

Barriers and Facilitators of Health-Seeking Behaviour and Treatment Adherence in Tuberculosis Care: A Narrative Review

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Abstract

Tuberculosis remains a significant infectious disease with substantial global and national impact, particularly in India. It primarily affects the lungs but may involve other organs, and untreated active disease can result in severe complications and death. Despite the availability of effective diagnostic methods and standardized treatment strategies, delayed health-seeking behaviour and poor treatment adherence continue to hinder disease control efforts. Socioeconomic disadvantage, limited awareness, stigma, distance to health facilities, and psychosocial challenges contribute to delayed diagnosis and interrupted therapy. The national programs provide free diagnostic and treatment services, structural and individual-level barriers persist. Strengthening early detection, enhancing patient education, improving accessibility, and addressing social determinants are essential to promote sustained adherence and accelerate progress toward tuberculosis elimination.

Keywords: Tuberculosis, Treatment, DOTS, Treatment

Introduction

Tuberculosis (TB) is an infectious disease caused by a bacterium called *Mycobacterium tuberculosis*. It mainly affects the lungs, which are known as pulmonary TB. However, it can also affect other parts of the body, such as the lymph nodes, bones, brain, and kidneys.¹

When a person becomes infected with the TB bacteria but does not exhibit any symptoms and cannot spread the disease, it is referred to as latent tuberculosis infection. People with latent TB do not feel sick. However, about 5-10% of them may develop active TB at some point in their lives, especially if their immune system becomes weak. If active TB is not treated on time, it can become life-threatening.²

Active pulmonary TB spreads through the air. When a person with active TB coughs, sneezes, talks, or spits, tiny infected droplets enter the air. Other people can inhale these droplets and become infected. In contrast, people with latent TB cannot spread the infection to others.

Some people have a higher risk of developing active TB, including those living with HIV, individuals suffering from malnutrition, patients with diabetes, and those with other conditions that weaken the immune system. There are several investigations available to diagnose TB, commonly examine sputum samples under a microscope, perform chest X-rays, and conduct laboratory tests such as culture or molecular testing of respiratory or other body fluids. To detect latent TB infection, healthcare providers use the tuberculin skin test or blood tests known as interferon-gamma release assays (IGRAs).³

Tuberculosis can be prevented by identifying cases early and starting treatment promptly. Screening people who are at high risk, especially close contacts of infected patients, also helps control the spread of the disease. The Bacille Calmette-Guérin (BCG) vaccine provides protection, particularly against severe forms of TB in children.⁴

Treatment of Tuberculosis requires a combination of designated anti-tuberculosis drugs taken for months. Completing the full course of treatment is very important to completely eliminate the bacteria and prevent the disease from returning. However, drug-resistant forms of TB, including multidrug-resistant TB (MDR-TB), are becoming a serious global concern and make treatment more difficult.

Why Tuberculosis is important to study

Tuberculosis (TB) continues to be a major global public health concern. In 2020, nearly 9.9 million people worldwide developed Tuberculosis. Approximately 5.5 million were male, 3.3 million were female and, about 1.1 million were children. During the same year, an estimated 1.5 million patients lost their lives due to the disease. People living with HIV represented around 8% of the total TB cases, and about 214,000 deaths occurred among this vulnerable group.⁵ Despite the ongoing burden, progress has been made in reducing the incidence of TB. Between 2015 and 2020, the global TB incidence rate declined by approximately 11%, decreasing from 142 to 127 new cases per 100,000 populations.⁶

Tuberculosis Treatment and Adherence

This long duration of therapy can be physically, emotionally, and financially demanding for patients. It also presents challenges for healthcare providers who must ensure continuous monitoring, counselling, and follow-up. Failure to complete the full course of treatment can have serious consequences. Irregular or incomplete therapy may result in continued transmission of infection within the community, development of drug-resistant tuberculosis, and increased risk of complications and death. For this reason, strict adherence to anti-tubercular therapy is considered a cornerstone in effective Tuberculosis control and patient recovery.

Health-seeking behaviour of tuberculosis patients

Health-seeking behaviour plays an important role in early diagnosis and timely initiation of treatment. Many individuals with TB symptoms prefer consulting non registered healthcare providers or traditional healers rather than public health facilities. Evidence suggests that nearly half of symptomatic TB patients initially approach private health services, while a smaller proportion seek care from government facilities. A considerable number of individuals do not seek formal medical care at all, and some resort to self-medication, particularly among adults in the middle-age group.⁷

Research conducted in India indicates that a substantial percentage of TB patients ranging from nearly half to three-quarters obtain medical care from private healthcare institutions. While patients have the right to choose their preferred healthcare provider and timing of consultation, delayed or inappropriate health-seeking behaviour can negatively influence treatment outcomes. Such practices may contribute to delayed diagnosis, worsening of disease, ongoing transmission, increased complications, and higher rates of morbidity and mortality.⁸

Tuberculosis (TB) remains one of the most serious infectious diseases affecting people across the world. Every year, millions of individuals from different age groups male, female and children develop this

disease.⁹ People living with HIV face a much higher risk because their immune systems are weaker, making it easier for the infection to become active.

Tuberculosis does not affect all countries equally. Some countries carry most of the global burden. India reports the highest number of cases, globally, followed by several other high-burden nations in Asia and Africa. This uneven distribution shows that social, economic, and health system factors strongly influence the spread and control of the disease.¹⁰

The main aim of Tuberculosis treatment is to completely cure the patient, prevent complications and death, and stop the infection from spreading to others.¹¹ To improve treatment success, global health agencies promoted a structured treatment approach in the 1990s that focused on supervised therapy, standard drug regimens, uninterrupted medicine supply, and regular monitoring. This strategy helped many countries improve patient adherence and treatment outcomes while reducing the development of drug resistance.¹² The global community has set a goal to end the Tuberculosis epidemic within this decade as part of broader international development commitments. However, drug-resistant forms of TB, including multidrug-resistant and rifampicin-resistant strains, continue to challenge these efforts and demand stronger public health action.

Health-seeking behaviour plays an important role in controlling tuberculosis (TB). When people develop symptoms such as a persistent cough or fever, they do not always seek care from government health facilities.¹³ Working-age adults, in particular, may postpone medical consultation because of job responsibilities. Delays in seeking proper care can lead to worsening of the disease and increase the risk of spreading the infection to others. People's decisions to seek timely treatment depend on several factors, including their understanding of TB symptoms, availability of nearby services, financial stability, and confidence in healthcare providers.¹⁴

Various reasons contribute to delayed or inappropriate treatment seeking. Some patients do not consider their symptoms serious and assume they will recover without treatment. Others give priority to work or family responsibilities. Dissatisfaction with health services, financial problems, long travel distances, lack of transportation, alcohol use, and demanding work schedules also create barriers. In many situations, individuals try home remedies for weeks or months before consulting a trained healthcare professional.^{13,15} Treatment adherence is another key component of Tuberculosis control. Adherence means that a patient takes medicines exactly as prescribed by healthcare providers and continues treatment for the full recommended duration. Tuberculosis treatment usually lasts several months, and patients must take multiple drugs regularly. However, many patients stop treatment early. Some feel better after a few weeks and believe they are cured. Others either forget taking medicine, lack proper information, experience side effects, face depression, or struggle with financial and social challenges. A few may prefer alternative systems of medicine instead of continuing standard therapy. These interruptions can result in treatment failure and drug resistance.¹⁶

In India, the National Tuberculosis Elimination Programme coordinates Tuberculosis prevention and control activities under the National Health Mission. The program offers free diagnostic tests and treatment through public health facilities across the country.¹⁷ It also provides technical guidance, monitoring, and support to ensure effective implementation. The program aims to achieve a TB-free India by focusing on early diagnosis, complete treatment, prevention strategies, and strengthening of healthcare systems to ensure that all individuals receive accessible and equitable care.¹⁸

To speed up progress, the government introduced a National Strategic Plan for Tuberculosis Elimination covering the period 2017-2025. This plan promotes collaboration among government departments,

research bodies, private healthcare providers, and civil society organizations. Through coordinated action and shared responsibility, the country continues to work toward reducing the TB burden. However, achieving elimination will require sustained political commitment, community participation, and strong partnerships across multiple sectors.¹⁷

Early identification of Tuberculosis cases is essential for effective control. Detecting the disease at an early stage helps reduce its severity and limits transmission to others. However, several health system challenges can slow down timely diagnosis. These include shortages of trained healthcare staff, limited diagnostic facilities, and irregular availability of services in certain areas. Social and practical difficulties also affect treatment adherence. Patients may struggle with frequent visits to health centres for supervised therapy, long and complex treatment schedules, and stigma associated with the disease. These barriers can discourage patients from completing their treatment.⁴

Completing the full course of anti-tuberculosis therapy is crucial for successful disease control. Research from different settings shows that adherence depends on multiple factors. A patient's knowledge about TB, family and community support, supervision by healthcare providers, socio-demographic conditions, and the overall functioning of the health system all influence whether treatment is completed successfully.¹⁹

A cross-sectional study conducted in Equatorial Guinea by Gabriela Fagundez and colleagues (2016) demonstrated that although a considerable proportion of patients had limited understanding of the cause of tuberculosis, the overall adherence rate was relatively high. The study also noted that many participants reported a family history of Tuberculosis, suggesting the influence of close household exposure and shared health beliefs on treatment practices. These findings indicate that knowledge gaps do not always directly correspond to poor adherence, but they remain an important area for intervention.²⁰

Similarly, Samal (2016) systematically reviewed studies on healthcare-seeking behavior among tuberculosis patients in India. Ten studies were analyzed, highlighting themes such as patient knowledge, diagnostic delay, gender differences, socio-cultural influences, and rural–urban disparities. The review found frequent delays in seeking formal care, often due to poor awareness, stigma, financial constraints, and reliance on informal providers. It concluded that improving awareness and strengthening timely access to TB services is essential.²¹

Pathak et al. (2025) conducted a mixed-methods study among 201 TB patients in rural Gurugram to assess healthcare-seeking behavior and barriers to diagnosis and treatment. About 58.2% demonstrated appropriate care-seeking practices, significantly associated with awareness of TB transmission and seeking care after failed home remedies. Major barriers included delayed evaluation, financial difficulties, stigma, and preference for private facilities. The study emphasized strengthening awareness and improving public healthcare accessibility.²²

Comparable observations were reported in Kosovo by Shaip Krasniqi and colleagues (2017), where most participants completed their treatment regimen. The nearly equal gender distribution in that study reflects that adherence challenges are not confined to one specific demographic group but are influenced by broader contextual factors.²³

A community-based cross-sectional study among newly diagnosed smear-positive pulmonary tuberculosis patients found that cough (93%) was the leading symptom prompting care. Only 45.7% sought medical help within two weeks. Most patients preferred private facilities, though illiterate and low-income groups opted for government services. Delayed care was significantly associated with low income, substance use,

family tuberculosis history, and longer distance to health facilities. Knowledge regarding TB was generally limited.²⁴

Research conducted in Ahmedabad by Harshul Gohel and colleagues (2017) explored determinants of non-adherence in greater detail. The study identified financial constraints, misconceptions about TB treatment, negative attitudes, low educational status, frequent travel, and inadequate social support as significant contributors to interrupted therapy. These results emphasize that adherence is not determined solely by the availability of free medication but also by social, psychological, and economic influences.²⁵ Collectively, the reviewed literature demonstrates that while adherence rates in many settings are encouraging, a consistent proportion of patients continue to experience difficulties in completing therapy. Factors such as inadequate knowledge, insufficient supervision, socio-economic hardship, gender-related influences, and limited social support repeatedly emerge as determinants of non-adherence.² The evidence suggests that strengthening patient education, ensuring effective supervision under national TB programs, and addressing socio-economic barriers are essential strategies for improving treatment completion rates and ultimately reducing the burden of tuberculosis.³

In another investigation, Ramnath Sunnatamman and Beena E. Thomas (2021) examined treatment adherence among adults with drug-resistant TB in Chennai, Vellore, and Mumbai. Nearly half of the participants were also living with HIV. The researchers conducted surprise home visits and collected urine samples to test for isoniazid, providing an objective measure of medication intake. A considerable number of patients tested negative, indicating missed doses. Participants commonly reported long travel distances, forgetfulness, depression, misplaced medicines, and fear of side effects as reasons for non-adherence. The study found that patients who did not follow treatment properly faced a higher risk of poor outcomes. The authors stressed the importance of addressing both structural and psychological challenges and suggested that biological monitoring tools can help detect non-adherence early.²⁶

Praveen et al. (2023) conducted a community-based cross-sectional study among newly diagnosed adult TB patients in Sonitpur district, Assam, to assess care-seeking patterns and socio-demographic factors. Over half (54%) reported delay in seeking care, while 42% initially approached pharmacies. Nearly 70% misinterpreted tuberculosis symptoms as mild and self-limiting. The findings highlight inadequate awareness and emphasize the need to strengthen health literacy and engage pharmacists in early TB detection.²⁷

Discussion

Improving treatment adherence in tuberculosis (TB) requires more than providing medicines. Patients need clear information about the disease and strong support to manage stigma and make informed decisions. Many barriers affect adherence, including personal, social, cultural, and treatment-related factors. Mental health problems, especially anxiety and depression, strongly influence patients' ability to continue treatment and often worsen feelings of stigma and isolation. At the individual level, poor awareness and limited understanding of TB frequently delay diagnosis and treatment. Low literacy and poverty further restrict access to reliable health information, particularly in rural and underserved communities, where some people prefer traditional healers before approaching formal health services. At the community level, fear of discrimination discourages individuals from disclosing symptoms or seeking care.

Healthcare limitations challenges also reduce treatment success. Inadequate infrastructure, limited staff training, weak supervision, and poor communication can discourage both patients and healthcare workers.

Long travel distances, transportation difficulties, and indirect expenses add further burden. Addressing these barriers requires patient education, trained staff, better planning, and improved access to affordable services.

Conclusion

Early diagnosis and timely treatment are essential for effective tuberculosis control. Although persistent cough and fever are common early signs of pulmonary TB, these symptoms alone often do not prompt individuals to seek immediate medical care. In the initial stages, TB symptoms are usually mild and non-specific, and many people mistake them for minor illnesses such as a common viral infection. As a result, medical attention is often sought only when the symptoms worsen or continue for a prolonged period. There is a need to create awareness among community regarding importance of regular treatment of tuberculosis.

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