

Psychological Distress And Stigma Among Tuberculosis Patients In Arunachal Pradesh, India

Dr. Bengia Seema,

Department Of Sociology, Rajiv Gandhi University, Arunachal Pradesh.

Dr. Bikash Bage,

Department Of Sociology, Rajiv Gandhi University, Arunachal Pradesh.

Abstract

Tuberculosis is widely recognized as a biomedical disease; however, its psychological, social, and cultural dimensions remain underexplored, particularly in remote and tribal regions of India. This paper examines the psychological reactions, stigma experiences, healthcare-seeking anxieties, social isolation, and coping mechanisms among tuberculosis patients in Arunachal Pradesh. Drawing on mixed-methods community-based study of 418 registered TB patients conducted during 2020–21, the study integrates quantitative survey data with qualitative narratives from patients, family members, and healthcare workers. Findings reveal that TB diagnosis often triggers intense emotional distress, including anxiety, fear, shame, and hopelessness. Nearly one-fourth of patients reported nervousness following diagnosis, while more than two-fifths experienced anxiety when seeking medical care. Stigma, rooted in misconceptions regarding TB transmission and moral judgments, led to social withdrawal, concealment of illness, delayed care, and disrupted social relationships. Faith-based practices such as prayer, fasting, and spiritual healing emerged as significant coping strategies, often coexisting with biomedical treatment. The study argues that tuberculosis control efforts must move beyond biomedical frameworks and integrate psychosocial support, stigma reduction, and culturally sensitive care to improve treatment outcomes in marginalized settings.

Keywords: *Tuberculosis, psychological distress, stigma, healthcare-seeking behavior, spirituality, social isolation, Arunachal Pradesh, India*

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I. Introduction

Tuberculosis remains one of the most persistent public health challenges globally, with India accounting for a significant proportion of the global TB burden. Despite the expansion of national TB control programs and the availability of free diagnostic and treatment services, TB continues to disproportionately affect socially, economically, and geographically marginalized populations. In India's northeastern state of Arunachal Pradesh, remoteness, difficult terrain, limited healthcare infrastructure, and socio-cultural beliefs intensify the challenges associated with TB control.

Tuberculosis remains a dominant global public health crisis, with India historically contributing over one-quarter of the global case burden (Pai, 2015). Despite the implementation of the Revised National TB Control Programme (RNTCP), the disease has continued to disproportionately affect geographically marginalized populations, particularly in the Northeast. In regions like Arunachal Pradesh, the rugged terrain and limited healthcare infrastructure have historically hindered the effective delivery of the DOTS (Directly Observed Treatment, Short-course) strategy, leading to significant delays in diagnosis (Sreeramareddy et al., 2014). Furthermore, socio-cultural beliefs and a reliance on traditional healers among indigenous tribes have been identified as primary drivers of diagnostic delay and social stigma (International Union Against Tuberculosis and Lung Disease, 2008). These systemic barriers are further exacerbated by high rates of malnutrition and poverty, which correlate with higher TB prevalence in tribal communities compared to the general population (Bhat et al., 2009).

While tuberculosis is commonly addressed as a biomedical condition, its diagnosis and treatment are deeply embedded in psychological distress, social stigma, and cultural interpretations of illness (Somma et al., 2008).

A TB diagnosis often disrupts the taken-for-granted routines of everyday life, triggering emotional crises that extend beyond physical suffering (Tesfaye et al., 2015). Patients frequently confront a fear of death,

anxiety about infecting loved ones, and uncertainty about the future, which are often compounded by deep-seated concerns related to social rejection and economic survival (Kipp et al., 2011). In the context of India, these psychological burdens are intensified by cultural stigmas that can lead to isolation and significant delays in seeking care (Sreeramareddy et al., 2014).

Erving Goffman's (1963) seminal work on stigma provides a foundational framework for understanding TB-related discrimination. Stigma, as defined by Goffman, arises when an individual possesses an attribute that is "deeply discrediting," reducing the bearer from a "whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). In TB-affected communities, this stigma is reinforced by pervasive misconceptions about transmission, such as the belief that it is hereditary or spread through sharing eating utensils (Sichinga & Tamba, 2005).

These perceptions often lead to the concealment of illness as patients attempt to manage their "spoiled identity" and avoid social exclusion (Goffman, 1963). Research consistently shows that such stigmatization results in significant delays in healthcare-seeking and contributes to non-adherence to treatment regimens, as individuals fear that being seen at a DOTS clinic will lead to being shunned by their community (Sreeramareddy et al., 2014; Yuen et al., 2015).

This study seeks to examine tuberculosis not merely as a disease of the lungs but as a social and psychological condition. It explores how TB patients in Arunachal Pradesh experience diagnosis-related distress, anxiety in seeking healthcare, stigma and discrimination, disruptions in social life, and coping mechanisms particularly the role of faith and spirituality.

II. Methodology

Study Design and Setting

A mixed-methods, community-based study was conducted in the Itanagar Capital Complex (ICC) and surrounding areas of Papum Pare district, Arunachal Pradesh. The region serves as a major referral center for TB diagnosis and treatment due to the presence of district hospitals and DOTS centers.

Study Population

The quantitative component included 418 registered TB patients, representing diverse age groups, genders, and socio-economic backgrounds. The qualitative component involved TB patients, family members, caregivers, and healthcare workers engaged in TB diagnosis, treatment, and field-level contact tracing.

Data Collection

Quantitative data were collected using structured schedules documenting:

Psychological reactions following TB diagnosis

Anxiety in seeking healthcare

Stigma experiences

Social interaction and isolation

Qualitative data were obtained through in-depth interviews, informal conversations, and field observations. These narratives explored lived experiences of illness, fear, stigma, coping strategies, and interactions with healthcare systems.

Data Analysis

Quantitative data were analyzed using descriptive statistics. Qualitative data were thematically analyzed to identify recurring patterns related to emotional distress, stigma, healthcare-seeking barriers, and coping mechanisms.

III. Results

Psychological Impact of Tuberculosis Diagnosis

A diagnosis of tuberculosis was experienced as a deeply distressing and transformative event. Among the 418 respondents, 22.01% (92 patients) reported feeling nervous or anxious immediately after diagnosis, while 77.99% (326 patients) reported no such reaction.

However, qualitative narratives revealed that even those who did not explicitly report anxiety experienced emotional turbulence. Common reactions included shock, disbelief, sadness, fear of death, guilt about infecting others, and concern for children's futures. For many, TB symbolized not just illness but social vulnerability and potential exclusion.

Patients described feeling overwhelmed, helpless, and uncertain about how the disease would affect their family, employment, and social standing. These emotional reactions often shaped subsequent healthcare-seeking behavior and treatment adherence.

Anxiety in Seeking Tuberculosis Treatment

Healthcare-seeking itself emerged as a source of psychological stress. Out of 418 respondents, 42.82% (179 patients) reported anxiety when seeking medical care following diagnosis, while 57.18% did not report such anxiety.

The primary sources of anxiety among tuberculosis patients were multifaceted and closely linked to both physical suffering and social perceptions of the disease. A significant proportion of respondents (16.7%) reported low self-esteem, persistent fatigue, and physical weakness as major contributors to psychological distress, reflecting the debilitating impact of TB on daily functioning and self-worth. Feelings of embarrassment and fear of social judgment were reported by 6.7% of patients, indicating the continued presence of stigma associated with TB within families and communities. Additionally, 5.02% of respondents expressed deep concern about the possibility of transmitting the infection to family members or the wider community, highlighting moral responsibility and fear of social blame as sources of anxiety. Emotional shock and worry immediately following diagnosis were reported by 3.6% of patients, particularly during the early phase of treatment when uncertainty and fear were most pronounced. Notably, 8.61% of respondents experienced anxiety arising from multiple overlapping causes, underscoring the complex and interrelated nature of physical, emotional, and social stressors faced by TB patients.

Healthcare workers reported that stigma significantly hindered contact tracing and field visits. Families often hesitated to disclose TB cases due to fear of quarantine, gossip, or social labeling. Misunderstandings about TB transmission further complicated cooperation with health teams.

Stigma and Its Social Consequences

Stigma emerged as a central theme in patients' experiences. 26.6% (111 patients) reported noticeable changes in people's attitudes after diagnosis, including avoidance, discrimination, and social distancing. In contrast, 73.4% reported either supportive or indifferent responses.

Patients attributed stigma to widespread misconceptions such as TB spreading through shared utensils, clothing, or casual contact. As a result, many patients concealed their diagnosis, often attributing their illness to socially acceptable diseases such as malaria or typhoid.

Stigma not only affected social relationships but also limited economic opportunities and emotional well-being. Fear of being labeled led to isolation, secrecy, and internalized shame.

Socialization, Isolation, and Mental Health

Approximately 25.36% of patients reported difficulties in socialization during treatment. Physical symptoms such as breathlessness, fatigue, and persistent coughing limited social interaction. Psychological factors including fear of judgment and guilt about transmission further intensified withdrawal.

Some patients experienced anxiety attacks, depression, and feelings of worthlessness. In extreme cases, prolonged distress led to suicidal thoughts, underscoring the urgent need for mental health integration within TB care.

Faith, Prayer, and Spiritual Coping

Faith and spirituality emerged as crucial coping mechanisms. Many patients interpreted TB through spiritual frameworks, attributing illness to ancestral sins, curses, or supernatural forces. Prayer centers functioned as spaces of healing, emotional support, and community belonging.

Interestingly, patients often viewed biomedical treatment as complementary to divine intervention, reflecting a pluralistic approach to healing. Faith provided hope, emotional resilience, and a sense of purpose during prolonged treatment.

IV. Discussion

This study highlights the profound psychological and social impact of tuberculosis beyond its biomedical dimensions, emphasizing how diagnosis, treatment-seeking, and social responses intersect to shape patients' lived experiences in Arunachal Pradesh. Although a majority of respondents did not explicitly report anxiety immediately following diagnosis, qualitative narratives reveal that emotional distress was pervasive, manifesting as shock, fear, guilt, and uncertainty. This discrepancy between quantitative self-reporting and qualitative accounts suggests underreporting of psychological distress, possibly due to normalization of suffering, limited mental health literacy, or cultural expectations of emotional restraint. Similar patterns have been documented in other TB-endemic settings, where emotional suffering is often internalized and expressed indirectly.

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The diagnosis of tuberculosis emerged as a critical *biographical disruption*, altering patients' sense of identity, social roles, and future expectations (Bury, 1982). Concerns about infecting family members particularly children were prominent, reinforcing the moral burden carried by patients and intensifying feelings of guilt and responsibility. TB was not perceived merely as a medical condition but as a marker of social vulnerability and potential exclusion, echoing Goffman's conceptualization of stigma as a "spoiled identity" (Goffman, 1963). Such perceptions significantly shaped subsequent healthcare-seeking behavior, with anxiety influencing the timing, frequency, and continuity of treatment engagement, as also observed in studies on illness narratives and moral experience in chronic and infectious diseases (Kleinman, 1988; Weiss et al., 2008).

Anxiety related to healthcare-seeking among tuberculosis (TB) patients is notably high, often affecting nearly half of those diagnosed, as they navigate the complex transition from a healthy individual to one with a "spoiled identity" (Goffman, 1963; Pang et al., 2024). Physical weakness, fatigue, and diminished self-esteem are the most frequently cited contributors to distress, underscoring the embodied nature of TB-related suffering where biological symptoms directly erode psychological resilience (Tesfaye et al., 2015). However, social dimensions especially embarrassment, fear of judgment, and concern about social labeling play a crucial role in shaping emotional responses, often forcing patients into secrecy to avoid being "discounted" by their peers (Kipp et al., 2011).

The presence of multiple overlapping stressors points to a cumulative burden of illness, where the threat of social exclusion intersects with severe socio-economic insecurity and the fear of infecting loved ones (Somma et al., 2008; Yuen et al., 2015). Furthermore, research in northeastern India indicates that this distress is exacerbated by the lack of integrated mental health services within TB clinics, leaving the psychological "syndemic" largely unaddressed (Pang et al., 2024).

Stigma remains a structurally embedded challenge in tuberculosis control, where the disease is often devalued by society as a mark of moral or personal failing

(Goffman, 1963; Yuen et al., 2016). While a majority of patients may report compassionate or neutral reactions from their immediate circles, research in India indicates that over one-quarter of patients experience definitive avoidance and discrimination, with some reporting direct verbal abuse and exclusion from social activities (Kipp et al., 2011).

Patients often employ stigma management strategies, such as attributing symptoms to more socially acceptable conditions like a common cold or asthma, to preserve their dignity and social standing (Goffman, 1963; Somma et al., 2008). However, this concealment frequently leads to diagnostic delays of several months, which in turn hinders contact tracing and increases the risk of community transmission (Sreeramareddy et al., 2014). By hiding their status to avoid being labeled as "tainted," patients may inadvertently undermine public health efforts to eliminate the disease (Goffman, 1963).

Healthcare workers' accounts historically demonstrate that stigma transcends individual experience to compromise programmatic effectiveness, as the reluctance of families to disclose cases and a fear of community gossip create tangible barriers to contact tracing and field interventions (Thomas et al., 2016). Social isolation during treatment remains a significant burden, driven by physical limitations and psychosocial fears that restrict social participation and intensify internalized withdrawal (Dhingra & Khan, 2010). The prevalence of anxiety, depressive symptoms, and occasional suicidal ideation affecting approximately 9% of patients in some Indian field reports highlights a critical gap in historical TB strategies, which primarily prioritized bacteriological outcomes and treatment completion over the profound psychological toll of the disease (Rajpal et al., 2003). Furthermore, faith-based coping often emerged as a vital pluralistic strategy, where patients utilized spiritual interpretations as a complementary emotional anchor alongside biomedical treatment (Kipp et al., 2011).

Amidst these challenges, faith and spirituality serve as central coping mechanisms, providing patients with emotional resilience through prayer and culturally embedded interpretations of illness (Jaggarajamma et al., 2008). Rather than rejecting modern medicine, many patients adopt a pluralistic approach, viewing divine intervention and biomedical care as complementary pathways to recovery (Sikdar, 2015). This integration challenges the binary of "traditional versus modern" healing and suggests that public health efforts should respectfully engage with indigenous belief systems to improve treatment adherence (Jaramillo, 1999). In the Indian context, religious sites and spiritual frameworks often provide the "meaning and hope" necessary to endure the physical toll of long-term therapy (Jaggarajamma et al., 2008). Furthermore, earlier ethnographic

research in India emphasized that patients often navigate between home remedies, religious healing, and evidence-based medicines, reflecting a deeply ingrained pattern of medical pluralism (department of ISM&2001).

Overall, the study underscores that effective TB control in regions such as Arunachal Pradesh requires approaches that extend beyond biomedical treatment to address psychological well-being, stigma reduction, and socio-cultural realities. Integrating mental health services, strengthening community-based education to correct misconceptions, and fostering supportive social environments are critical for improving treatment adherence and patient outcomes. Addressing TB as a social and emotional experience, rather than solely a clinical condition, is essential for achieving sustainable public health impact.

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