

VOICES FROM THE FIELD

Need to make **TB** programmes

gender-sensitive

We are sharing some voices from women and transgender people who have dealt with TB and/or multidrug-resistant TB (MDR-TB) and female care providers in families with TB.

These voices underline how **gender based inequalities** adversely impact TB prevention, infection control, accurate and confirmed diagnosis, access to standard treatment, adherence, care and support...

Voices	Some issues
<p>“Over 100,000 women are thrown out of their husband’s houses every year due to TB in India” <i>(Then-Health Minister of India in 2008 Mr Ambumani Ramadoss said to CNS)</i></p>	<p>Stigma Internalized stigma Discrimination Social exclusion Desertion Violence Patriarchy Poverty Low treatment literacy Low health literacy Economic-dependence</p>
<p>“There is still a lot of stigma attached with TB in case of girls and women. They are generally dependent on others to take them to the hospital for diagnosis and treatment which often delays care. They are often deserted by their families. It is generally seen that if a woman is having TB then she is being looked after by her parents but not in-laws or husband” <i>(Sayantani Ghosh, counsellor at MDR-TB care facility in West Bengal said to CNS)</i></p>	
<p>“A lot of stigma is still there for female persons. Just 15 days back we had a woman from Midnapore district in West Bengal who told that her husband had left her because she had MDR-TB” <i>(Bansari Mondal, a nurse in Kolkata said to CNS)</i></p>	
<p>“Please keep me admitted in the hospital otherwise my mother-in-law will make me do hard work” <i>(a woman with MDR-TB said to a counsellor in Kolkata as recorded by CNS)</i></p>	
<p>“Another woman with MDR-TB who had become culture negative, was still not allowed by her mother-in-law from even touching her 3 years old son” <i>(Sayantani, a counsellor with CARE India said to CNS)</i></p>	
<p>“Nusrat had TB in 2007 when in Class 7. She had to discontinue her studies because of her illness and lost two years. She was later diagnosed with MDR-TB in February 2012 and is in the continuation</p>	

phase of treatment. Her counsellor advised her family to send her back to school as she was now ‘infection free’. She thought that she had become overage for her class” *(An excerpt from a CNS interview with a Counsellor at Calcutta Rescue Centre)*

“My elder daughter is admitted for MDR-TB treatment. My house is in a mess as I have to stay with her in the hospital day and night. I have another 12 year old daughter who is looking after the house and therefore has **stopped going to school** as there is no one else to do the family chores *(a mother of a 17 years old female MDR-TB person told to CNS in Kolkata)*

Reena got cured from TB in 2007. But in 2010 she was sent to look after her elder married sister who was suffering from TB and contracted the disease again from her. Her teacher asked her not to come to school. Reena who was in class 9 at that time was forced to leave her studies because of her illness. Reena then got diagnosed for MDR-TB treatment for which started in July 2011. She has suffered irreparable hearing loss due to drug toxicity and not reporting early symptoms to the clinic. Reena said to CNS: *“Earlier I was not able to walk properly and I lost a lot of hair—I almost turned bald. Now I just have hearing problem otherwise I am okay. My two married sisters died of TB, but I want to live and lead a normal TB free life and go back to my studies once I am okay”* *(An excerpt from a CNS interview)*

“My husband earns around Rs 100 to Rs 150 (US\$ 2-3) per day, in which I have to run a family of seven. There is never enough to eat in the house, let alone milk or any other nutritive food for my child with TB. My husband had TB about 7 years ago. He had taken treatment for 6 months and was cured. But of late he has been coughing a lot, perhaps because of his smoking. He has not gone to the doctor, as he feels he has already completed the treatment of TB once, so he will not have it again. I do not know anything about cough hygiene or cleanliness or how to protect others from infection in my family. No other member of the family has been tested for TB. The child with TB sleeps with me on the same bed along with my other kids” *(Excerpt from a CNS interview with a mother of a 6-years old child with TB)*

“People with TB are not empowered with enough medical information about the disease. They do not even know the names of the drugs they have to eat, they do not know why they have to take them without a break and complete the treatment even though they may start feeling better after sometime. This disconnect has to break down. There has to be simplification of messages which convey all information about TB” *(Carol Nyirenda, TB HIV activist said to CNS)*

“Chandrika Gaud is a 28 years old transgender who is living with HIV as well as with drug-resistant TB (DR-TB). She recalls the discrimination she faced in her community because of her disease. Her own people would look down upon her and shun her like an untouchable. They would all stay away from her. If she asked somebody to oil her hair, she was shooed away. She could not go and visit her village and other

Impact of having TB in family on female care-givers and other women and children

Severe socio-economic impacts

Drug toxicities etc leave deeper & indelible scars on female persons with TB

Low treatment (and health) literacy

Severe stigma (such as internalized stigma, stigma within TG community) & discrimination faced by transgender

places. She stayed indoors and would not sit with others. She could not go out for work also” (Excerpt from CNS interview with transgender person at a MSF clinic in Mumbai)

Genital TB is a major cause of tubal infertility. Only 2% of women with genital TB have live births. Globally genital TB is responsible for infertility in 5-10% of women. In India, 19% infertility in women is attributed to genital TB.

Also the impact of genital TB is more severe on lives of women because mostly genital TB impacts women of age group 15-35 years. Only 10% of genital TB in women is post-menopausal.

(As told to CNS by Dr Nerges Mistry of The Foundation for Medical Research and Mamta Jacob of Global Health Advocates India)

TB in pregnant women increases risk of adverse pregnancy outcomes. Pregnant women with TB have double risk for low birth weight, double risk for premature birth, five times for perinatal death, ten times higher risk for foetal death as compared to pregnant women without TB.

(As told to CNS by Dr Nerges Mistry of The Foundation for Medical Research and Mamta Jacob of Global Health Advocates India)

Genital TB is one of the major causes of tubal infertility. With deeply entrenched gender-based inequalities, where infertility can increase severity of stigma, discrimination, exclusion, violence, etc for a woman, genital TB has too long been neglected in MCH clinics

TB in pregnant women needs more attention

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