

Women survivors who won over TB

Some years ago, Nandita Venkatesan took a power nap only to wake up deaf. She could “see” the music playing on a mobile phone and her brother talking but her world had turned silent.

Nandita, who was then getting treated for tuberculosis, later learnt that she had lost her hearing due to the side-effects of the drugs. She is now part of a sisterhood of TB patients, revolutionising TB support in India. If you think TB is only a poor man’s disease, or that it makes all women patients infertile, or that there is only one kind of TB you can contract, you are Nandita’s target audience.

She along with a small band of female TB survivors have come together to start the “Bolo Didi” campaign to support female patients, who invariably have little support navigating India’s labyrinthine, capricious, health-care system.

India shoulders the highest TB burden in the world, with over two million of the 10 million cases reported here. It also accounts for the maximum drug-resistant (DR) patients — nearly 130,000 people do not respond to first-line drugs.

At the 48th Union World Conference on Lung Health in Guadalajara, Mexico, Dr. Saurabh Rane, a TB survivor, spoke about the struggles unique to Indian TB patients. “In a country with the world’s most TB patients, it is tragic that each of us feels so alone,” he said highlighting the complete lack of support for patients in a health system struggling to diagnose and treat patients.

In such a system, there is no redress for social stigma, misinformation and the abuse that patients have to often cope with. This is a reason why patients are starting to form informal networks using social media. With hospitals overwhelmed and doctors short of time, patients are finding peer support to deal with issues that the medical system does not fully address such as stigma, marital issues, sexual health and depression.

“It is impressive that female TB survivors in India have stepped up to fight stigma. It is clear from research that too many patients are falling through the cracks in the Indian health system (both public and private), and patients, particularly women, are seeking support from their peers to make up for inadequacies in the health system,” said Prof. Madhukar Pai, Associate Director, McGill International TB Centre., Canada.

“I would like to see these informal networks become more organised, with adequate training for survivors on technical issues, and clear protocols to link patients to the medical system for complex or life threatening issues (for example, suicidal thoughts),” he added.

The “Bolo Didi” campaign came about when film-maker and TB survivor Rhea Lobo decided to set up what she calls a ‘pay-it-forward’ programme for women TB patients. Her two minute film, on the stories of fellow survivors, was screened at the Union conference. “Women find my film on YouTube and start contacting me via Facebook or WhatsApp. The conversations invariable start with, “Didi, can you please help me?” Some cries are more desperate. There was a woman who once messaged me in panic asking for help as her husband and family did not (and could) know she had TB. She wanted contacts of doctors and counsellors — basic information that should, ideally, not be this hard to access.”

Rhea soon realised other survivors like Nandita were also getting similar messages, asking “Didis” for any and all help. “The stigma associated with it doesn’t allow patients to openly talk about their struggles. As a woman and TB survivor, I feel it is a social responsibility towards these women...

like a pay-it-forward concept. This is a treatable, bacterial infection and women should not be made to feel guilty about contracting an infectious disease and be forced to hide it from their families. We respond to each of them and reassure them that TB is completely curable and guide them through the process of navigating India's health system," Rhea added.

While patients are banding together, the government is digging in its heels further. Dr. Sunil Khaparde, head of the Ministry of Health's TB division, said that the "government was an enabler but not solely responsible for [the] care of patients." At international conferences, the Indian government has faced serve criticism for the glacial pace at which access to newer TB drugs has been scaled up. The government has maintained that it is doing the best it can. Given the lack of support for patients, Dr. Khaparde added that it was "good that patients are coming together". "Our government plan is talking about community participation. We will try to involve them in policy implementation," he said.

Meanwhile, patients like Rhea and Nandita are not waiting. "We are trying to organise patient groups and start a virtual institution for women. This could be a game changer in India's TB response. I came up with the name 'Bolo Didi' over coffee with a couple of friends because that is how every message to me ends: "Didi, please reply". We will be applying for grants in the coming months to fund the "Bolo Didi" campaign. No one," said Rhea, "should feel alone when battling TB."

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Lifestyle-related risk factors are being cited, compounded by an inadequate number of treatment centres in the region

Without policies to stop the worrying spread of antimicrobial resistance, the mortality rate could be disturbing

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