

Challenging experiences of children, adolescents, and their caregivers during the treatment journey for drug-resistant tuberculosis: qualitative study, Mumbai, India

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Introduction

Drug-resistant TB (DR-TB) still affects around 25,000 children every year worldwide. Although treatment success rates for DR-TB in children are higher than in adults, children and adolescents face unique hurdles during DR-TB treatment. We aimed to understand the perspectives of patients, guardians, and healthcare providers in relation to the DR-TB treatment journey for children, adolescents, and their caregivers.

Methods

We did a qualitative study involving in-depth interviews of purposively selected adolescents (n=6; who had received more than one year of DR-TB treatment or were cured at the time of interview), patients' guardians (for children and adolescents, n=5) and healthcare providers (n=8) for patients attending a MSF clinic in Mumbai, India. The adolescents and guardians were identified by the patient support (counsellor) team. In-depth face-to-face interviews were conducted in English or Hindi, using interview guides during September-November 2019, and audio was recorded following informed consent. Assent was obtained from adolescents (aged under 18 years), in addition to their guardians' consent. Thematic network analysis was used to summarize textual data. [ATLAS.ti](https://atlas.ti.com/), version 7, was used for analysis.

Ethics

This study was approved by the MSF Ethics Review Board and by the Institutional Review Board, Tata Institute of Social Sciences, Mumbai, India.

Results

Adolescents interviewed were aged 15-19 years, and four of them were female. Five guardians (of three child and two adolescent patients) and eight healthcare providers were interviewed, including two clinicians, two directly observed treatment providers, two counsellors, and two programme managers. Our analysis fell under the overarching theme of "challenging DR-TB treatment journey", with four sub-themes identified. The four sub-themes covered physical trauma; emotional trauma; unavailability of social support; and poorly adapted healthcare services. Family and peer support was identified as the cornerstone for successful treatment completion. Adherence issues and treatment interruptions were more commonly reported in adolescents than children. It was also noted that treatment decisions (eg relating to regimen or provider) for children and adolescents relied heavily on the input of patients' families and/or caregivers. Though the challenging experiences of patients and caregivers during DR-TB treatment varied within and between age categories, most patients and caregivers reported the experience of treatment fatigue and burnout. Participants offered recommendations for developing child/adolescent-friendly care during DR-TB treatment. These included providing injectable-free regimens, palatable medications, meaningful interaction and information sharing with healthcare providers, peer-support platforms, patient-friendly counselling/adherence tools, and improved TB awareness in families, schools and communities.

Conclusions

TB programmes for adolescents and children must consider the patient and family as one unit when designing packages of care. Development of child- and adolescent-friendly services, such as paediatric formulations, age-specific counselling tools, and regular interaction with patients and caregivers, will help minimise burnout in patients and caregivers.

Conflicts of interest

None declared.



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Dr Mrinalini Das is an epidemiologist and operational researcher. She has completed her PhD in Public Health. Her area of interest is paediatric and adolescent drug-resistant tuberculosis. She has been involved in operational research activities for more than eight years in the fields of HIV, malaria and tuberculosis, including a focus on new drugs for treatment of tuberculosis. She has presented her work in various national (India) and international conferences. She has also contributed in multiple research publications for international peer-reviewed scientific journals. She is currently working with Médecins Sans Frontières / Doctors Without Borders India as a Deputy Medical Coordinator (Epidemiologist).