

Gasping For Breath

Episode 14: Treating TB is hard, it is worse if you are a woman

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Last year when I went to Sewri TB hospital in Mumbai, I met a woman, probably in her 50s. She was hard of hearing.

Lata: "Yeshu aahe ka?" (Have you come here from a Church?)

Menaka (Host) : "Nahi nahi patrakar." (No no I am a reporter)

Lata asks me if I was from a church. Church-based organisations often donate food and other provisions for patients at the hospital.

Lata: Nobody comes here. It has been seven months. Nobody comes.

Menaka: Where do you live?

Lata: In Naigaon. I do not know where my family is.

She says again and again that nobody has come to pick her up. This despite the fact that her family belonged to Mumbai city. She lives in an area not far from the hospital.

Lata: I was admitted before Diwali. In a month, the doctor gave me chutti (leave). But nobody came. I have a daughter and a son. They don't come. The doctor has asked me to go. But they don't come. It has been seven months. The other patients get visitors. But I do not get any. Nobody comes.

Lata says that she has a son and daughter who do not visit her. She says that while other patients get visitors, she doesn't get any. Nearly every question I asked her ended with the refrain - "*Nobody comes for me. Nobody comes to pick me up.*"`

In one of Asia's largest hospitals for treating tuberculosis, the male wards are often teeming with people during the visiting hours when relatives come armed with fruits, coconut water, and food from home. Often the wives of these men from areas far from the hospital come after work making arrangements for their children's care. But in the ladies wards, many do not have visitors for days or weeks.

Hi I am Menaka Rao, the host of this podcast Gasping for Breath. This show is hosted and produced by Suno India, a podcast platform for issues that matter.

During the COVID-19 pandemic, we have already seen how doctors, nurses and other health workers have been attacked. In many parts of the country, Muslims were discriminated against and sometimes assaulted. This is based on the assumption that these people are carriers of the disease, A disease which is life-threatening. But, the more marginalised the person is in society, the more stigma he or she is likely to suffer in a pandemic like this.

This kind of stigma and resulting discrimination has been observed and studied very well in other stigmatised diseases such as TB and HIV. During the HIV pandemic, the gay community, the sex workers community, the people who use injectable drugs and the others suffered discrimination. Overall, trans individuals and those from non-heteronormative sexual orientations are more likely to face discrimination and abuse by health authorities.

In this podcast, I will look at the kind of stigma women who have TB suffer more because of their gender. We will look at the way in which a woman's status determines the way TB is detected, diagnosed and treated. This is not to say men do not face discrimination. But, it is important to understand the gendered ways in which women are discriminated against. The names of patients have been changed to protect their privacy.

More men as compared to women are diagnosed with TB each year. The National Framework for Gender-Responsive Approach of TB in India that was released this year quotes studies that show that diagnosis is often delayed for women for various reasons. The symptoms presented are often different for women, like say women are less likely to report blood in their sputum. Many women are likely to be detected clinically - as in the doctor looks at symptoms and gives the diagnosis of TB as opposed to being confirmed microbiologically where sputum tests positive. Pregnant and lactating women are vulnerable to TB. Undernutrition among women also poses a threat.

Women have lesser access to healthcare facilities than men. I met 30-year old Beena whose husband refused to take her to a doctor for six months when she was sick. In 2018, while living with her husband and in-laws in Barabanki, near Lucknow she would get seizures. Often she had to continue doing house work through it. She was finally diagnosed last year after she returned to her mother's house in Mumbai. She was diagnosed with TB in her brain. When I met her last year, she was still on treatment. Her mother said that she would have died if she was left in the village.

Beena's mother: If she was still in the village, she would have died.

Beena: He never took me for check ups.

Menaka: How long did you have fits?

Beena's mother: For six months.

Menaka: How often would you get these fits?

Beena: I got many fits when I was living in Barabanki. There was no time table.

Beena said she didn't get enough food to eat when she lived in Barabanki and was also beaten up often.

Studies show that men and children are perceived as receiving more care and attention when they suffer from TB. Women experience the disease differently. These voices can tell us how women, an already marginalised group, suffer more when they have TB. The stigma of the disease sometimes alters their life in a significant way.

Last May, I met two sisters who were detected with TB in Bihta, a town close to Patna in Bihar. I went to their house with Rajesh Dubey and Pradeep Sinha of World Health Partners which works with the private sector for TB control. The two sisters were on treatment. They go to school and college. They would not talk about their hobbies, or what they like to do. They did a considerable amount of work at home. The family speaks in a Bihari dialect.

Neha Kumari and Rita Kumari (Sisters)

Menaka: You work at home?

Sisters: I do sweeping, swabbing.

Menaka: Do you cook?

Sisters: Yes We cook at least one time at home. We also wash the vessels.

Menaka : When do you get time to study?

Sisters: We study between 7 pm to 9 pm.

Menaka : Do you get to go out of home?

Sisters: We don't.

Their father: Just to school and back.

Menaka: Not even to the bazaar?

Their father: We don't allow them to go.

Rajesh Dubey asked if they told the neighbours about the sisters having TB? Their parents said - *NO*. I asked them about their fears.

Sisters' mother: No. The entire village will know about it.

Menaka: What do you think will happen if someone knows they have TB. What is the fear?

Sisters' father: There will be a problem in getting them married.

Menaka: Is that why you are hiding it?

Sisters' father: Not really hiding. Nobody asks us. Nor are we telling them.

Sisters' mother: If someone asks, I tell them there is swelling in the lung.

Sister's mother: If we tell anyone about my daughters' having TB, they will be incited and will spread the news. Nobody will talk to us.

Rajesh Dubey- (translates what she says) - She is saying that if she tells her neighbours that their children have TB, then the neighbours won't come.

Menaka : Has such an incident occurred?

Sisters' mother: Yes, it has happened in the past. If my children have to be married, they will incite the community that my daughters had an illness and no family should have an arranged match with them. This is my fear.

Menaka (to sisters) : Did you tell anyone in school (about them suffering from TB)?

Sisters: No.

Menaka : What are you scared of?

Sisters' mother: Nobody will sit with them.

Sisters' father: Our elders told us that people have been kicked out of home because they had TB.

The disease appears to lessen the person it infects, or devalues that person. In a Mumbai-based study conducted by Medicines Sans Frontiers, a 29-year old woman who was interviewed said -and I quote - ***“If there is a person on the road who hasn't taken bath for days and is smelly, then we won't go near him as we find him revolting. That's how I feel about myself.”***

Like the father of those sisters said, studies have shown that having TB decreases a single woman's marriage prospects. Dr Lalit Anande, the medical superintendent of Sewri TB Hospital talks about this problem

Dr Lalit Anande: For females it is a very bad thing. From what I can say is that once you get tuberculosis.. As a young girl once you get tuberculosis, the scars remain over there. It is never told at the time of marriage. It might so happen that you might lose part of your lung. It's damaged. It's an old thing. It is lying silently over there. Post marriage, you develop some cough and for the same you take an X-ray. The doctor who sees the X-ray does not know if it is old or new. If you give a history it is all right. But you never give a history. He will say- it is TB. Poor girl knows that it's old. But what can she say? If you say it's an old scar, all those problems start. I have practically had divorce cases here. The mother-in-law came and said- She never told us. I had to explain to them. It keeps happening here. Women have a big problem.

Many women suffering from TB are sent to their parents' homes. Take the case of Farzana, who is 24 years old. She also has a 3-year old son and lives in a slum in Mumbai.

Unable to bear the torture in her marital home, Farzana was staying with her mother when I met her last year. I went with the staff of Lok Seva Sangh, a nonprofit that works with TB patients there. Farzana had been taking treatment for about six months, and had almost finished her treatment. But she had been in and out of her husband's house, due to the constant rifts in their house. This despite the fact that she has extrapulmonary TB, that does not infect others. She claims that many members of her husband's family had TB, including her brother-in-law, sister-in-law among others.

Farzana: Since my medication has started, my mother in law is troubling me. She tells me to keep my food and water separate. She tells me to cover my mouth when I cook. I do not even get a cough. My mother in law told my husband to separate from me. Come after her treatment is over. They tell me- You gave him TB. I got him tested, but he does not have TB. They still tell me - You will take him with you (he will die with you). My mother-in-law told my husband to divorce me. She told him I will find you someone in the village.

She was skinny when she was detected with TB - just 35 kgs. It increased a little, and then reduced even more.

Farzana: My food has been cursed by my mother-in-law. When I would sit to eat, she would tell me to feed my husband and in-laws first. By the end nothing would remain. Even if I cook for myself, she would feed everyone in the house and give me little. I was supposed to feed everyone and eat last.

Farzana: They tell me- Why do you argue with us. I do not even argue. Only because of TB they are treating me so badly. They beat me so much. They hurt my face badly.

Menaka: Who hit you?

Farzana: My husband.

Farzana's narrative was sometimes hard to follow. She often blamed her mother-in-law and then said that her mother-in-law was the one who incited her husband to beat her up. Whatever the case maybe, it was clear that Farzana faced harassment at home because she had TB.

While Farzana could speak openly about her ordeal, Savita was not allowed to speak. She was 30-years old and has a five-year-old daughter and was living with her parents when I met her. She lived in Govandi near the largest garbage dump of Mumbai and earned a daily wage separating garbage.

Savita: I used to get a fever, cold. When I went to the doctor. It turned out to be TB.

Menaka: When was this?

Savita: Two years ago when my daughter was a small baby. Now I got it again.

Savita was on a 9-month treatment for TB. But she couldn't speak much as her brother-in-law and some other neighbours were hovering near the door of her parents house.

Savita: Whenever I was sick, I would come to my mother's house. My husband is a drunk. He doesn't work consistently. There was no one to take care of me.

Menaka: Did he say something to you?

Savita: He would say- You keep falling sick. What kind of tension do you have? You keep getting TB.

She wanted to say something but couldn't.

Savita: He used to say a lot of things. But my brother-in-law is here.

When the group left her briefly, she spoke a little.

Savita: My husband would taunt me. But what do I say? I am only sick.

They would tell me not to touch here or there. I got angry and left.

There was no scope for Savita to express her ordeal. She was expected to silently suffer.

The National Framework document quotes many studies in which women suffering from TB have reported facing extreme forms of rejection including being sent away to maternal homes, facing domestic violence, being deserted by their husbands among others.

The rejection is pronounced when the women are just left in hospitals, some of whom die without anyone in the family being around. Vaishali who suffers from extremely drug resistant tuberculosis has spent two months in Sewri TB hospital in 2018. We have heard her in an earlier episode on access to new drugs, where she spoke of how she fought to get treatment with the newer TB medicines, Bedaquiline and Delamanid. She had many stories about the way women admitted in Sewri TB Hospital were treated by their families.

Vaishali: I have seen female patients stuck in the ward for 8 months to a year. A patient in a bed next to mine--she was in the hospital for 8 months. And then she died. Her in-laws had left her. On that bed, another patient was admitted. She also died. Even her in-laws had left her. She got TB after delivering a child. They wouldn't even come to see her.

To be clear Vaishali is well loved in her family who supports her through her illness and harrowing treatment. But the stories of those around her haunt her. Vaishali particularly remembers one patient who had multi-drug resistant tuberculosis. The woman had a 9-year old son.

Vaishali: One woman, I remember. She had a son in the fourth standard. She was admitted in Somaiya hospital in Ghatkopar and then finally admitted to Sewri TB hospital. She had MDR-TB. She was getting better. She used to feel happy when she would see her reports which showed that she was recovering. She was ready to go home. But her husband would say- No. You will stay till the course is over. She lived in a congested area. She would long for him, and his touch. She would also long for her child. When her husband would come, she would tell him to at least show his face. He would say- No, I will also get TB.

The woman stayed in the hospital despite the fact that she could go home. MDR-TB treatment lasts two years. The patient need not stay in the hospital for the entire duration. Often the patients stay for a week to a month. When serious patients started coming into the ward, the hospital authorities told her that her bed will be moved.

Vaishali: The hospital authorities told her that even if your husband takes you or doesn't take you home, we will have to move your bed now. They told her that she will be transferred to the old building. This woman was in one bed for 8 months. It became her home. She was attached to this ward. She knew the staff in the ward. She would wake up

and get ready in the same ward. She had celebrated Raksha Bandhan in the same ward. She had four sisters. Not one of them stayed the night with her. The patients and staffers only spent time with her. She was in good health. She was just 40 years old. As soon as she moved to the old building, she died in 15 days. She was not a patient who was to die. She must have taken tension. Must have been breathless. Her husband did not take her only.

As per protocol, only if the patient is infectious and is tested sputum positive, does he or she have to maintain distance from others. The chance of infection falls dramatically once the patient is sputum negative. But the stigma surrounding the disease ensures that the patient is not touched, or loved.

A resident of Bhayander at the outskirts of Mumbai, Mira suffered from TB for more than 5 years. She contracted it soon after she delivered her son. The 29-year-old had the extremely drug resistant form of tuberculosis for which she was treated at Medecins Sans Frontieres in Mumbai with new drugs, that is Bedaquiline and Delamanid. But in the five years she was taking treatment, she suffered discrimination and harassment in her marital home.

Once she was detected with TB, she says everyone in her house treated her differently.

Mira: They did not like we spent money on my treatment, and that I was admitted. My husband's attitude changed.

My husband would be frustrated and would often blame me. He would often scold me -You have brought me bad luck.

Everyone's behaviour changed. Everyone changed. They started keeping away from me. I was given a separate room. They would not let me shadow even to fall on my son.

Menaka : How did you feel?

Mira: I felt horrid. I can't express how I felt. I faced so many struggles. If a child is crying in front of a mother for his mother's milk and the mother is not able to even pick him up, it is the worst thing for the mother. But I also felt that it is probably good for my son. The doctor has said that I should keep him away. That is why I kept my distance from my child. They also scared me and told me to keep away from him.

If I tried to go close to my child, I was not allowed. I wanted to wear a mask and pick him up. She wouldn't allow me. I spent my days crying there. I didn't even get enough food. I used to just take the medicines. My doctor has told me to pay attention to my diet. That was not possible there.

One night, she felt very scared and called her father. She told him to come pick her up.

Mira: My father came in the night to pick me up. I had called him. I told him I cannot bear to live here. My child was away from me. I couldn't get any emotional support from my husband. For whatever financial support he gave me, he would just feel frustrated and shout at me.

Now Meera is cured, and is living with her parents. She is now a patient-rights advocate. I met her in the World Conference on Lung Health in Hyderabad last October.

Mira: I am fully separated from my husband. My child has been taken away from me.

Menaka: Do you get to meet him?

Mira: I do meet him. After calling them a lot of times on the phone. I have to fight to see him. My son himself says I do not want to live with you. The child is used to them. He knows that I exist. But I missed my chance to have a deeper bond with him.

If I get him sometimes with me, he cries and says I want to go back to my father. It is hard for me to hear that. He says that I do not want to stay with you. I wonder If I am doing the wrong thing by keeping my son away from them. But then I think about it and feel that I can at least watch my son grow from a distance. I will live for him. I will live for myself.

Like Mira, many women who survived TB have had a hard time grappling with their lives even after TB is cured. The disease is not just bacterial, but has a social impact that can significantly change the lives of women who are infected.

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