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12/24, Muthuranga Mudali St, next to Deepam Hospital,
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TB control in India calls for person-centred solutions

Globally, and in India, tuberculosis (TB) continues to loom large as a public health challenge impacting millions. Despite ambitious goals set by India's health authorities to eliminate TB, the challenge is huge and progress is not fast enough. Access to efficient and high quality care – diagnosis, treatment and support – is still not available to every person suspected to have TB or diagnosed with the disease. As India grapples with the complexities of controlling TB, we need a paradigm shift urgently – one that places those affected and their lived experiences at the centre of tackling this ancient disease.

At the core of this shift lies a fundamental recognition: the needs and the interests of patients and communities must be prioritised within the care paradigm and the health-care system. This principle, echoed by survivors, communities, health experts and policymakers, underscores the need for a person-centred approach to TB care and management.

Understanding lived experiences

Perhaps our greatest gap has been in understanding the lived experiences of the affected individual fighting and surviving TB. Too easily, we assume their needs, their challenges, and their expectations. In no other service paradigm are the voices of end users ignored. We have, at times, been guilty of over-medicalising this disease, as doctors and public health folks often do. We have often forgotten to see TB as a human crisis, a gendered crisis, an economic challenge, and a social and environmental one as well.

Over the years, this has been changing, with the emergence of strong TB survivor advocates who have stridently worked to put the needs of



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Even though World TB Day (March 24) has passed, recognising the needs and the interests of patients and communities must form the basis of disease elimination

affected communities on the table. They have sought change in key areas and governments have listened and modified their own approach to meet community needs. A case in point is nutritional support, which while limited, is an important step. Further, the growing focus on patient support, addressing stigma, and gendered aspects of TB has also been important.

Is this enough? Not entirely. To provide high quality, person-centred care, we need to bridge the gap between policy intent and on-the-ground realities. For instance, India needs to prioritise targeted interventions aimed at improving and expanding access to TB diagnosis and treatment. We need to expand the reach of TB testing facilities, particularly in rural and underserved areas, and ensure the availability of free, affordable and quality-assured TB drugs. Molecular testing is the gold standard and less than a quarter of symptomatic patients are getting that as their first test. Recent reports of drug and diagnostics stockouts are troubling and unacceptable.

Care needs to be more humane

Additionally, we need to focus on efforts to make care more humane. Hence, mental health support and gender responsive care become critically important. Efforts are also needed to strengthen community-based TB care models, empowering frontline health-care workers to deliver comprehensive care which addresses not just treatment but also social, economic and mental health needs and is closer to where patients live. This is important as survivor narratives tell us the stigma, discrimination and mental stress they go through, not to mention the side-effects of treatment.

By supporting frontline TB workers, strengthening supply chains and procurement mechanisms, decentralising TB services and empowering local communities, India can reduce

stigma, overcome barriers to access and enhance treatment outcomes.

While TB can affect people of any class, religion, ethnicity, and socioeconomic status, it disproportionately affects the most marginalised in society, including children, the urban poor, prisoners, and people living with HIV/AIDS. The disease has gone beyond being a health crisis alone. It is an economic crisis which by some estimates, costs India billions in losses each year and pushes families and communities into debt and poverty.

Addressing the socio-economic determinants of TB requires a multi-sectoral approach. Poverty alleviation, improvement in nutritional status, well-ventilated housing and better air quality will all contribute towards reducing TB. Recent research has shown that nutritional supplementation reduced TB incidence substantially in household contacts of adults with microbiologically confirmed pulmonary TB. By tackling the underlying root causes of TB, India can make significant strides towards eliminating the disease and improving the overall health and well-being of its population.

Tapping technology

Leveraging technology and innovation holds promise in enhancing TB care efforts in India. The adoption of AI and digital health solutions for TB diagnosis, adherence and surveillance can revolutionise the way TB care is delivered and accessed in the country. By investing in developing better vaccines, we can hope to ultimately eliminate this airborne disease.

The path to TB elimination in India requires a concerted effort to prioritise person-centred care, address social determinants of health, and embrace innovation. By adopting a holistic and person-centred approach, India can overcome the barriers that stand in the way of TB control and create a healthier future for all its citizens.

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Actionable ideas for TB control

Every day, 3,500 people worldwide lose their lives to tuberculosis (TB), and around 30,000 people become infected with TB bacilli, according to World Health Organization (WHO) estimates. India alone accounts for 27% of global TB cases. This is jarring, given that TB is a detectable and curable disease and TB diagnosis and treatment protocols have been a part of existing health systems for a long time.

World TB Day, on March 24, commemorates Dr. Robert Koch's discovery of *Mycobacterium tuberculosis* (the bacteria that causes tuberculosis) in 1882. Despite its discovery then, possible treatments using streptomycin in 1943 and the discovery of antibiotics such as isoniazid and rifampicin in the 1950s and 1960s, the war against the pathogen is far from been won, and there are multiple challenges to be overcome in combating the disease.

Still a disease hotspot

India remains a TB hotspot. The TB control programme in India has undergone several changes since its inception in 1962, incorporating evidence from various domains of public health and health systems, including pharmacology, microbiology, epidemiology, the social sciences, and information technology.

The theme for World TB Day 2024 (March 24), 'Yes! We can end TB!', underscores the potential to eradicate TB with existing disease control mechanisms, infrastructure, training, and the political will. Yet, TB in its various avatars – drug-resistant (DR-TB), totally drug-resistant (TDR-TB), extensively drug-resistant (XDR-TB), pulmonary TB (P-TB) and non-pulmonary TB – seep out, akin to trying to hold sand in one's hand, only to have it slip through one's fingers.

We are in an era of hope where public health discourse has gained importance and technology has narrowed the gaps that were previously unimaginable. The COVID-19 pandemic, despite its disruptive and uncertain nature, has brought to the fore preventive aspects of public health, highlighting social determinants of health in the scheme of things. Despite the passage of World TB Day 2024, looking at rapid urbanisation, migration, and the stresses on the existing health



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India remains a TB hotspot but there can be change with early diagnosis and continuous treatment that is accessible to all

systems, I propose a 10-point agenda towards 'ending TB'.

First, early detection. Given TB's aetiology, early detection is the key. Symptoms are often ignored and mistaken for other common ailments, leading to delays in reporting. Compulsory screening for family and contacts of each index case is essential, necessitating availability of laboratory facilities and efficient follow-up mechanisms within health systems.

Second, precise treatment categorisation. With increasing DR-TB, it is imperative to know the resistance status at the time of diagnosis to assign appropriate treatment regimens as per their phenotypic susceptibility.

Third, treatment adherence and follow-up. Unlike other bacterial diseases, TB requires a long period of sustained treatment. Often, this leads to non-compliance, which could be due to observable improvement in health status, or change of residence, movement across States and districts. Even though the TB control programme has a built-in follow-up system, compliance to complete treatment is not 100%. Leveraging technology to monitor compliance needs focus.

Fourth, zero mortality. Mitigating mortality due to TB, be it DR-TB or non-pulmonary TB, is necessary.

Issue of drug resistance

Fifth, controlling drug resistance. Drug resistance in TB remains a man-made phenomenon. Unregulated use of antibiotics and non-compliance with treatment regimens lead to selective evolutionary pressure on the bacillus, in turn resulting in developing drug resistance. Poor regulatory mechanisms for drug control and non-compliance with treatment regimens are the main reasons for such a high degree of drug resistance.

Sixth, assessing the extent of drug-resistant TB. There needs to be data on the proportion of people diagnosed with TB who have rifampicin-resistant TB (RR-TB) and multidrug-resistant TB (MDR-TB) – this is resistance to both rifampicin and isoniazid,

collectively referred to as MDR/RR-TB. This helps in better plan and design of the control programme, resource allocation for diagnosis, the treatment regime as well as availability of trained staff mandated for DR-TB.

Seventh, availability of appropriate medicines. Assured medical supply is mandated under the TB control programme. However, procurement challenges for DR-TB medications such as bedaquiline and delamanid must be addressed, in addition to ascertaining treatment facilities for all DR-TB cases which require in-patient care.

Integration of intra-systems

Eighth, integration into larger health systems. Strengthening referral networks within and between different levels of public health systems and private health systems is vital to ensure no symptomatic cases are lost, no patients miss their dosages and are non-compliant, and, importantly, the screening of contacts for all positive cases of pulmonary TB cases (DR or non-DR).

Ninth, dynamic notification system. A robust notification system will ease the burden of health system personnel. While Ni-kshay has evolved – 'Ni-Kshay-(Ni-End, Kshay)-TB' is the web enabled patient management system for TB control under the National Tuberculosis Elimination Programme (NTEP) – it requires improvements to capture real-time TB data between sectors, practitioners, time, and locations.

Tenth, considering population mobility and migration. Often, the productive aspects of life are overlooked when discussing disease and health care seeking, particularly in the context of TB, which suffers from social and cultural stigma. Interestingly, once TB is diagnosed and positive cases are put on treatment, health is restored quickly for the patient to resume their daily activities. Therefore, portability of TB treatment within the country is crucial at the policy level.

Let us pledge to create a TB-free India and world. With early diagnosis and continuous treatment accessible to all, we can achieve the goal of 'Yes! We have ended TB!'

