THE HINDU

In treatment, how women always bear the brunt

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Radha is a 32-year-old married woman who lives in Dharavi, Asia's largest slum. Diagnosed with multi-drug resistant TB, she now weighs barely 35 kg. Stuck somewhere between hope and exhaustion, she wonders if she will survive to see her two children go to college.

She is among the lakhs of Indian women affected by TB every year, many of whom do not get appropriate or timely treatment, and have to face the double burden of being ill and having to keep the family together.

TB kills more women in India than all causes of maternal mortality combined. Because a woman's immune system undergoes changes during pregnancy, she is especially vulnerable to infections such as TB that can be fought only with a good immune system. TB during pregnancy or after delivery naturally poses a grave risk to the newborn child as well. The incidence of low birth weight, prematurity and other complications in the baby is higher when the mother has TB.

TB's impact on women and children is far wider than its clinical manifestations. It is estimated that more than 1,00,000 women lose their status as mothers and wives because of the stigma of TB. A study done by the National Institute for Research in Tuberculosis, Chennai, revealed that 11 per cent of children drop out of school on account of parental illnesses and 20 per cent have to take up jobs to support families because their parents have TB. It is estimated that more than 3,00,000 children may have left school permanently because of parents' TB.

In a deeply patriarchal society, stigma, poor socio-economic status and lack of awareness lead to significant delays in the diagnosis and treatment of TB among women and children. A study in Mumbai revealed that married women tried, often unsuccessfully, to hide their disease condition for fear of desertion, rejection or blame for catching the disease. Women dropped out from treatment because of the pressure of housework and the stress of keeping their condition secret, particularly when their movements outside the home were routinely questioned. Also, with little access to stable income or social support, when women lose their partners to TB, they are often abandoned by families. Health programmes, unfortunately, are rarely sensitive to the constraints faced by women and children in accessing care, or to completing treatment.

Exposure

As TB is airborne, everyone is exposed to it, and about half the adult population in India has some evidence of latent or dormant infection. So, what activates the latent bacteria to multiply and produce symptoms only in some people, while the majority are able to contain it? The most important risk factor in India is under-nutrition — it has been estimated that at the population level, under-nutrition accounts for over half of all TB cases. This association is even stronger in the case of women and marginalised communities. Additional risk factors in women are exposure to indoor air pollution, especially in rural areas where many women still cook in poorly ventilated spaces using biomass fuels and are more likely to develop not only TB but also chronic lung diseases.

Young children who stay with their mothers are also exposed.

If we need to address TB in women and children, we must begin by mobilising political commitment and resources to ensure gender-equitable access, including women and child-friendly services. For this to happen, we need to create synergies across the health system. Vertical programmes for TB, HIV, maternal, neonatal and child health and primary care services need to work together to create greater access to TB services everywhere. For instance, we need to integrate TB screening into reproductive health services, including family planning, ante-natal and post-natal care and immunisation visits, and the work of accredited social health activists, self-help groups, village health and nutrition committees and panchayati raj institutions.

We need to create specific campaigns focussed on women and children to sensitise communities to TB. An important follow-up to this is to make clinics more gender-friendly with more counsellors as well as soft skills training for existing staff, so that they can be more sensitive to the patient's needs. Improving the nutritional status of women and children will help prevent TB, while those with the disease may need additional nutritional supplementation. We need to invest in the development of tools, including shorter treatment regimens, child-friendly diagnostics and medicines.

Finally, we need to improve surveillance, as our understanding of this epidemic among women and children remains uninformed.

More research is needed into better methods of prevention as well as interventions that reduce social stigma. A TB-free India cannot be a reality without the involvement of communities, especially its women.

(The author is Director of the National Institute for Research in Tuberculosis, ICMR, Chennai)

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