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Original Research Article

Surveillance of Pulmonary and Extra-Pulmonary Tuberculosis Cases Notified Via Nikshay Portal and Challenges Encountered in Notification in Retrospective, Prospective, Observational Study Conducted in Tertiary Care Hospital, Telangana

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Abstract

Background: Tuberculosis (TB) remains a major public health challenge in India. The National TB Elimination Programme mandates notification of all TB cases through the Nikshay portal to ensure effective surveillance, treatment monitoring, and outcome evaluation. However, challenges in timely and complete notification persist, particularly in tertiary care settings.

Aim of the Study: To assess the pattern of pulmonary and extra-pulmonary tuberculosis cases notified through the NIKSHAY portal and to evaluate clinical characteristics, treatment outcomes, and challenges associated with tuberculosis notification in a Tertiary Care Hospital, Telangana.

Methods: A retrospective and prospective observational study was conducted at a tertiary care hospital in Telangana. Data from hospital records and the NIKSHAY portal were analyzed for patient demographics, type of tuberculosis, notification status, treatment initiation, and challenges in notification from between April 2018 and March 2023.

Results: Pulmonary TB constituted the majority of notified cases, while extra-pulmonary TB showed lower notification completeness. Retrospective data revealed under-notification compared to prospective surveillance, indicating improvement with active follow-up.

Conclusion: The study highlights gaps in TB surveillance and notification despite the availability of a robust digital platform. Strengthening training, improving interdepartmental coordination, and addressing technical barriers can enhance TB notification and contribute to improved TB control efforts under the National TB Elimination Programme.

Keywords: Extra-Pulmonary Tuberculosis; Nikshay Portal.

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Introduction

Tuberculosis (TB) remains one of the leading infectious causes of morbidity and mortality worldwide, with India accounting for nearly one-fourth of the global TB burden. The COVID-19 pandemic significantly disrupted TB services across the country, resulting in an estimated 25% decline in TB notifications during 2020.

Movement restrictions, diversion of healthcare resources, and reduced access to diagnostic services contributed to under-detection and under-reporting of TB cases. Despite these challenges, India's National Tuberculosis Elimination Programme (NTEP) demonstrated resilience and recovery, achieving a record notification of 24.2 lakh TB cases in 2022, representing a 13% increase compared to 2021. This recovery was accompanied by improved private sector participation and enhanced detection of drug-resistant TB cases. The National Strategic Plan for Tuberculosis Elimination (NSP) 2017–2025 outlines ambitious strategies to achieve the Sustainable Development Goal targets for TB elimination by 2025, ahead of global timelines.

Strengthening surveillance and ensuring universal TB notification are central components of this strategy. In this context, the NIKSHAY portal, a web-enabled, case-based TB notification system developed by the National Informatics Centre and

launched in 2012, serves as the backbone of TB surveillance in India. The platform integrates e-health and m-health technologies to facilitate mandatory notification, real-time case tracking, treatment adherence monitoring, and financial support delivery.

NIKSHAY also plays a vital role in engaging the private healthcare sector, which manages a substantial proportion of TB patients in India. Digital tools such as mobile-based reminders, 99DOTS, and electronic adherence monitoring systems have strengthened patient follow-up and reduced loss to treatment.

These technological interventions provide real-time data to programme managers, enable timely decision-making, and support service delivery in resource-limited and remote settings. Despite the widespread availability of the NIKSHAY platform, under-notification of TB remains a major concern, particularly in private healthcare facilities. Barriers to complete notification include limited awareness of mandatory reporting requirements, operational challenges, concerns regarding patient confidentiality, lack of coordination between private and public sectors, and time constraints faced by healthcare providers. Evidence on the extent and quality of TB notification from private tertiary care teaching hospitals remains limited. Against this background, the present study was conducted in a Tertiary Care Hospital in Telangana to assess the surveillance of pulmonary and extra-pulmonary TB cases notified through the NIKSHAY portal and to identify challenges encountered in TB notification. The findings aim to inform strategies for strengthening TB surveillance and supporting India's goal of TB elimination

Aim and Objectives: To enumerate pulmonary and extra-pulmonary tuberculosis cases notified through the NIKSHAY portal.

- To determine the proportion of pulmonary and extra-pulmonary tuberculosis cases notified.
- To analyze the clinical profile of notified tuberculosis patients.
- To evaluate treatment outcomes among notified tuberculosis patients.
- To assess awareness, perceptions, and barriers related to tuberculosis notification among private practitioners.
- To identify challenges encountered in the tuberculosis notification process among notified personnel.

Materials and Methods

This was a retrospective and prospective observational study conducted in the Departments of General Medicine & Respiratory Medicine at a Tertiary Care Hospital in Telangana, India.

A total of 500 TB cases and 25 practitioners involved in TB care, registered between April 2018 and March 2023, were included in the study.

Inclusion Criteria

- Patients aged more than 5 years.
- All tuberculosis patients notified on the NIKSHAY portal between April 2018 and March 2023.
- Patients diagnosed with pulmonary and/or extra-pulmonary tuberculosis.

Exclusion Criteria

- Patients aged 5 years or less.
- Tuberculosis patients not notified on the NIKSHAY portal.
- Patients whose data were inaccessible or incomplete on the NIKSHAY portal.
- Patients diagnosed with conditions other than pulmonary or extra-pulmonary tuberculosis.

Results

Table 1: Age Distribution of Study Participants [N=500]

Age Group (in year)	Number	Percentage
< 10	3	0.5
11-30	129	25.9
31-50	164	32.8
51-70	168	33.6
> 70	36	7.2
Mean + SD	44.8 + 17.6	

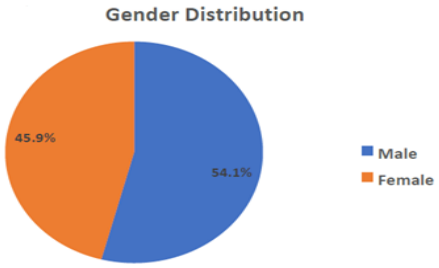

Figure 1: Gender Distribution

Table 2: Distribution of Study Participants According to Method of Diagnosis [N=500]

Method of Diagnosis	Number	Percentage
CBNNAT	277	55.5
Histopathology	56	11.2
Cytopathology	17	3.5
Chest X ray	7	1.3
Culture	7	1.3
Gene Sequencing	7	1.3
ZN stain	3	0.5
Other	127	25.3

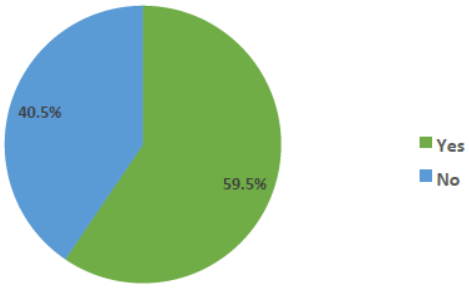

Figure 2: Microbiological Confirmation of Cases [N=500]

Table 3: Distribution of Study Participants According to Type of Case [N=500]

Type of Case	Number	Percentage (%)
New	495	98.9
Retreatment	5	1.1

Table 4: Distribution of Study Participants According to Site of Disease [N=500]

Site of Disease	Number	Percentage (%)
Pulmonary	167	33.3
Extra pulmonary	333	66.7

Table 5: Distribution of Study Participants According to Treatment Outcome [N=236]

Treatment outcome	Number	Percentage (%)
Cured	55	23.2
Died	17	7.3
Treatment Completed	137	58.2
Lost of follow up	1	0.6
Not evaluated	25	10.7

Table 6: Awareness, Perception and Barriers on TB Notification among Private Practitioners [N=25]

Perception	Number of PP	Percentage (%)
No follow up from RNTCP	16	64
No proper information on the reason of TB notification	9	36
No perceived benefits are stated by RNTCP	8	32
No trainings or meetings or communication materials given	13	52
Confusion on intervention earlier done on public private mix strategy and TB notification	20	80
Suggestions		
DOT centres should be provided to private health care providers	24	96
Follow up process from RNTCP will be an effective solution to improve notification	21	84
Notification process should be made convenient and easy	25	100
Group for qualified and nonqualified private health care providers (PHCP) should be build and educate them from RNTCP	16	64

Discussion

This retrospective and prospective observational study was conducted in the Departments of General Medicine and Respiratory Medicine at Tertiary Care Hospital, Telangana, following IEC approval. A total of 500 TB cases registered in the NIKSHAY portal and 25 private practitioners involved in NTEP were included. The study aimed to enumerate pulmonary and extra-pulmonary TB cases notified, assess their clinical profiles and treatment outcomes, and identify challenges, awareness, perceptions, and barriers in TB notification. Inclusion criteria were patients aged over 5 years, notified on NIKSHAY between April 2018 and March 2023, with pulmonary or extra-pulmonary TB.

A community-based survey conducted in 2011 reported that 46% of the TB patients in India were treated outside the public health system (private sector) and hence are not part of the national TB notification system. A diverse private health sector is known to manage over 50% of these cases, either partly or completely, 1 yet its contribution in overall case notification remains only 0.2% (3533) of 1,467,585 notified cases in 2012.

According to the WHO, TB remains a major public health challenge in many developing countries, including India, and is among the top 10 causes of global mortality. Over the past 17 years, timely diagnosis and effective treatment have saved approximately 53 million lives. Despite this progress, TB incidence and mortality continue at 2% and 3% per year, respectively. Early diagnosis and prompt treatment remain key challenges. Programs like RNTCP and DOTS have effectively addressed these issues, reducing complications. Since 2003, the Foundation for Innovative Diagnostics (FIND) has enhanced TB diagnostics and improved access to new tools globally.

The present study found a male-to-female ratio of 1:0.8, indicating higher TB prevalence among males. Similar findings have been reported by Neyrolles et al., showing greater TB positivity in men both in India and globally. Factors contributing to this gender difference include better healthcare-seeking behavior among men, self-medication tendencies among women, and a combination of socioeconomic, cultural, and biological factors, as noted in previous studies.

India uses the NIKSHAY platform as its national, case-based TB notification and surveillance system, covering all TB units and facilities nationwide. Introduced in 2012, NIKSHAY has evolved into a real-time TB information management tool, utilized by both public and private healthcare providers across the country.

Babu DS et al. reported that 6.9% of TB patients were HIV positive, 90.2% HIV negative, and 2.9% had unknown HIV status. In the present study, most cases were diagnosed using CBNAAT (55.5%), followed by histopathology (11.2%).

India bears the highest burden of tuberculosis globally. According to Hopewell PC and Getahun H, sputum smear microscopy is simple, inexpensive, rapid, and specific but has low sensitivity. Moore DF and Pai M highlighted challenges in early TB diagnosis in rural India, including lack of rapid test facilities, costly culture methods, inadequate biosafety measures, and insufficient trained staff. Helb D et al. noted that time-consuming methods like the LJ culture result in many cases remaining undiagnosed. CBNAAT offers a rapid alternative, detecting TB, MDR-TB, and rifampicin resistance within 2–3 hours.

In a study by Raj A et al., CB-NAAT showed over 45% higher sensitivity compared to smear microscopy, as also reported by Zeka AN et al. Suleiman K et al. highlighted its advantages: rapid results, minimal training requirements, and lower biosafety needs compared to culture. Umrao J et al. noted CB-NAAT allows rapid detection of MTB in samples. However, in areas with high incidence of

nontuberculous Mycobacteria (NTM), the assay may be less effective. Raizada N et al. suggested improving CB-NAAT to differentiate NTM from MTB. Limitations include high cost, limited cartridge shelf life, need for continuous power supply, and periodic servicing and calibration of the equipment.

Babu DS et al. reported that among patients tested with CBNAAT, 411 (10.5%) were rifampicin-sensitive, while 26 (0.6%) were resistant. In the same study, 587 cases were clinically confirmed, with 79.8% microbiologically positive and 20.2% negative. Additionally, 76.5% were new cases and 8.5% were recurrent cases. Present study found that lymph node (26.4%) was the most common site noted among extra pulmonary cases followed by spinal site (10%). A study done by Babu DS et al noted the Majority 82.5 were had pulmonary and 11.4% had extra-pulmonary TB in their study**.**

The present study shows that the district has nearly achieved the targets of the RNTCP with respect to cure rate (80%) and lost of follow up was also very less which shows strength of surveillance activities in present district.

India pioneered a digital solution for real-time, case-based TB surveillance with the Nikshay platform. The launch of Nikshay 2.0 in 2017 strengthened private sector engagement, significantly increasing TB notifications. Active case finding (ACF) strategies further added 0.7 million notifications by 2019, a 40% rise from 2017, narrowing treatment gaps. With dashboards accessible from peripheral to national levels, Nikshay has empowered local TB program management. During the COVID-19 lockdowns, it enabled effective monitoring of notifications and treatment adherence, helping the country rapidly recover TB services.

The Ayushman Bharat Digital Mission (ABDM) aims to create a robust digital health infrastructure in India. It provides safe, paperless access to medical records, secure consent-based control over health data, and the ability to manage or revoke consent. The system reduces prescription and clinical errors, ensures inclusive access to the digital health ecosystem, and allows enrollment for people with smartphones, feature phones, or even no phones.

Complete information on all TB cases is essential for accurate diagnosis, effective case management, reducing transmission, and controlling drug-resistant TB. Despite state-level initiatives improving case notification, private practitioners' participation remains limited. Major challenges include the absence of regulatory policies and low awareness among private healthcare providers. Strengthening TB notification requires coordinated public health efforts through both regulatory and supportive measures to ensure effective vigilance.

India has not only envisioned a comprehensive digital TB surveillance system but has also demonstrated that such systems can be effectively implemented at scale, even at the lowest levels of healthcare facilities, despite significant infrastructure and socio-economic challenges. According to the National Strategic Plan 2017–2025, India aims to leverage the existing NIKSHAY platform as a foundation to develop and scale additional innovative interventions.

Thomas BE et al. emphasized that program managers, particularly district TB officers, should proactively engage private healthcare providers (PHCPs) through meetings or workshops. Subsequently, TB health visitors (TBHV) and senior treatment supervisors (STS) should maintain regular follow-ups with PHCPs. Program personnel must be adequately trained and provided with necessary transport support. Collaboration with the Indian Medical Association (IMA), the country's largest medical organization, is also recommended to enhance TB notification.

The present study found that the most common barrier to TB notification reported by private practitioners (PP) was "confusion regarding earlier public-private mix interventions and TB notification" (80%), followed by "lack of follow-up from RNTCP staff" (64%). All PPs suggested that a simpler and more convenient notification process would greatly facilitate smooth implementation. These findings are consistent with the studies by Satpati M et al. , Yeole RD et al., and Kundu D et al.

Conclusion

- Extra-pulmonary tuberculosis constituted a significant proportion of notified cases, with lymph nodes being the most common site.
- Most patients were newly diagnosed, microbiologically confirmed, and showed a satisfactory cure rate.
- The NIKSHAY portal effectively captured demographic, clinical, and treatment-related data.
- Notification gaps were mainly due to lack of awareness, system complexity, and inadequate follow-up mechanisms.
- Simplification of the notification process, regular training, and data quality audits are recommended to strengthen tuberculosis surveillance.

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