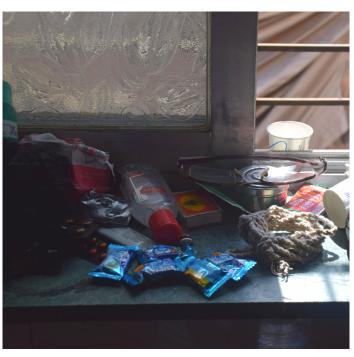
The women recalled that earlier they had no clue about health services too. It was due to the interventions by Prerana and organisations like SAI that they not only got to know of medical services but also were saved from ill-treatment by the medical staff. The women recalled how difficult it was for them to share about their involvement in the sex trade with the medical professionals. But with time, doctors have become more understanding, a woman said.

### Life in the Sex Trade and Its Long-Term Impact on Health

Apart from sexually transmitted diseases, there are many who continue to deal with other health issues due to being in the sex trade.

"In the sex trade I was forced to consume alcohol and solicit. I started to drink to overcome the pain and violation while a customer was forced on me," said a woman, adding how drinking became a habit for her and finally damaged her liver.

Many of them complained of regular body pain and joint pain that started when they were into the trade and continues to afflict them till date. "When I get body pain, I use massage oil with my own discretion. I do not take pills. The doctor has asked me not to because that could affect my kidneys. I can't consume things like cold drinks," said an HIV positive woman.



Medical supplies of one of the women inside a brothel

One woman also lamented as to how for a very long time she had suffered from vaginal infection as she was forced to solicit even during menstruation. "There used to be blood all over. Often, I used to bleed for many days, yet customers were forced on me. Everything was really unhygienic. I used to be given just some plain water to clean myself up," said a 52-year-old interviewee.

#### **Health Awareness - Then and Now**

Once out of the sex trade and rehabilitated, the women have shown a remarkable improvement in their health. But, for many, the irreversible damage had already been done. By the time, the women were economically and socially rehabilitated, they had already faced a lot of sexual exploitation, had suffered from various diseases and a deep psychological trauma.

With the interventions of civil society organizations, like appointment of counsellors, in the last 10 years women have a much better access to services resulting into better physical and psychological well-being. The women also mentioned of being guided and led by these organisations to the avenues of employment for economic rehabilitation.

All the seven women interviewed were of the opinion that:

- There is an increased awareness around the use of condoms, the spread and control of HIV infection, and presence of health facilities.
- Compared to the past the public hospitals have a more enabling environment "they don't scorn at us any more" they said.
- More women access public hospitals to get sterilised.
- Hospitals follow-up on them to ensure that there is regularity in ART and tuberculosis treatment.
- Customers are better informed about the necessity of using condoms.
- None of them had heard of any new born child who was HIV positive.
- Lesser women were testing HIV positive.

P.S. We are sure that most of you must be doing such data gathering and analyzing exercises at your end too. If you are, please do share the same with us. We shall be more than happy to share it on our website

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