
People with tuberculosis falling through the cracks

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Country Office for India (RNTCP-TSN), New Delhi, India; Indian Council of Medical Research, New Delhi, India; The Fenway Institute, Boston, Massachusetts, USA.) The tuberculosis cascade of care in India's public sector: A systematic review and meta-analysis. *PLoS Med* 2016;13:E1002149. doi: 10.1371/journal.pmed.1002149. eCollection 2016 Oct.

SUMMARY

Subbaraman *et al.* present a cascade of care for tuberculosis (TB) in India's public sector for the year 2013. Drawing from the World Health Organization (WHO) Global TB Reports, the Revised National TB Control Programme (RNTCP) of the Government of India annual reports as well as three systematic reviews conducted by the authors, this study provides estimates of the number of patients with TB in India who reach each step along the pathway from care-seeking to cure. Although prior research has characterized barriers to specific stages of care¹ or components of the cascade in subnational samples,² this study is considered to be the first to describe a national-level TB care cascade.³

The authors conceptualize the pathway of public sector TB care to include six separate steps and the corresponding gaps: (i) total prevalent active TB cases; (ii) evaluation for TB in public sector facilities; (iii) successful diagnosis with TB; (iv) treatment registration through RNTCP; (v) treatment completion or cure; and (vi) 1-year recurrence-free survival. Starting with the WHO figure of 2.7 million individuals with active TB in India in 2013, it was estimated that only 39% of patients with TB successfully reached the final cascade step. Overall, the largest gap in the cascade was access to care with 28% of all prevalent TB cases not reaching public sector TB diagnostic facilities. The attrition between each of the remaining steps in the care cascade was similar, ranging from 13% to 16%.

As individuals with different forms of TB may face disparate barriers to care, separate public sector care cascades were also constructed for different categories of TB: new smear-positive, new smear-negative, retreatment smear-positive, retreatment smear-negative, extrapulmonary and multidrug-resistant (MDR)-TB. Notably, the gaps in public sector care were different for different categories of TB. For example, new and retreatment smear-positive patients had high levels of pre-treatment loss to follow-up (i.e. diagnosed with TB but not initiating treatment; 15% attrition), poor treatment outcomes (i.e. treatment loss to follow-up, treatment failure or death; 12% new, 29% retreatment) and recurrence or death within 1 year of treatment completion (16% new, 27% retreatment). In contrast, reaching public sector diagnostic facilities but not being successfully diagnosed was the largest gap for extrapulmonary (20% attrition), MDR (59%) and both categories of smear-negative TB (38% new, 29% retreatment). MDR-TB patients also experienced high levels of poor treatment outcomes (54%).

COMMENT

India accounts for approximately one-quarter of the estimated global burden of TB and MDR-TB.⁴ Achieving the 2015 WHO End TB Strategy⁵ and the latest Government of India target of TB elimination by 2025⁶ will require substantial efforts and funding to continue to improve TB care in India. The present research identifies major gaps in both the measurement and implementation of India's public sector TB programme with implications to inform the programme's activities and to guide future research.

The cascade of care model, more frequently used in other fields, such as HIV⁷ and maternal and child health,⁸ is a useful framework that defines all or part of the pathway from care-seeking to a specific health outcome. However, a linear cascade model is unable to account for the complex dynamics of care-seeking and transfers that have been documented with TB⁹ as well

as HIV.¹⁰ For example, there is the potential to conflate loss to follow-up from the public sector programme with an individual being undiagnosed or off treatment entirely. In reality, individuals lost to follow-up at any stage along the cascade may be linked into alternative care programmes (e.g. private sector providers or non-governmental organizations) or have silently transferred to another public sector facility.¹¹ Furthermore, the completion of steps along this pathway is necessary but does not guarantee timely, high-quality TB care. Indicators of care without a time element for example may inadequately capture crucial barrier information.¹² Being evaluated for TB at a public sector facility within 2 weeks of symptom onset versus within 6 months of onset have profoundly different implications to both patients and public health programmes.

To their credit, the authors discuss many of these caveats as well as several other specific limitations in the available data and their analysis, including: uncertainty in the WHO estimate of prevalent active TB in India, assumption that all TB patients in the private sector were undiagnosed or not on treatment, inability to control for small numbers of duplicate patient records, misdiagnoses of TB and misclassification of TB categories, availability of only composite treatment outcome data, among others. One of the greatest strengths of this laudable work is the extensive documentation of the research methodology, including explicit descriptions of the assumptions underlying and sources of uncertainty in the estimation of each step and gap along the cascade of TB care. Sensitivity analyses could have been useful though to assess the impact of conservative assumptions that were made where limited data were available (e.g. 1-year recurrence for MDR-TB and pre-treatment loss to follow-up for smear-negative patients).¹³

A key contribution of this work is in clearly describing what is known about India's public sector TB cascade of care and laying the groundwork for future research aiming to improve these estimates. Beyond the steps included in the present cascade model, future refinements could include a variety of other patient-centred aspects of care from early HIV screening and adequate TB counselling to community reintegration or palliative care.¹⁴ Characterizing the temporal¹⁵ and spatial¹⁵ variation in the TB care cascade could also provide more nuanced information to evaluate programme changes and geographically target programme activities. Important differences in the cascade by gender, HIV status, socioeconomic status and other variables may also be crucial to evaluate to ensure equitable care. Some of these knowledge gaps may be addressed through the utilization of more detailed existing programmatic data not currently reported at the state or national levels, such as duration of delays, timing of loss to follow-up from treatment and disaggregated outcome data. Despite implementation challenges,¹⁶ Nikshay, an online governmental platform for the notification and monitoring of TB patients in India's public and private sectors,¹⁷ shows promise in facilitating patient reporting, data standardization and timely data availability.¹⁸

Subbaraman *et al.* provide compelling evidence of the utility of programmatic data and focused systematic reviews to inform interventions and future research on TB care in India. Their estimation of the extent of attrition along the public sector TB care pathway provides considerable opportunities to direct interventions to specific gaps to maximize the impact of available resources. However, focusing on single stages of the cascade may 'shift attrition downstream'¹⁹ due to weak linkages, additional barriers to care and operational challenges.²⁰ Integrated and patient-centred

approaches to addressing access, implementation and quality barriers along the entire cascade have the greatest potential to improve patient outcomes and reduce transmission.^{13,21,22} The latest RNTCP policy changes have attempted to address several identified gaps in care. Successful pilot projects in India have shown the potential of scaling-up molecular diagnostics,²³ public-private partnerships²⁴ and alternative treatment models such as directly observed therapy by family members.²⁵ The ongoing roll-out of daily treatment regimens for drug-susceptible TB, fixed-dose combination drugs and the latest recommendation of a 2-year follow-up of all TB patients after treatment²⁶ is likely to improve treatment outcomes and reduce relapse. Continued political commitment, increased funding and leadership at all levels²⁷ will, however, be essential for demonstration projects to be brought to scale and for effective policy implementation.

Conflicts of interest. None

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