

Original Research Article

PEDIATRIC TUBERCULOSIS - EPIDEMIOLOGY, CLINICO-SOCIAL PROFILE AND CHALLENGES: A MULTICENTRIC CROSS-SECTIONAL STUDY IN WESTERN REGION OF GUJARAT

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ABSTRACT

Background: Tuberculosis (TB) remains a major global health concern to all age groups especially in high-prevalence countries like India. Pediatric TB presents unique diagnostic and management challenges due to atypical symptoms, difficulty in microbiological confirmation and social factors. The objective is to comprehensively assess the socio-demographic, epidemiological and clinical profiles of pediatric TB patients, along with challenges during disease management.

Materials and Methods: A multicentric cross-sectional study was conducted in three districts of Western Gujarat (Surendranagar, Botad and Morbi). A total of 91 pediatric TB patients (0–18 years) registered under NTEP between January and June 2023 were included. Data were collected through house visits and caregiver interviews using a semi-structured questionnaire and analyzed using descriptive statistics and thematic analysis.

Results: Majority of patients were adolescents (54.9%). Lymph node involvement was most common among EPTB cases. Treatment success was high, with 53.8% cured and 35.2% completing treatment. However, malnutrition, overcrowding, financial burden (74.7%) and treatment-related challenges such as side effects (40.7%) and adherence issues (37.4%) were prominent. Social stigma and psychological distress were also noted.

Conclusion: Pediatric TB predominantly affects socioeconomically backward groups. While treatment outcomes are favorable, addressing nutritional, financial and psychosocial challenges is essential for improving health status of children.

Keywords: Pediatric TB, Challenges, Stigma.

INTRODUCTION

Tuberculosis (TB) is a communicable disease that is a major cause of ill health and one of the leading causes of death worldwide. Globally, people of all age groups are affected by tuberculosis (TB). As per

the Global TB Report 2020, 56% adult males, 32% adult females and 12% children have TB.^[1,2]

In India, approximately 3.42 lakh children (0-14 years of age) are estimated to get TB every year which accounts for about 6% of total TB cases reported to NTEP in 2020. In 2020, approximately one lakh children with TB (0 to 14 years of age) were

reported to the NTEP.2 Children up to the age of 14 years constitute 35% of the population in our country and are estimated to contribute approximately 10% of the caseload.^[2]

Pulmonary TB is the most common form of TB in children; however, extra-pulmonary TB (EPTB) in children forms a more significant proportion of cases than adults.^[2,3] Children, especially those under five years, are more vulnerable to TB because of their low immunity. Children may develop disease rapidly with atypical symptoms and may also progress to severe illness. Also, It is difficult to diagnose TB in children, firstly because the symptoms of TB among children are similar to other childhood illnesses and secondly, because of difficulties in accessing pulmonary samples as children more often swallow sputum. The lower sensitivity of microbiological tests in children further add to this difficulty.^[2,4] Also Raising awareness and dispelling misconceptions about the disease is important to encourage affected families to seek care promptly, reducing the negative impact of stigma on children and their communities.

In view of these challenges, understanding the specific epidemiology and clinical-social profile of pediatric TB in this region provides valuable insights for healthcare providers. Knowledge in this area also can aid in early detection, accurate diagnosis, and appropriate treatment strategies, ultimately improving the management of pediatric TB cases.

Aim and Objectives

- To assess the socio-demographic profile of pediatric TB patients.
- To analyze the epidemiological profile of pediatric TB patients.
- To describe the clinical profile and treatment protocols for pediatric TB patients.
- To identify challenges encountered by patients and their families during TB management.
- To determine the sources of support for patients throughout the treatment process.

MATERIALS AND METHODS

Study Design: A Multicentric Cross Sectional Study

Study Setting: Three District of Western Gujarat were selected purposively for the study

- Surendranagar
- Botad
- Morbi

Inclusion criteria:

- All the Pediatric TB patients (upto 18 years)
- Clinically or Microbiologically confirmed Pediatric TB Registered under NTEP in two quarter of 2023 (January 2023 – June 2023)

Exclusion criteria

- Transferred out
- Dead Patient

Sample Size: All the Pediatric TB patients registered in two quarters of 2023 (January 2023 – June 2023) under NTEP from the selected districts. Final sample

size achieved for the study was 91 pediatric TB patients.

Data Collection Method and Tool: Data were collected through direct house-to-house visits and in-depth personal interviews with the selected study participants and their caregivers. A pre-validated, pre-tested, semi-structured questionnaire was used to for interviews.

The methodology included comprehensive data collection and included the following aspects:

Epidemiological Details: Information related to exposure history, living conditions, and potential risk factors for TB.

Clinical Data: Symptoms at the time of diagnosis, types of TB (pulmonary or extra-pulmonary), diagnostic methods used (clinical or microbiological confirmation), and the severity of the disease.

Treatment Details: Treatment regimens, adherence levels, and any modifications to the prescribed treatment.

Challenges and Support Systems: Issues faced by patients and their families during the course of treatment, and sources of emotional, financial, or logistical support.

Ethical Consideration:

- Institutional Ethical approval was obtained before starting the study
- Written consent was taken from the guardians/caregiver before commencing the interviews

The semi-structured questionnaire covered various domains such as: Demographic Information: Age, gender, educational status, and family background of the pediatric TB patients.

Data Management and Analysis: Data collected from the interviews and medical records were systematically entered in Microsoft Excel 2019 and verified for accuracy. The information was anonymized to maintain participant confidentiality. Descriptive statistics were used to summarize the socio-demographic and clinical characteristics of the participants. Qualitative data from interviews were analyzed thematically to identify common challenges reported by the participants and their families.

RESULTS

Based on the methodology and line listing of patients total 91 patients were enrolled in the study. Total 54(59.34%) patients were from Surendranagar, 25 (27.47%) were from Botad and 12 (13.19%) were from Morbi.

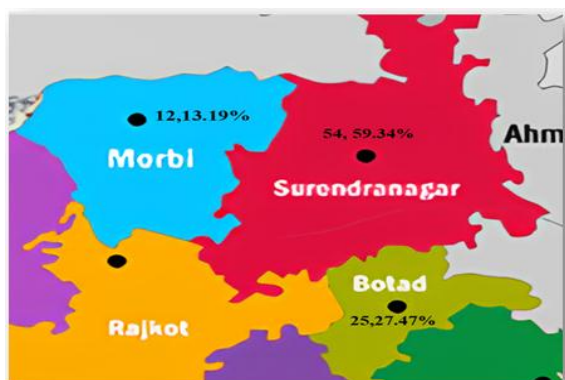


Figure 1: District wise distribution of cases (n=91)

As this study was carried out among pediatric age group the informants were either mother (n=72, 79.12%), father (n=12, 13.19%) or grandparents (n=7, 7.69%).

Out of total 91 participants aged between 2 to 18 years, distributed into age groups. Half of the participants (54.94%) were between 15 and 18 years, while 14 (15.38%) between 7 to 10, and 12 (13.1%) were between 2 and 6 years. The least frequency was noted among age group of under 2 years (4.39%). There was a slight female majority noted with 50 females (54.9%) and 41 males (45.1%). Out of total, 76 (83.51%) participants were Hindu. The educational level of the mothers shows that notable participants had received primary education (n=52, 60.5%) and only a few had secondary education (4.7%). A notable portion of mothers were illiterate (34.9%). There were 5 mothers whose education was not assessed because either they were separated/divorced or dead. Regarding education of the guardian or caregiver, 11 (68.8%) were illiterate, 4 (25%) had completed primary education, and only 1 (6.3%) had completed secondary level. The fathers' occupation shows that most of them had skilled jobs (n=55, 60.4%). Among the mothers, 47 (54.7%) were housewives. The occupation data for guardians or caregivers indicated that nearly half (n=8, 50%) were unemployed. Majority of the patients belongs to either Middle class (60.4%) or below middle class.

The majority of cases were newly diagnosed (87.9%) cases with a smaller proportion (12.1%) were retreatment cases. This indicates scope of initial TB treatment. Half of the cases were pulmonary (51.6%) and rest were extra pulmonary showing similar prevalence of both type of TB. Among EPTB cases, lymph node involvement was the most common (72.7%), followed by abdominal, pleural and miliary TB. This distribution indicates vulnerability of sites for EPTB. Most of the patients were non-diabetic (96.7%) and HIV-negative (97.8%). This suggests that limited co-morbidity had role in pediatric TB but presence of this can worsen the outcome in adult TB. Diagnosis was mainly done through chest X-rays (29.7%), followed by microscopy (20.9%) and clinical diagnosis (28.6%), which reflects a reliance on both radiological and clinical aid in TB diagnosis in these cases. The majority received the standard TB

regimen (96.7%) while a smaller proportion had multidrug-resistant TB (M/XDR-TB) regimens (3.3%) which underscores the lower prevalence of drug-resistant TB in this cohort.

Immediate treatment initiation is one of the crucial parts in TB treatment. After diagnosis was confirmed, in 80.2% of cases treatment was started promptly. However, treatment delays (19.8%) were noted due to various factors like waiting for additional reports, seeking second opinions, and initial reluctance to accept medication. All of these can be addressed like critical barriers that need improvement for the prompt treatment access. New initiative of TB Mitra (support networks) engagement seen in half of the patients (50.5%) which plays a pivotal role as family and community support. Yet, 20.9% were unaware of TB Mitra.

Outcomes were noted as favorable, with a nearly half of them achieving cure (53.8%) and treatment completion (35.2%). Side effects were noted in 25.3% of patients, with common issues including nausea/vomiting (60.9%) and diarrhea (47.8%), which emphasizes the importance of managing these adverse effects to enhance patient compliance and quality of life. Children's Nutrition status was assessed using Waterlow and IAP classifications for malnutrition. A significant number of patients displayed malnutrition in which 27.5% had wasting while 18.7% had severe to very severe malnutrition. Malnutrition underscores its pivotal role in TB vulnerability and the need for nutritional interventions in TB management programs.

A known risk factor for TB transmission which is close contact with a TB-positive individual was confirmed by 11.0% patients. However, 45.1% were uncertain about exposure history, which emphasizes an area where health education and awareness are critical, as identifying close contacts is essential in TB control. Most of the mothers (76.9%) had received the BCG vaccine, which can confer some immunity against severity of TB. Only 4.4% had a known history of TB.

The majority of children were born via normal vaginal delivery (81.3%), with most of the births occurring at term (84.6%) and a small fraction being preterm (13.2%). Birth weight was noted within the normal range (82.4%) and nearly all children (96.7%) cried immediately after birth. Possibly due to early neonatal complications 29.7% required NICU support after birth. Exclusive breastfeeding rates were high (91.2%).

Majority children (95.6%) received the BCG vaccine, which is coherent with public health guidelines for TB prevention. However, only 74.7% had completed their age-appropriate immunization indicating children's vulnerability to various infections.

Environmental condition affects the TB prevalence as well as outcome and also plays a major role in epidemiological trend. Overcrowding was present in 83.5% of homes which is a significant risk factor for TB transmission. Adequate ventilation was reported

in 71.4% of homes but inadequate lighting (24.2%) could indirectly affect disease outcomes.

Findings related to Preference of Health care facility:

Most families in the present study live within a manageable distance to the nearest healthcare facility as 41.7% residing 1-3 km away, 39.6% 4-6 km and 18.7% farther than 6 km. Distance from the healthcare facility as it can influence healthcare utilization. Children residing farther from facilities might face various challenges in accessing timely care specially follow up. Public transport is the primary mode of reaching healthcare facilities (48.4%), followed by private vehicles (42.9%).

Most of the nearest facilities offer essential diagnostic services (79.1%) and TB medications (72.5%), though some respondents were unaware of the availability of these resources. However, counselling services were noted notably lacking as only 13.2% reporting it's availability. As Counselling is critical

in TB management to support adherence, address stigma, and manage psychological factors it's need should be addressed to overcome the various hurdles. Nearly half of the respondents (47.3%) had satisfactory communication with healthcare providers. Clear communication helps patients and their guardian to better understand treatment and follow-up needs. Out-of-pocket expenses were noted in 48.4% of the participants indicating a significant financial burden in chronic infection like TB. Although 46.2% of informants stated that they received financial assistance, rest were not aware about it.

Nutritional support is a critical component in TB management, as malnutrition is a identified risk factor that can worsen TB outcomes. Nutritional assistance was received by 42.9% of patients through various schemes, while Anganwadi support was widely accessed.

Table 1: Challenges faced by Participants (responses from informants) (n=91)

Challenges	Number of cases (%)
Diagnostic Challenges	12 (13.2)
Treatment Adherence	34 (37.4)
Side Effects of Medication	37 (40.7)
Psychological Impact	29 (31.9)
Stigma and Social Isolation	23 (25.3)
Nutritional Challenges	39 (42.9)
Access to Education	8 (8.8)
Financial Burden	68 (74.7)
Access to Healthcare	4 (4.4)
Language and Cultural Barriers	3 (3.3)
Follow-up Care and Monitoring	21 (23.1)
Healthcare Provider Communication	7 (7.7)
Social Stigma	22 (24.2)

TB is a chronic disease and particularly in children challenges are different compared to adults they were assessed and dived into different themes. Some of the verbatims by caregivers are mentioned here related to theme.

As TB treatment is long and can be difficult to maintain, especially if patients experience barriers to regular follow-up or if diagnostic delays occur. Treatment adherence related challenges were noted in 37.4% and diagnosis related challenges in 13.2%.

Quote: “ Dava no samyado lambo lage chhe, chhokra ne roj apvi pade che” (language : Gujarati)
Medication side effects were reported by 40.7% which is a noteworthy issue that can lead to non-adherence. Managing these side effects through improved support, counselling and regular monitoring can be done.

Quote: “TB ni Dava to made chhe government mathi pan chhokara ne apo ek var pchhi Ghani var lidha pchii chhokra ne aad asar thai to e levani anakani kare chhe” (language: Gujarati)

Social stigma and isolation (25.3%), psychological impact of TB (31.9%) were significant concerns as TB affects social health as well. That's why addressing these issues can be beneficial for improving patients' quality of life. Although the proportion of affected participants was relatively small but the presence of stigma is still remaining a

concern as it can contribute to psychological stress, social isolation and even affects in seeking care.

Among those who reported stigma, after prompting reasons of stigma were segregated as avoidance (31.8%), gossips (27.3%), verbal abuse (4.5%), labeling as "untouchable" (27.3%), and being seen as a child "cursed to stay ill" (9.1%). These highlights deep-rooted negative perceptions about TB within certain communities. Avoidance and labeling as “untouchable” may lead to social isolation which ultimately impacts a child's self-esteem.

The emotional clang on children who experience this forms of stigma can also affect their social engagement in routine activities, schooling and friendships and ultimately their developmental milestones and mental health.

Quote: “TB thaya pachhi ena mitro nathi ramta eni jode, ene pote pachhi bahar javanu occhhu kari didhu che, emna mummy pappa ne dar lage che k TB thai jase emna chhokra ne pan”

Nutritional challenges (42.9%) and financial burdens (74.7%) were prominent issues, underscores the importance of nutritional support and financial assistance programs.

Quote: “TB thaya pachhi ena vajan ma farak padi gayo chhe, vadhatu to phla pan ochhu hatu pan have to jane vadhare ghatava lagayu chhe”

Quote: “TB na checkup karaava , dava leva javu pade, eni sambhad rakhva ek manas hamesha roka yelo rahe che”

Approximately 23.1% of patients faced challenges with follow-up care and monitoring, which is essential for TB management and preventing relapse. [Table 1]

The majority of patients informants were assessed regarding awareness of TB. Most of them had awareness regarding TB symptoms (80.2%), transmission (95.6%), diagnostic methods (86.8%) and treatment (80.2%). However, only 38.5% were knowledgeable about TB prevention which can be a targeted area that requires focused health educational interventions. Encouragingly, 69.2% of patients expressed a willingness to learn more about TB. Healthcare workers (80.2%) remained the primary source of TB information, underscoring the importance of their role in patient education and community awareness.

DISCUSSION

In the present study, the age of participants ranged from less than 2 years to 18 years, with the majority (54.9%) belonging to the 15–18-year age group, followed by 15.4% in 7–10 years, 13.1% in 2–6 years, and the least (4.4%) below 2 years. This finding suggests that adolescents constituted the predominant affected group in this region. In contrast, Yerramsetti et al. in their global modelling study reported that pediatric TB burden is highest among children under 5 years (48%) and decreases with age.^[6] Similarly, Ramanathan et al. from Tamil Nadu found the mean age of affected children to be 7.47 years, with most cases in the 7 to 12-year range.^[7] The observed age difference in the present study may be due to the inclusion of adolescents up to 18 years (while most other studies restrict pediatric TB to <15 years) and better diagnosis among older children, who are more capable of expressing symptoms and undergoing sputum examination. Moreover, younger children are more likely to remain undiagnosed due to non-specific clinical presentations.

Almost similar gender distribution was noted in the present study with a slight female predominance (54.9%). Similar findings were noted by reported by Ramanathan et al. and Seddon and Shingadia, in their review on global pediatric TB, noted that gender distribution is usually balanced in children, with no consistent male or female bias.^[8]

Most participants (83.5%) were Hindu, followed by Muslims (13.2%) and Christians (3.3%), mirroring the general demographic composition of the region. Such distribution has also been seen in community-based TB studies in Gujarat and Tamil Nadu, where religion did not show any direct association with TB occurrence.^[7] The vast majority of parents were married (94.5%), indicating family stability and availability of parental support during treatment, which is essential for adherence.

Educational status of mothers revealed that 60.5% had primary education, 34.9% were illiterate, and only 4.7% had completed secondary schooling. This finding is consistent with Ramanathan et al, who reported that 71% of mothers of pediatric TB patients had education up to primary level, indicating the persistence of limited educational attainment among caregivers of affected children.^[7]

Lower maternal literacy is a known social determinant of delayed diagnosis, poor treatment adherence, and undernutrition, which in turn increase vulnerability to TB infection and progression. Occupationally, 54.7% of mothers were housewives, whereas 60.4% of fathers were engaged in skilled work. Ramanathan et al. observed similar findings, where most fathers were daily-wage workers and mothers homemakers.^[7] This suggests that pediatric TB continues to disproportionately affect families of lower- and middle-income socioeconomic groups, often dependent on daily labor, which may limit their ability to access timely healthcare. In the present study, 60.4% belonged to the middle class, and 34.1% were in lower and lower-middle categories. This is in partial agreement with Ramanathan et al, who found a predominance of lower socioeconomic class (68%) in their sample. Socioeconomic deprivation contributes to overcrowding, malnutrition, and poor healthcare access, which are well-established risk factors for TB transmission and progression.^[8]

In our cohort, 87.9% were new cases, while 12.1% were retreatment cases, which is almost identical to Ramanathan et al.'s finding of 88.7% new cases.^[7] With regard to disease site, pulmonary TB (51.6%) slightly exceeded extra-pulmonary TB (48.4%) in the present study. This differs from Ramanathan et al. who found extra-pulmonary TB (67.5%) to be predominant,^[7] and from global data reported by Seddon & Shingadia, which suggest that extra-pulmonary TB forms are more common in younger children due to their immature immune responses.^[8] Among the extra-pulmonary TB cases, lymph-node TB (72.7%) was the most frequent, followed by abdominal (13.6%), pleural (9.1%), and miliary (4.5%) forms. These proportions align closely with Ramanathan et al., who reported lymph-node involvement in 69% of their EPTB cases.^[7] Diagnosis was primarily made using chest X-ray (29.7%), followed by microscopy (20.9%), CBNAAT (14.3%), and clinical diagnosis (28.6%). In comparison, Ramanathan et al. reported higher reliance on cytopathology and CBNAAT,^[7] Yerramsetti et al. (2022) highlighted that globally, only 41–63% of pediatric TB cases are detected, largely due to diagnostic limitations and under-reporting.^[6]

Nearly all participants (96.7%) received the standard first-line regimen, while only 3.3% were on longer M/XDR-TB regimens, indicating low prevalence of drug-resistant TB among children, consistent with national and global estimates.^[8]

Prompt treatment initiation was achieved in 80.2% of cases, whereas 19.8% experienced delays, mainly due to awaiting additional reports or reluctance to accept the diagnosis. Comparable delays have been reported in other Indian studies, attributed to poor awareness and social stigma. The involvement of TB Mitra (community treatment supporters) was noted in 50.5% of patients, reflecting the positive impact of community-based support mechanisms. Treatment outcomes were favorable, with 53.8% cured and 35.2% completing therapy. Ramanathan et al. also documented an overall 87.5% treatment success rate, demonstrating consistency.^[7]

Using Waterlow classification, 27.5% of children showed wasting, and 9.9% had stunting. Based on IAP criteria, 31.9% were malnourished (mild to severe). These findings align with Ramanathan et al, who reported 45% undernutrition among pediatric TB cases,^[7] and Yerramsetti et al., who attributed nearly 27% of global pediatric TB burden to undernutrition. Malnutrition weakens immunity, increases disease susceptibility, and worsens outcomes, underlining the need for integrated nutritional support in TB management.

A high proportion (95.6%) of children in the present study were BCG-vaccinated, consistent with the national immunization coverage reported by Ramanathan et al. (2025) (96%) (Seddon and Shingadia (2014) reaffirmed BCG's effectiveness in preventing severe disseminated TB in children.^[8]

Only 11% had a known history of contact with a TB case, whereas 45.1% were unaware. Similar underreporting of contact history was observed in South African studies where recall bias and social stigma hinder accurate reporting.^[8]

Overcrowding (83.5%), poor ventilation (28.6%), and inadequate lighting (24.2%) were frequent, all of which are recognized risk factors for TB transmission. Seddon and Shingadia (emphasized that household crowding and poor air circulation increase infection risk by several folds, particularly among children in endemic regions.^[8]

A large proportion (74.7%) of caregivers reported financial burden, 42.9% reported nutritional challenges, and 31.9% mentioned psychological distress in children. Medication side effects (40.7%) and treatment adherence issues (37.4%) were also common. Such psychosocial stressors have been repeatedly identified as major barriers to pediatric TB care.^[7,8]

Stigma was reported by 25.3%, with manifestations like avoidance (31.8%), gossip (27.3%), and labeling as "untouchable" (27.3%), reflecting persistent misconceptions within the community. Similar stigmatizing attitudes were discussed by Seddon & Shingadia, who stressed that social stigma delays diagnosis, reduces adherence, and worsens mental well-being.^[8]

CONCLUSION

Most of the pediatric TB patients were from low-income, low-educated families, with a minor female preponderance. Lymph node TB was the most prevalent extrapulmonary TB, with pulmonary and extrapulmonary cases being about equal. The close-contact screening and nutritional supplementation is utmost important in this chronic disease. Despite a high rate of medication adherence, patient comfort was sometimes impacted by adverse symptoms faced by children. Challenges faced by their caregivers can be managed efficiently by potential interventions.

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