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Original Research Article

Reimagining care: unravelling the psychological toll of tuberculosis through patient narratives in Mysuru, India: a qualitative study

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ABSTRACT

Background: Tuberculosis (TB) remains a major public health issue in India, with significant psychological and social consequences. Despite medical advancements, the emotional toll of TB is often neglected. Stigma, isolation, and fear can adversely impact patients' mental health and treatment adherence. The objective of the study was to explore the psychological experiences of TB patients and understand the psychosocial barriers affecting their treatment in Mysuru, India.

Methods: A qualitative phenomenological study was conducted using in-depth interviews with 20 TB patients from public health facilities under the National Tuberculosis Elimination Programme (NTEP) in Mysuru. Participants were purposively sampled across age, gender, TB type, and treatment phase. Data were collected through semi-structured interviews in Kannada, focusing on emotional experiences, stigma, support systems, and treatment challenges. Depression was assessed using the patient health questionnaire (PHQ-9). Interviews were transcribed, translated, and thematically analyzed using NVivo 12.

Results: Four major themes emerged: psychosocial burden, marked by stigma, isolation, and fear of mortality; barriers to adherence, including side effects and emotional strain; socioeconomic hardship, such as financial insecurity and lack of support; and stigma-driven avoidance of healthcare engagement. PHQ-9 scores indicated moderate to severe depression in nearly half the participants. Stigma and emotional distress significantly influenced patients' willingness to seek care and follow treatment.

Conclusions: TB patients face substantial psychological and social challenges. Integrating mental health support, addressing stigma, and providing economic aid are essential to enhance treatment adherence and patient well-being. A holistic, patient-centered approach to TB care is urgently needed.

Keywords: Tuberculosis, Stigma, Depression, Qualitative study, Treatment adherence, Patient narratives

INTRODUCTION

Tuberculosis (TB) remains a significant public health challenge in India, affecting nearly a quarter of the human population and accounting for over 10 million deaths each year.[1] It not only results in physical burden but also leads to profound psychological and social consequences. Although significant progress has been made in the clinical management of TB through advanced diagnostics and treatment strategies, the psychological impact of the disease frequently remains overlooked. Patients face stigma, isolation, and emotional distress, which can affect their adherence to treatment and overall well-being. Addressing the psychological toll of TB is crucial to ensuring a holistic approach to patient care.

In 2023, TB probably returned to being the world's leading cause of death from a single infectious agent, following 3 years in which it was replaced by coronavirus disease (COVID-19), and caused almost twice as many deaths as human immune-deficiency virus/acquired immune-deficiency syndrome (HIV/AIDS).[2] In 2023, an estimated 10.8 million people fell ill with TB worldwide, including 6.0 million men, 3.6 million women and 1.3 million children. TB is present in all countries and age groups. TB is curable and preventable.[3] Despite India's involvement in various TB control activities, it has remained a major public health challenge to overcome. The worst-hit eight countries account for two-thirds of new TB cases in 2019, with India leading the way.[4]

Previous research has shown that TB patients are more likely to experience depression and anxiety, highlighting the link between physical and mental health. Children and adolescents with TB also may experience mental health issues and negatively impact their socioeconomic status due to the stress of a chronic condition.[5] Both TB and depression have common risk factors, explaining the high prevalence of their comorbidity, which has been shown to range between 10-52%.[6] Their interaction is complex since one disease might contribute to the development of the other.[7]

In Mysuru, a city with a complex socio-cultural fabric, tuberculosis patients face a variety of psychological issues that are intricately linked to their personal, familial, and societal circumstances. Their accounts provide significant insights into the lived experiences of persons battling the disease, offering light on the emotional battles, coping methods, and support systems that define their journey towards recovery. This qualitative study aims to investigate the psychological impact of TB through patient narratives, collecting their voices and perspectives to develop a more compassionate and patient-centered treatment strategy. By publicizing these tales, we aim to bridge the gap between pharmacological therapy and psychosocial support, ultimately rethinking tuberculosis care in a way that prioritizes both mental and physical health. This promotes a holistic approach in managing tuberculosis that goes beyond typical medical interventions and accepts the diverse requirements of patients and their families.

METHODS

This study employed a qualitative research design utilizing in-depth interviews (IDIs) to examine the lived experiences of individuals diagnosed with TB in Mysuru district, Karnataka, India. Conducted in November 2023, a phenomenological approach was adopted to explore participants' emotional, social, and psychological dimensions. The patient health questionnaire (PHQ-9) was used to assess levels of depression. The study was carried out across four public health facilities actively engaged in TB care under the National Tuberculosis Elimination Programme (NTEP): Urban Health Centre (Medhar Block) Bannimantap, CHC Jayanagar, and PHC Kuvempu Nagar. These facilities serve a diverse population and are actively involved in the NTEP.

Participants were recruited through purposive sampling to ensure diversity across age, gender, urban residence, treatment phase, and time since diagnosis.

Inclusion criteria

Adults aged ≥18 years and diagnosed with pulmonary or extrapulmonary TB, on treatment for at least one month, and willing to provide informed consent were included.

Exclusion criteria

Patients with cognitive impairments or residing outside Mysuru were excluded.

Data were collected using a semi-structured interview guide in Kannada, focusing on diagnosis experiences, emotional impact, stigma, treatment challenges, support systems, and mental health. Each IDI lasted 45–60 minutes. Audio recordings were transcribed verbatim and translated into English, with care to preserve participants' original meaning. Field notes captured non-verbal cues—such as prolonged pauses, lowered voice, or visible distress—which were integrated into analysis to enrich interpretation, especially around themes of shame and emotional withdrawal. Additionally, interviews with healthcare workers were conducted to triangulate findings and enhance contextual depth.

Ethical approval was obtained from the Institutional Ethics Committee and the Mysuru District Tuberculosis Officer. Written informed consent was collected from all participants. Confidentiality was ensured through anonymization, and those experiencing distress were referred to mental health services.

Data saturation was reached by the 20th interview, with no new codes or insights emerging. Inter-coder reliability was ensured through independent coding of initial transcripts by two researchers, followed by consensus building to finalize the coding framework. Peer debriefing sessions refined emerging themes and addressed researcher bias. NVivo 12 software was used for managing transcripts, creating the coding tree, and analysing theme co-occurrence. Memos and queries facilitated a transparent and structured thematic analysis.

Stigma was explored as a multidimensional construct, including social exclusion, anticipated stigma, and internalized shame. These were examined in relation to social isolation and care-seeking behaviours, enabling a comprehensive understanding of the psychological burden of TB in the local context.

RESULTS

The study included 20 participants diagnosed with TB. Of these, 13 were male and 7 were female, with ages ranging from 19 to 75 years. In terms of employment status, 8 participants were engaged in formal employment, 7 in informal occupations, 3 were unemployed, and 2 were students. The majority were diagnosed with pulmonary TB (n=18), while 2 had extrapulmonary TB. At the time of data collection, 4 participants were undergoing the intensive phase (IP) of treatment and 16 were in the continuation phase (CP) (Table 1).

Table 1: Socio-demographic distribution of participants (n=20).

Characteristics	Number of participants (N)
Gender	
Male	13
Female	7
Age range (years)	
19–75	20
Employment	
Formal	8
Informal	7
Unemployed	3
Student	2
Type of TB	
Pulmonary TB	18
Extrapulmonary TB	2
Treatment phase	
Intensive phase	4
Continuation phase	16

Theme 1: Psychosocial burden of TB includes navigating fear, stigma, and isolation

Subtheme 1.1: Stigma-induced isolation and emotional distress

Fifteen participants reported significant emotional distress, particularly during the early stages of diagnosis and treatment. Stigma emerged as a key factor, prompting participants to hide their diagnosis and isolate themselves. The participant who spoke confidently about still displayed frequent fidgeting and avoided eye contact when discussing societal reactions, suggesting unresolved anxiety and stigma.

"I didn’t tell anyone at work. I was afraid they’d treat me differently or fire me. I wore a mask and sometimes covered my face with a cloth so they wouldn’t recognize me. No one from the scheme helped me financially, even though I registered."— 28-year-old male (Transcript B5).

"When I finally went to the hospital, I had no strength left. I had to be admitted. My family had to take up extra jobs to manage expenses. Even though some neighbours helped, I felt ashamed… I didn’t want to be seen. People think TB means you are dirty or dying."— 57-year-old male (Transcript J1).

Social withdrawal was often self-imposed as a coping mechanism, although it frequently led to loneliness and emotional exhaustion. The participant broke into tears while describing his isolation—though the transcript merely reflected a pause, field notes recorded prolonged silence, trembling hands, and lowered gaze, indicating overwhelming distress.

"My family moved away. The initial days alone at home were scary. The darkness and silence, with me lying on the bed disease-ridden, were haunting."— middle-aged male participant (Transcript K2).

Subtheme 1.2: Fear of mortality and uncertainty about prognosis

Several participants linked TB with fatality due to prior experiences within their communities.

"When I knew I was TB positive, I had heard of people dying from it. Am I destined for the same fate? Why did this happen to me?" (Transcript B3).

This fear intensified during the night, reflecting a recurring anxiety pattern.

"I anxiously anticipated the night, fearing the worsening of my cough and the discomfort of falling ill after sunset. Each night, I eagerly awaited the break of dawn." (Transcript K4).

These reflections reveal how existential anxiety and uncertainty about prognosis contributed to mental health deterioration.

Theme 2: Barriers to treatment adherence

Subtheme 2.1: The burden of TB medication such as side effects, fatigue, and emotional strain

Participants described physical and emotional burdens caused by daily treatment, including severe side effects. One participant conveyed the psychological toll of pill fatigue.

"Daily popping of 6 tablets is very tough, appetite is gone, at times I feel why should I eat so many tablets, it's better to die peacefully than these." (Transcript B1).

Medication-related nausea, isolation, and pill fatigue affected adherence and motivation.

Theme 3: Socioeconomic challenges in TB care - coping with financial and social hardships

Subtheme 3.1: Financial hardship and barriers to timely healthcare

Loss of livelihood and economic hardship were major concerns.

"Who will look after my family if I die? I am the breadwinner, and no one comes for you in difficult times." (Transcript J1).

This financial pressure frequently delayed medical attention and contributed to emotional distress.

Subtheme 3.2: Financial insecurity and lack of institutional support

"I knew the risks. I asked my family to move to my in-laws' place temporarily. I applied for the government scheme, but I never received any money. It was hard in the beginning, no job and had to borrow money from other people."— 34-year-old housemaid (Transcript K2).

The testimonies of TB patients illustrate the profound challenges posed by financial instability, lack of institutional support, and disrupted family dynamics. Economic strain frequently delays treatment-seeking behavior, while the absence of reliable aid forces individuals into precarious survival strategies. Addressing these vulnerabilities requires a stronger safety net, timely financial support, and community-driven interventions to mitigate the burden faced by affected individuals.

Theme 4: Stigma as a barrier to healthcare engagement in TB treatment

Subtheme 4.1: Stigma-driven healthcare avoidance strategies

Healthcare providers consistently emphasize the importance of treatment adherence, explaining both the benefits of medication and the potential adverse effects. Patients are also advised to comply with their prescribed treatment plans to ensure effectiveness. One notable effort comes from Accredited Social Health Activist (ASHA) workers, who actively check in on patients to monitor their medication intake and remind them about upcoming refill visits to the health centre.

"Our area ASHA workers call us to ask how we are taking our medications and whether we have missed any tablets. They also inform us when to visit the centre for refills." (Transcript B3).

However, when asked about home visits, patients revealed a deep-seated fear of stigma. Many refuse to allow healthcare providers into their homes, fearing that neighbours will become aware of their condition.

Seeking further understanding, healthcare providers were questioned about patient attitudes toward diagnosis and treatment adherence. They observed behaviours shaped by stigma, with patients intentionally modifying their healthcare-seeking practices to avoid public scrutiny.

"Patients visit the hospital in the afternoon when fewer people are around. They do not allow us to conduct home check-ups, as they fear questions from their neighbours."— healthcare provider.

These responses highlight the persistent stigma surrounding TB, which not only affects patients emotionally but also dictates their willingness to seek care and engage with available support systems. Such concerns were universally echoed by all healthcare providers interviewed).

Conceptual framework of core themes and their subthemes from TB patient narratives are illustrated in Figure 1.

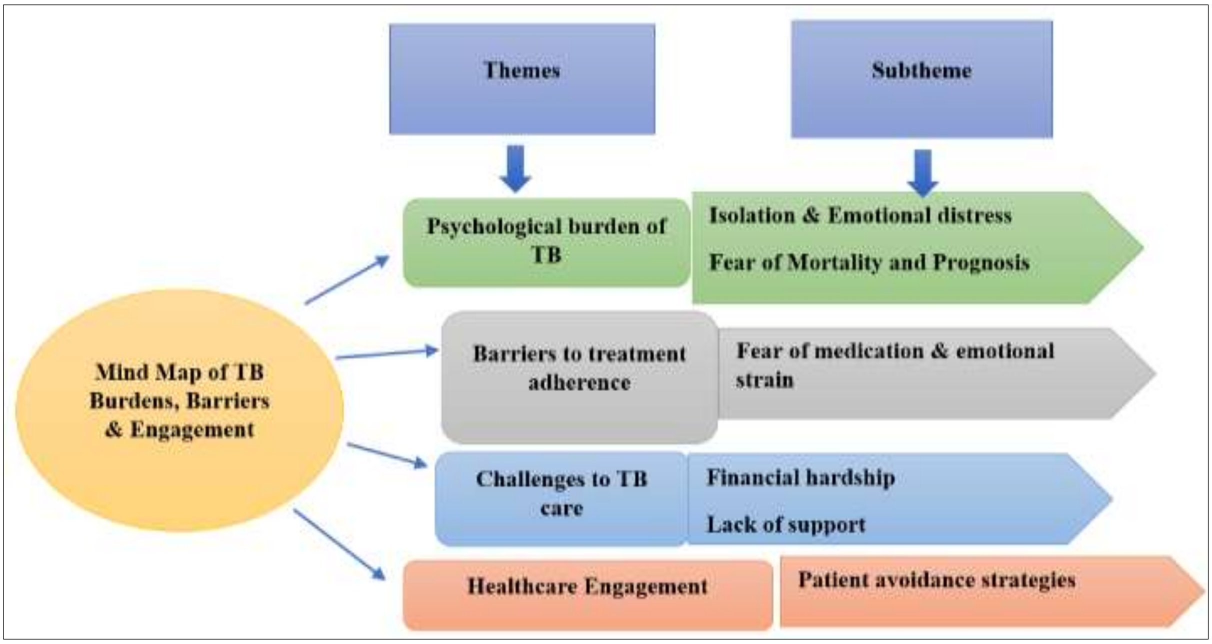

Figure 1: Conceptual framework of core themes from TB patient narratives.

Assessment of depressive symptoms

Participants with PHQ-9 scores of 10 or higher reported significant anxiety, impaired daily functioning, and persistent emotional burden. In alignment with clinical guidelines, these individuals were referred for further psychological counselling to address their mental health needs. Those with minimal symptoms demonstrated higher resilience and better adjustment (Table 2).

Table 2: Depressive symptoms assessed using patient health questionnaire-9 (PHQ-9).

PHQ-9 score range	Number of participants	Interpretation
0–4	3	Minimal depressive symptoms
5–9	8	Mild depression with preserved function
≥10	9	Moderate to severe depression

DISCUSSION

In our study, 17 participants reported significant emotional distress, particularly during the initial phases of diagnosis and treatment. This finding aligns with the results of Ramachandran's study, where 10.7% of participants exhibited a Kessler psychological distress scale (K-10) score of 30 or higher at month 20, indicating severe psychological distress.[8] Moreover, psychological distress was found to increase the likelihood of treatment noncompliance, whether distress was experienced "sometimes" or "most of the time," as noted by Lakara et al.[9] These findings highlight the critical impact of emotional well-being on patient adherence and suggest the need for integrated psychological support during the treatment process.

In our study, participants reported that fear intensified during the night, reflecting a recurring pattern of anxiety. One participant shared, "I anxiously anticipated the night, fearing the worsening of my cough and the discomfort of falling ill after sunset. Each night, I eagerly awaited the break of dawn" (Transcript K4). This testimony highlights how existential anxiety and uncertainty about prognosis contributed to the deterioration of mental health. Similarly, Shiratani's mixed-methods study conducted in Japan in 2019 identified key emotional themes related to treatment experiences.[10] Categories such as "non-acceptance," "frustration," and "anxiety" were recognized as treatment barriers, while "fear," "acquiring a partner," "relief," and "belief" were identified as treatment drivers. These findings collectively emphasize the complex emotional landscape patients navigate, underscoring the importance of addressing both psychological barriers and facilitators to optimize treatment adherence and outcomes.

Economic hardship and loss of livelihood were prominent concerns among participants in our study. Financial pressure not only contributed to emotional distress but also frequently delayed seeking medical care. One participant poignantly stated, "Who will look after my family if I die? I am the breadwinner, and no one comes for you in difficult times" (Transcript J1). Similarly, a 34-year-old housemaid shared, "I knew the risks. I asked my family to move to my in-laws' place temporarily. I applied for the government scheme, but I never received any money. It was hard in the beginning, no job and had to borrow money from other people" (Transcript K2).

These experiences echo findings from Ramachandran et al who reported that at treatment initiation, 17.4% of participants used household savings and 4.4% borrowed money to cover treatment costs.[8] Additionally, social isolation—experienced "sometimes" or "most of the time"—was linked to increased odds of noncompliance (ORs 0.316 and 0.197 respectively), as highlighted by Lakara et al.[9]

The burden of care extended beyond patients to their spouses, family members, and occasionally healthcare providers. One male participant reflected on the strain placed on his spouse: "I am not working and all the pressure (financial demands) is on my wife including the payment of school fees of the children and feeding expenses" (41-year-old male, facility 3 in the study by Gyimah et al.[11]

These testimonies underscore the profound challenges of financial instability, lack of reliable institutional support, and disrupted family dynamics faced by TB patients. Addressing these vulnerabilities requires strengthening social safety nets, providing timely financial support, and implementing community-driven interventions to reduce the burden on affected individuals and their families.

In-depth interview explored by Rajalakshmi et al shows that major perspectives of cases affecting quality of life were side effects of drugs, loss of social support, loss of employment and psychological factors like anxiety, depression which aligns with our findings.[12]

In our study, stigma was a key factor driving participants to hide their diagnosis and socially isolate themselves. Even those who spoke confidently about their condition showed signs of unresolved anxiety and stigma, such as frequent fidgeting and avoiding eye contact when discussing societal reactions. Consistent with this, Gyimah et al found that some patients resorted to hiding and sneaking in and out of treatment facilities to avoid drawing attention.11 One participant remarked, "I always hide and make sure no one sees me. I think the DOTS centre should be situated away from this place, where lots of people are not there" (34-year-old male, facility 1). These experiences reveal widespread misconceptions about tuberculosis and a strong fear of social rejection, which can cause significant psychological stress.

Although factors such as social stigma, transportation difficulties, and lack of family support were examined, Lakara et al found no significant associations.[9] In our study, participants highlighted the support they receive from ASHA workers: "Our area ASHA workers call us to ask how we are taking our medications and whether we have missed any tablets. They also inform us when to visit the centre for refills" (Transcript B3). Despite this support, many patients expressed a deep fear of stigma surrounding home visits, often refusing healthcare providers entry to avoid neighbours learning about their condition.

Healthcare providers confirmed that stigma influences patients' healthcare-seeking behaviours. Patients frequently alter their routines to avoid public scrutiny by visiting clinics during off-peak hours and declining home check-ups: These observations align with findings by Chen et al, who reported that 49.0% of TB patients experienced high levels of stigma.[13] Together, these insights underscore the urgent need for stigma-reduction interventions to enhance treatment adherence and support the mental health of individuals living with tuberculosis.

In our study, based on PHQ-9 score ranges, three participants exhibited minimal depressive symptoms, eight had mild depression with preserved function, and nine experienced moderate to severe depression. Similarly, Fang et al reported a high prevalence of depression among patients with pulmonary tuberculosis, with 52.7% of 237 participants screening positive for depression using a self-rating depression scale.[14] Specifically, mild, moderate, and severe depression were observed in 31.6%, 15.2%, and 5.9% of participants, respectively. These findings underscore the significant burden of depressive symptoms among TB patients, highlighting the need for routine mental health screening and integrated psychosocial support within TB care programs.

CONCLUSION

This study highlights the profound psychological and social impact of TB on patients in Mysuru, India. The narratives reveal a consistent thread of stigma, isolation, fear of mortality, emotional distress, and financial hardship that significantly shape patient behaviors and treatment adherence. Majority of the participants experienced moderate to severe depression, underscoring the urgent need for integrated mental health screening and psychosocial support within tuberculosis care frameworks.

The findings advocate for a holistic, patient-centered approach that not only addresses the biomedical aspects of TB but also prioritizes mental well-being, economic support, and stigma reduction. Strengthening community engagement, ensuring timely payment of government support schemes, and enhancing the role of frontline workers like ASHA in delivering empathetic care are key steps toward improving outcomes.

By cantering the lived experiences of TB patients, this study reinforces the importance of listening to patient voices in shaping effective and humane health policies. Future interventions must move beyond medication compliance to include emotional resilience, community reintegration, and dignity in care.

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