

## Student IJMR

# Psychosocial challenges of drug-resistant tuberculosis: A qualitative study in Deoghar, Eastern India

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Received July 2, 2025; Accepted November 24, 2025; Published February 28, 2026

**Background and objectives:** Despite therapeutic advancements, patients with drug-resistant TB (DR-TB) experience substantial psychosocial challenges that adversely affect treatment adherence and outcomes. Limited research has explored these psychosocial barriers. This study aimed to explore the psychosocial challenges encountered by DR-TB patients from diagnosis through treatment completion.

**Methods:** A cross-sectional qualitative study was conducted in the department of Pulmonary Medicine at a tertiary care hospital in eastern India from November to December 2023. Using criterion sampling, 20 DR-TB patients who had successfully completed treatment were recruited. Semi-structured, face-to-face interviews were conducted in Hindi, audio-recorded, transcribed verbatim, and thematically analysed using QDA Miner Lite software following Braun and Clarke's six-step framework.

**Results:** Six major themes emerged: (i) Diagnosis-related challenges such as delays, lack of awareness, and misguidance; (ii) Physical and mental health impact, including severe drug-related side effects leading to distress and suicidal thoughts; (iii) Emotional instability, marked by fear, anxiety, and hopelessness; (iv) Family isolation and disruption of social relationships due to stigma and misconceptions; (v) Lack of social support, resulting in discrimination and reduced self-esteem; and (vi) Financial burden, including job loss, treatment-related costs, and debt.

**Interpretation and conclusions:** Psychosocial barriers substantially influence treatment adherence and overall well-being among DR-TB patients. Integrating mental health services, strengthening counselling, addressing stigma, and providing financial assistance within the National TB Elimination Program (NTEP) are essential to improve patient support, adherence, and clinical outcomes.

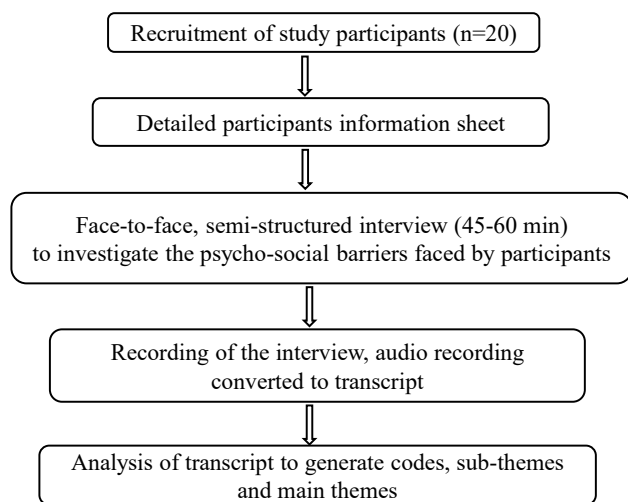
**Keywords** Drug-resistant tuberculosis (DR-TB); Face-to-face interview; Psychosocial barriers; Qualitative study

India bears the highest burden of tuberculosis (TB) and multidrug-resistant tuberculosis (MDR-TB), contributing to nearly one-fourth of global TB cases.<sup>1,2</sup> Globally, less than half of DR-TB patients complete treatment, with poor adherence attributed to prolonged treatment duration, drug toxicity, and psychosocial barriers.<sup>3,4</sup> The psychological impact of MDR-TB can be as distressing as the disease itself, with stigma leading to depression, anxiety, and social isolation. Stigma manifests in two forms: self-imposed withdrawal from family and community interactions due to internalised stigma, and socially driven discrimination from others. Both forms worsen mental health and quality of life but have different implications for intervention.<sup>5</sup>

Treatment burden further compounds these challenges. Patients undergoing MDR-TB therapy face adverse drug effects—such as gastritis, dermatological reactions, neuropathy, and hearing loss—that disrupt their physical, psychological, and social well-being. In addition, severe neuropsychiatric side effects, including depression, psychosis, and, in rare cases, suicide, occur in 7–7.5% of patients, often leading to poorer treatment outcomes.<sup>6–8</sup> Economic hardship further compounds the burden of DR-TB. Drug-sensitive TB patients may lose 3–4 months of work and up to 30% of household earnings, with MDR-TB patients facing even greater financial strain.<sup>9,10</sup> Social consequences include challenges related to marital prospects, family separation, and isolation during hospitalisation.<sup>11,12</sup>

**How to cite this article:** Babu R, Juhi A. Psychosocial challenges of drug-resistant tuberculosis: A qualitative study in Deoghar, Eastern India. *Indian J Med Res.* 2026;163:62-8. DOI: 10.25259/IJMR\_1697\_2025.

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**Fig. 1.** Flow chart of the patient recruitment and data collection.

Although existing literature acknowledges these challenges, qualitative research exploring psychosocial barriers faced by DR-TB patients in India remains scarce.<sup>13-15</sup> This gap limits understanding of patients lived experiences and hinders the development of holistic interventions that integrate physical, psychological, and social dimensions.

This study aims to explore the psychosocial barriers experienced by DR-TB patients in India from diagnosis through treatment completion. Understanding these barriers is critical for improving treatment adherence and patient well-being.

## Methods

This exploratory qualitative descriptive study was carried over two months (November–December 2023) in the department of Pulmonary Medicine, All India Institute of Medical Sciences, Deoghar, Jharkhand, India after obtaining the ethical clearance from the Institutional Ethics Committee. Written informed consent was obtained, with verbal consent reconfirmed before recording.

Using criterion sampling, adult participants (>18 yr) with drug-resistant tuberculosis (DR-TB) who had successfully completed treatment without interruptions of more than two consecutive days were recruited. Of the 24 patients initially screened, 20 were enrolled after excluding those with language barriers, lack of consent for audio recording, or withdrawal from participation. Data collection proceeded until saturation was reached, defined *a priori* as the point at which no new themes or subthemes emerged across three consecutive

interviews. This criterion guided the final sample size and ensured adequate depth and variation in capturing participants' psychosocial experiences.

**Data collection:** A semi-structured interview guide was developed from literature and expert input (pulmonology, psychiatry, public health) and piloted with three patients. Face-to-face interviews in Hindi (45–60 min) were conducted by a trained researcher, exploring health, stigma, social, financial, and occupational impacts. Demographic data were collected. Interviews were audio-recorded, transcribed in Hindi, anonymised, and translated into English; 10% were back-translated to ensure fidelity.

**Analysis:** Data were analysed in QDA Miner Lite using Braun and Clarke's six-step thematic analysis. Two coders independently coded all transcripts; discrepancies were resolved by consensus or senior review. An iterative codebook, peer debriefing, and audit trail supported analytic rigor. Data saturation was considered achieved when no new themes emerged in three consecutive interviews and the proportion of new codes became negligible.

Interviews were conducted by a researcher trained in qualitative methods and experienced in TB research, with oversight from a multidisciplinary team. Reflexivity was maintained *via* journaling and team debriefings.

## Results

**Figure 1** depicts the patient recruitment, data collection and analysis.

**Participant characteristics:** Twenty patients (12 male, 8 female) participated. The mean age was 34 years (range 20–60). Six were illiterate, nine had attended school, and five were graduates. Nine participants were married and 11 unmarried; 7 were employed while 13 were unemployed.

**Themes emerging from interviews:** As shown in **Table**, analysis generated six overarching themes with interrelated subthemes. Each theme is summarised narratively, followed by illustrative participant quotations (coded for anonymity).

**Theme 1: Diagnosis-related challenges:** Participants commonly reported delays in diagnosis due to misguidance, lack of awareness, and repeated consultations before confirmation of DR-TB. This often caused frustration, financial strain, and worsening symptoms.

**Table. Depicting the generation of codes, extraction of sub-themes and final formation of main themes**

| Codes   | Sub themes  | Main themes  |
|---|---|--|
| Delayed diagnosis.<br>No proper guidance for the diagnosis of disease.<br>Had to visit multiple doctors for confirmation of disease. Treatment delayed due to delayed diagnosis.  | Lack of resources Lack of guidance<br>Lack of medical care Poor resources   | Diagnosis related challenges.  |
| Was told that this type of TB is different from other TB disease.<br>Would take longer for treatment.<br>Almost felt nauseated, lethargic, and weak after taking drugs. Every day was a bad day due to side effects of drugs for initial 1 year.<br>Symptoms took a very long time to go away.  | Side effects due to treatment.<br>Delayed adaptation for treatment. Adverse effects caused lots of irritation and distress.<br>Long duration of treatment.      | Ill effects on physical and mental health arising due to medication. |
| Side effects, lethargy and weakness developed after initiation of treatment.<br>Pain, disturbed sleep, changes in body, intolerance, irritation.<br>Continuous feeling of nausea.   | Adverse physical and psychological changes due to treatment.<br>Long duration of treatment.   |  |
| Was hopeless and worried to return to normal life. Thought would die during the treatment.<br>Always depressed due to long treatment course. Distressed due to symptoms of disease.<br>Thought of killing oneself.  | Emotional breakdown.<br>Anxious about duration of treatment. Suicidal thoughts.<br>Fear of getting back to normalcy   | Emotional instability  |
| Family was in denial about the disease.<br>Isolated from family, created more fear initially for survival. Relationship with family gradually weakened due to isolation and weakness irritation side effects from treatment. Isolated from parents, siblings, spouse and children due to fear of spreading infection<br>Sometimes felt discriminated, depressed and distressed from the behaviour change in family members.<br>Fear of getting back to the family and have the same family bonding before the TB. | Isolated from family. Loss of family bonding.<br>Fear of spreading infection<br>Hopelessness due to lack of mingling with family<br>Lack of care and affection. | Break in family bonding  |
| Unempathetic neighbourhood<br>Lost all contact with colleagues and peers.<br>Emotional distress after having lost communication with them.<br>Few friends and peers encouraged but gradually lost touch due to isolation.<br>Fear of making relationship again in future life.<br>For any community event I was not allowed to participate due to isolation.<br>Mental breakdown due to lack of social support sometimes. Was forced to wear mask in gathering which gave feeling of                              | Weak social bonding Lack of social support<br>Feeling lost<br>Lack of motivation need help  | Lack of social support   |
| Lost job after diagnosis of TB due to isolation. Forced to take debts for medical care<br>Unable to take up the responsibility of family due to loss of job.<br>Burden on family members for medical treatment due to treatment.<br>Extra financial burden due to extra nutritional need.   | Work absenteeism Loss of job<br>Borrowing money for self-extra medical care and family care.  | Financial burden and instability                                     |

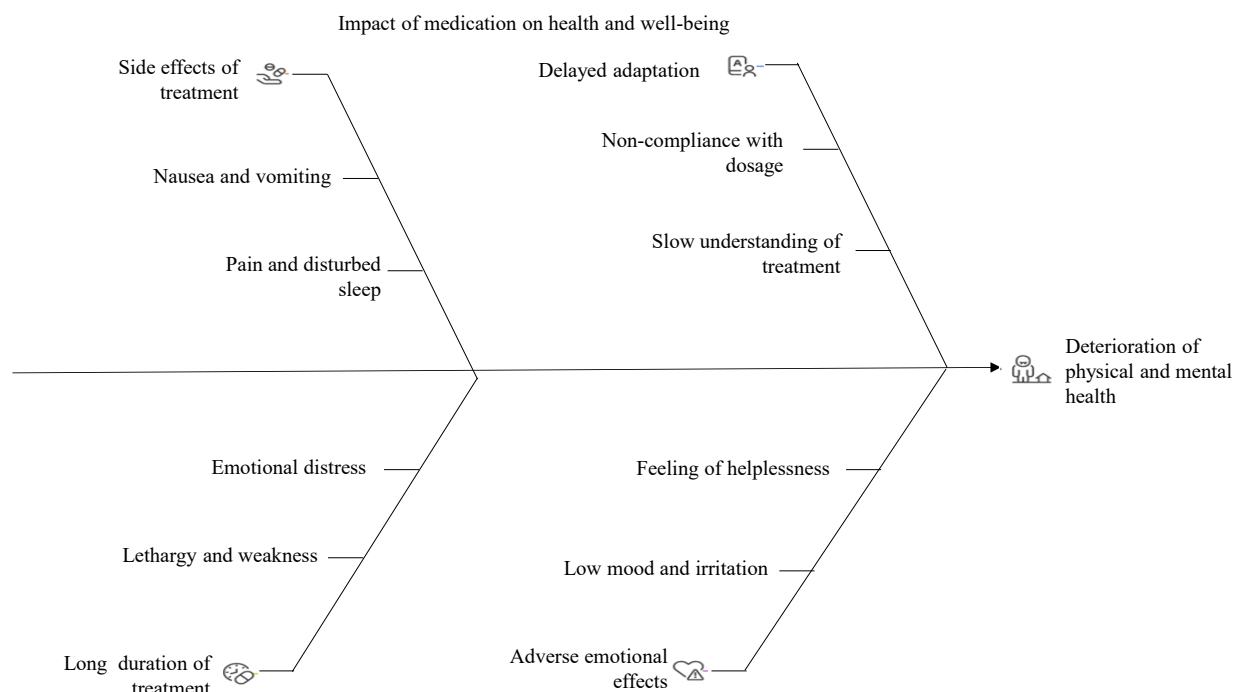
*'I had been to more than six doctors... I used to continuously have cough, headache, fever and weakness for more than 3 months.'* (30 yr, Male)

*'My elders asked me to use ginger, honey, Tulsi and turmeric... until I started spitting out blood.'* (25 yr, Female)

**Theme 2: Physical and mental health impact of treatment:** Most participants described significant

drug-related side effects—vomiting, sleeplessness, bowel changes, and injection-site pain—that negatively influenced both physical and psychological well-being. These effects fostered hopelessness and suicidal thoughts. **Figure 2** shows the ill effects on physical and mental health arising due to medication.

*'I vomited after every meal during the first 9 months... I thought I would die soon eating these tablets.'* (40 yr, Male)



**Fig. 2.** Showing ill effects on physical and mental health arising due to medication. The figure is generated using Napkin AI version beta 0.12.2.

*'I used to feel I am getting punished by God... my child used to run away seeing me vomit all the time.'* (43 yr, Male)

**Theme 3: Emotional instability:** Beyond physical suffering, participants commonly experienced anxiety, fear of death, and loss of hope for recovery. This emotional instability compounded depression and feelings of helplessness.

*'I had lost 10 kg in just 2 months... hopeless, just like a non-living body lying in one corner.'* (35 yr, Male)

*'I was hopeless and worried to return to normal life... always depressed due to the long treatment course.'* (38 yr, Female)

**Theme 4: Family isolation and breakdown of bonds:** Family support varied, but many participants reported being isolated by relatives due to fear of infection. This disrupted relationships, causing loneliness and emotional distress.

*'My husband and in-laws didn't allow me to meet my children... I felt so lost and depressed.'* (48 yr, Female)

*'I became unstable as I stopped interacting with my brothers... I needed somebody with me to spend time in my loneliness.'* (60 yr, Male)

**Theme 5: Lack of social support:** Stigma extended beyond the family to the community. Patients faced discrimination, broken engagements, and damaging beliefs linking TB to sin or black magic, which eroded self-esteem.

*'My fiancé broke the marriage... I felt like killing myself as I was a burden to my family.'* (24 yr, Female)

*'I have heard people say God is punishing me for my previous sins... or that I was under black magic.'* (60 yr, Male)

**Theme 6: Financial burden and instability:** Prolonged treatment resulted in job loss, debts, and dependence on relatives. Participants described pawning valuables and borrowing money to meet medical and household needs.

*'Each admission cost my parents 40,000–60,000 rupees... my mother had to ask money from relatives.'* (27 yr, Male)

*'I lost my job due to absenteeism... had to borrow money after submitting my wife's jewellery.'* (25 yr, Male)

## Discussion

The findings of this study provide critical insights into the multifaceted psychosocial challenges faced

by patients undergoing treatment for drug-resistant tuberculosis (DR-TB). Beyond the biomedical burden, patients reported profound disruptions to emotional well-being, family life, social relationships, and livelihood, highlighting the need to consider DR-TB as both a medical and psychosocial crisis requiring holistic interventions.

A major disruption identified was patients' reduced capacity to meet social and familial obligations, which they found particularly distressing. Similar observations were reported by Hatherall *et al*<sup>16</sup> who emphasised the importance of timely and sensitive communication when disclosing a DR-TB diagnosis. These findings underscore that DR-TB affects not only individual health but also social identity and familial roles, necessitating counselling strategies that address role loss and facilitate social reintegration, alongside treatment adherence.

Participants described a wide range of negative experiences and drug-related side effects. These observations mirror previous reports of hopelessness and scepticism about recovery by Aziz *et al*.<sup>17</sup> Furthermore, psychosocial burdens such as concerns about the future, fear of death, fatalistic attitudes, social stigma, and self-stigma compounded the emotional distress associated with DR-TB.

Stigma and social isolation emerged as central themes; these patterns are consistent with prior findings: Mukerji *et al*<sup>18</sup> documented non-disclosure, guilt, and suicidal ideation among women with TB, while Redwood *et al*<sup>19</sup> highlighted isolation as a coping strategy. Interpreted through stigma theory, these experiences illustrate how labelling, stereotyping, and social separation exacerbate psychological distress. Women appeared particularly vulnerable to these effects, with high levels of depression, anxiety, and insomnia reported.

The Health Belief Model provides an additional lens to interpret these experiences: perceptions of disease severity, prolonged treatment, and side effects eroded confidence in recovery and reduced motivation to adhere to treatment. Patients often interpreted weight loss and side effects as signs of worsening illness, reflecting gaps in counselling and communication regarding positive health progress during treatment.<sup>20</sup>

Financial constraints were another prominent theme. Although DR-TB treatment and hospitalisation are provided free under the National Tuberculosis Elimination Programme (NTEP), indirect costs—

including travel, lost wages, and nutritional support—imposed considerable hardship, corroborating earlier evidence on the catastrophic economic impact of DR-TB in India.<sup>21,22</sup> From a social determinant of health perspective, structural inequities such as poverty, unstable employment, and limited social protection amplify treatment-related distress and underscore the need for systemic policy interventions.

Evidence suggests that psychosocial support interventions can improve adherence. For instance, structured group and individual counselling in Kazakhstan significantly enhanced adherence and reduced default rates among DR-TB patients.<sup>23</sup> An Indian study emphasised repeated counselling for both patients and families to bridge knowledge gaps and sustain motivation.<sup>24</sup> Our findings strongly support integrating psychosocial and economic support within the NTEP framework, highlighting the potential of holistic care models to enhance adherence and improve treatment outcomes.

This study is subject to certain limitations. It was conducted at a single centre with a relatively small sample size, which limits generalisability. Patients who had defaulted or dropped out of treatment were not included, potentially underestimating the most severe psychosocial challenges faced by this group. Social desirability bias may have also influenced responses, with participants less willing to disclose sensitive experiences such as suicidal ideation or strained family dynamics.

To conclude, DR-TB patients face profound psychosocial burdens, distress, stigma, disrupted family roles, and financial hardship that compromise adherence and quality of life. NTEP must adopt a holistic, patient-centred approach with psychosocial, counselling, peer, and financial support.

**Author contributions:** RB: Conceptualization, study design, literature search, data acquisition, manuscript writing; AJ: Conceptualization, study design, supervision, intellectual input, data analysis, statistical analysis, manuscript writing. All authors read and approved the final edited version of the manuscript.

**Financial support and sponsorship:** The study received funding support from Indian Council of Medical Research-Short Term Studentship (Project no.: 2023-00155) awarded to first author (RB) under the guidance of AJ.

**Conflicts of Interest:** None.

**Use of Artificial Intelligence (AI)-Assisted Technology for manuscript preparation:** The authors confirm that AI-assisted technology ChatGPT version 5 was used for assisting in

### शोध-संदेश

यह अध्ययन भारत में दवा-प्रतिरोधी तपेदिक (DR-TB) से ग्रसित रोगियों द्वारा सामना की जाने वाली मनोसामाजिक चुनौतियों पर केंद्रित है, जो निदान से लेकर उपचार पूर्ण होने तक उपचार अनुपालन और समग्र स्वास्थ्य को प्रभावित करती हैं। यद्यपि उपचार पद्धतियों में प्रगति हुई है, फिर भी DR-TB रोगियों को मानसिक तनाव, सामाजिक कलंक, और आर्थिक कठिनाइयों जैसी बाधाओं का सामना करना पड़ता है। अध्ययन से स्पष्ट हुआ कि ये मनोसामाजिक कारक उपचार के पालन और रोग परिणामों पर महत्वपूर्ण प्रभाव डालते हैं। अतः राष्ट्रीय क्षयरोग उन्मूलन कार्यक्रम (NTEP) के अंतर्गत मानसिक स्वास्थ्य सेवाओं का एकीकरण, परामर्श सेवाओं को सुदृढ़ करना, कलंक को कम करना, तथा वित्तीय सहायता प्रदान करना रोगी-सम्बल, उपचार अनुपालन, और क्लिनिकल परिणामों में सुधार के लिए आवश्यक है।

the writing of the manuscript and Napkin AI version beta 0.12.2 was used for creating Figure 2.

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