Sex-disaggregated patterns in tuberculosis treatment coverage and outcomes among a nationally representative sample of deaths in India: 2019–2022

Rakhi Dandona,[a] G Anil Kumar,[a] S Siva Prasad Dora,[a] Md Akbar,[a] Kultar Singh,[b] Sibin George,[a] Moutushi Majumder,[a] Navin Kumar,[b] Rajendra P. Joshi,[c] Mrigen Deka,[c] Dimple Panchal,[c] Venkatesh Roddawar,[d] Amar Shah,[e] Vikas Choudhary,[b] Yogesh N. Patel,[d] Bhavin Vadera,[e] Kiran Rade,[f,g] Lalit Dandona,[a] and Raghuram Rao[c,*]

[a]Public Health Foundation of India, New Delhi, India
[b]Sambodhi Research and Communication Pvt Ltd, Noida, India
[c]Central TB Division, National TB Elimination Programme, Ministry of Health and Family Welfare, Govt. of India, New Delhi, India
[d]TIFA India, John Snow India Pvt. Ltd, New Delhi, India
[e]Health Office, USAID/India, New Delhi, India
[f]World Health Organization, India Office, New Delhi, India
[g]Stop TB Partnership, India

The Lancet Regional Health - Southeast Asia 2024;31: 100448

Published Online 9 July 2024
https://doi.org/10.1016/j.lansea.2024.100448

Summary

Background We report on TB treatment coverage and outcomes by sex among a nationally representative sample of deaths in the background of the national framework for a gender-responsive approach to TB adopted by India.

Methods Detailed interviews were undertaken for a nationally representative sample of deaths of all ages between 2019 and 2022 from the adult most knowledgeable about the deceased. Details about TB treatment were documented for females and males for whom history of TB diagnosis ever.

Findings Detailed data were available for 26,957 (92.1% participation) deaths. The prevalence of TB diagnosis ever was 2.9% (95% CI 2.6–3.2) and 5.8% (95% CI 5.4–6.1) among females and males, respectively. TB treatment coverage was similar for females (81.4%; 95% CI 76.7–85.3) and males (82.4%; 95% CI 79.8–84.7). TB treatment coverage was significantly lower for males with TB diagnosis in years 2021 and 2022 as compared to those diagnosed in 2019 (–12.1%; 95% CI –22.7 to –1.5). A similar proportion of females (55%) and males (58.9%) were on TB treatment at the time of death, had completed TB treatment (39.3% females and 35% males, and had discontinued TB treatment (5.3% females and 5.2% males); significant variation in treatment status was seen by age and state for both, and by wealth index quartile for males. Majority took TB treatment from public sector (females 72.9% and males 76.0%).

Interpretation The sex-disaggregated findings from this nationally representative sample of deaths are a value-add to effectively address TB in India as majority of such understanding towards gender-responsive strategies is available from those who are alive.

Funding United States Agency for International Development (USAID).

Keywords: Tuberculosis; TB; India; Treatment coverage; Survival; Gender

Introduction

India contributes the largest number of Tuberculosis (TB) patients and TB-related deaths globally.[1] The National Strategic Plan (NSP) to end TB in India 2017–2025 is aimed at enhancing the coverage, quality, equity, efficiency and effectiveness of the National Tuberculosis Elimination Program (NTEP).[2] Significant achievements have been made in TB prevention, care and control in India between 2017 and 2019, including the implementation of the Ni-kshay national digital information system, yet challenges remain largely due to social stigma, poor access to quality services in the public sector, and treatment seeking in mostly the unregulated private health system with very little information available

*Corresponding author. Central TB Division, National TB Elimination Programme, Ministry of Health and Family Welfare, Govt. of India, Jeevan Vihar, Ground Floor, Sansad Marg, New Delhi, India.
E-mail address: raor@rntcp.org (R. Rao).

Research in context

Evidence before this study

India contributes the largest number of Tuberculosis (TB)-related deaths globally. A variety of barriers to health care seeking in TB are known for females and males in India; much of the literature available on health seeking behaviour in TB patients is based on either small sample size, patients in a particular hospital or health facility or state, and in those who are alive. Trends in TB treatment coverage and treatment outcomes over time are modelled at the national level as these data not readily available.

Added value of this study

In a nationally representative sample of deaths of all ages between 2019 and 2022 enumerated from 1,000,000 population across nine Indian states, this study documents trends in TB treatment coverage and outcomes, and in barriers to completion of treatment over time in deceased females and males disaggregated by wealth index, place of residence, state, and type of TB treatment provider. TB diagnosed cases among these deaths ranged from those diagnosed with TB in 1960s–2022, thereby, providing a reasonable understanding of trends over time. Furthermore, implications of Covid-19 pandemic on TB treatment coverage are reported. Additionally, trends in mean survival post TB diagnosis are reported by the status of TB treatment at the time of death in females and males disaggregated by wealth index, place of residence, state, and type of TB treatment provider.

Implications of all the available evidence

The findings from this nationally representative sample of deaths in India highlight the importance of sex-disaggregated data in monitoring of equity in access to and benefits of TB treatment for both females and males. This evidence contributes to development and implementation of gender-responsive strategies under the national framework for a gender-responsive approach to TB adopted by India in 2019.

on quality and treatment completion.[2] Furthermore, the socio-cultural gender aspects of TB in India compounds many of these challenges both for females and males.[3–5]

Gender analysis and gender-responsive TB programming is recommended as gender influences TB transmission, testing, treatment, adherence, and outcomes.[6–8] To this effect, India launched its national framework for a gender-responsive approach to TB in India in 2019 in line with the NSP.[9] Significant recent literature has captured the gendered aspects of TB diagnosis, care and treatment outcomes in India, however, most literature is predominately based on small sample size or patient population on TB treatment.[10–14] Furthermore, COVID-19 pandemic has resulted in a substantial reduction in TB testing and case notifications and increase in mortality in many countries in the recent years, including in India.[1,15–17] In this background, we utilize data from a nationally representative survey of deaths that occurred between 2019 and 2022 of all ages in India designed to estimate TB mortality to understand TB treatment coverage and outcomes by sex among the deceased. The aim of this analysis was to understand if any change was needed in the gender-responsive strategies in the TB program based on the gendered experiences of the deceased in these recent years.

Methods

This study was approved by the Institutional Ethics Committee of the Public Health Foundation of India. All participants provided written informed consent, and for those who could not read or write, the participant information sheet and consent form were explained by a trained interviewer and a thumb impression was obtained.

Sampling

The data reported in this paper are from a nationally representative survey of deaths for all ages that occurred between 2019 and 2022 in India designed to estimate TB mortality at the national level. A stratified sampling approach was used to select the nine states, using a 3 × 3 matrix constructed considering the state TB prevalence rate from the National TB prevalence survey of 2019–2021,[18] and the socio-demographic index as estimated by the Global Burden of Disease study for each state.[19] One state was randomly selected from each of the nine matrix cells to obtain a reasonable geographic spread across India (Appendix Table 1). A multi-stage sampling procedure was used to select 1000 clusters from 50 districts in nine states of India with the aim of having a sample representative of the population of India. The number of districts were distributed across the 9 sampled states based on the total population in these states. Accordingly, different numbers of districts were sampled in different states as per the distribution of population in the sampled states to overall population. Four districts each were sampled in the states of Odisha, Kerala, Jharkhand, Assam and Haryana; six districts each in Gujarat and Tamil Nadu; eight districts in Maharashtra; and ten districts in Uttar Pradesh. Three iterations of random sampling were undertaken to select the required number of districts from each state. In each iteration for each state, districts arranged alphabetically were randomly sampled as per the required number. These districts were plotted on the state map which was reviewed independently by three

people to assess the geographic spread. Each person indicated the preferred iteration that allowed for maximum geographic spread. If the assessments of all the three persons corroborated, that iteration was selected as the final district sample for a particular state. If the assessments did not corroborate, another round of iteration was repeated until corroboration was achieved. District sampling of all states was completed in round 1 except for Uttar Pradesh for which two rounds were needed.

The sample size for all deaths was estimated for a 1,000,000 population sample based on crude death rate for each of the sampled states and the assumed excess deaths in these sampled states during January 2020–December 2021. To estimate the TB deaths, we assumed an annual TB death rate as 30 per 100,000 population for both sexes, with TB death rate to be twice in males as in females assuming an annual TB death rate of 20 per 100,000 in females and 40 per 100,000 in males in India. We assumed a design effect of 1.5 for the sampling strategy, to get the 95% confidence intervals within ±10% around the TB death rates for India. With this a sample of 25,800 deaths was arrived at for this survey.

Based on the Census 2011 data,[20] 20 study clusters of about 1000 population were sampled in each district using stratified systematic sampling technique, with the proportion of rural-urban clusters similar to the proportion of rural-urban population in each district. The rural-urban population proportion in each district during the study period was estimated by applying the percentage increase in urban population in each sampled state between Census 2001 and Census 2011[20,21] to the period after 2011. In the selected districts, we divided large villages into segments of 1000 population each, and combined villages with smaller population with others to make a cluster size of 1000 population each. We then systematically selected the rural clusters from the villages with the first cluster sampled randomly, and similarly the urban clusters from the wards. The same method of cluster selection was followed for each of the selected districts in the study. Our survey sample listed was similar to the National Commission Population (NCP) projected population by age and sex, and the rural population sample was 8% higher than the NCP.[22]

All households in the sampled cluster were mapped in a serpentine pattern starting from the north-east corner and ending in the opposite corner, with usual residents in a household defined as people eating from the same kitchen and on a regular basis. A trained interviewer documented the number of current usual residents, in-migration and out-migration, and deaths between January 2019 and December 2022 in each household. All deaths between January 2019 and December 2022 were considered eligible for the survey.

Data collection

Relevant to this paper, after confirming the year of death and usual resident status for deaths between January 2019 and December 2022, trained interviewers documented socio-demographic information about the deceased in confidential interviews undertaken in local language with the adult who was most knowledgeable about the deceased. History of TB diagnosis ever was asked for all deaths. For the deaths for whom history of TB diagnosis ever was reported, the year of TB diagnosis, whether TB treatment was taken, status of TB treatment at the time of death, and type of TB treatment provider was documented for the most recent episode of TB. If TB treatment was not taken or discontinued by the deceased, the reasons for the same were documented from the respondent. In addition, for the deceased who were alive during the Covid-19 pandemic period (2020–2021) and had not completed TB treatment, the respondents were asked if the deceased had TB related symptoms during that period and if a health provider was seen for these symptoms during the pandemic period. The reasons for not seeking care from the health provider in the presence of TB symptoms were documented.

The study questionnaire was developed in English and translated into local languages of the sampled states, and then back-translated into English to ensure the accurate and relevant meaning and intent of the questions. Pilot testing of the questionnaire and study logistics was carried out in 6373 (83.2% participation) households for enumeration and 667 (86.5%) respondents for survey across the nine states and modifications made as necessary. The interviews were captured using the Open Development Kit software in hand-held tablets.[23] Data entered were scrutinized using the built-in consistency checks based on logic of the questionnaire to detect and correct errors using the procedures standardized in the study to meet the data quality. At least three attempts were made to reach all eligible deaths, including visit at a later time if the eligible respondent was travelling or not available during the initial round of data collection in a particular cluster. Data collection was undertaken from January 2023 to August 2023.

Data analysis

The main objective of this paper is to report on TB treatment seeking pattern by sex for the deceased who were reported to be diagnosed with TB ever. The distribution of year of TB diagnosis is presented by age at diagnosis for females and males separately. We report on the TB treatment coverage (defined as started TB treatment irrespective of completion) by place of residence, wealth index quartile, and year of TB diagnosis; and present the TB treatment status among those who started TB treatment by age, place of residence (rural vs urban), wealth index quartile, year of death, type of TB

(pulmonary and extra-pulmonary), and state of residence separately for female and male deaths. Distribution of the type of TB treatment provider (public sector vs private sector) is presented for the two sexes by the place of residence, wealth index quartile, and year of TB diagnosis. For those reported to have undertaken TB treatment, treatment outcome is presented by the type of TB treatment provider and year of diagnosis. The reasons provided for never starting TB treatment and for discontinuing TB treatment were reviewed and categorized for meaningful interpretation (Appendix Table 2), and are presented by sex of the deceased and by year of death. We report on the reasons for not seeking health care for those who were alive during the Covid-19 pandemic period and had not completed TB treatment but were reported to have TB symptoms during this period by the two sexes (Appendix Table 3).

Lastly, we report the mean age at death, and the gap between TB diagnosis and death calculated in years considering the year of TB diagnosis and the year of death. The mean age at the time of death and mean gap between diagnosis and death is reported separately for males and females by the year of TB diagnosis, place of residence, wealth index quartile, year of death, type of TB, TB treatment status, and the state. Wealth index was calculated using the standard methods used in the National Family Health Survey to calculate the wealth index.[24,25] We report 95% confidence interval for estimates as relevant, and descriptive statistics are reported. Z-test and Chi square test were used to report significance between categories where relevant. All analyses were performed using STATA V.13.1 software (StataCorp, USA).

Results

A total of 276,738 households were enumerated (87.1% participation) with an average population of 1,002,098 across the four years. A total of 29,273 deaths between January 2019 and December 2022 were identified in this population (Appendix Table 4). Detailed survey data were available for 26,964 (92.1%) deaths, including 15,866 (58.9%) male deaths and 19,296 (71.6%) deaths in rural area.

TB treatment coverage

A total of 322 (2.9%; 95% CI 2.6–3.2) deceased females and 915 (5.8%; 95% CI 5.4–6.1) deceased males were reported to have been ever diagnosed with TB. Data on the year of TB diagnosis was available for 1132 (91.5%) cases. The year of TB diagnosis ranged from 1961 to 2022 for females and from 1960 to 2022 for males, with the median year of diagnosis as 2019 for both. A total of 298 (26.3%) of all cases with the year of diagnosis available were diagnosed in year 2016 or earlier, 164 (14.5%) between 2017 and 2018, and 670 (59.2%) cases in year 2019 or later. The proportion of diagnosis in females was significantly higher in younger ages (29 years or less) than in males of similar age, was similar for both between 30 and 59 years of age, and then was higher in males for 60–69 years of age than for females in the same age group (Appendix Figure 1).

Data on TB treatment coverage was not available for 15 (4.7%) females and 51 (5.6%) males who were reported to be diagnosed with TB. Irrespective of the year of diagnosis, TB treatment coverage was similar for females (81.4%; 95% CI 76.7–85.3) and males (82.4%; 95% CI 79.8–84.7) and also by the place of residence for both (Table 1). This coverage was lower in females belonging to wealth index quartile 1 (75.0%; 95% CI 65.3–82.7) from the other wealth index quartiles but was not statistically significant. The proportion of never starting TB treatment was 1.57 times higher among those diagnosed in year 2022 as compared with those diagnosed in year 2021 for females, and was 1.7 times higher for those diagnosed in years 2021 and 2022 as compared with those in year 2020 for males (Fig. 1). There was a statistically significant reduction in TB treatment coverage for those diagnosed in years 2021 and 2022 as compared with year 2019 for males (–12.1%; 95% CI –22.7 to –1.5) and borderline significant reduction for females (–13.9%; 95% CI –32.7 to 5.0).

Overall, 45 (14%) females and 110 (12%) males were reported to have never started TB treatment. The distribution of never starting TB treatment by the age at TB diagnosis is shown in Appendix Figure 2, and it was broadly higher for males across the age groups as compared with females except in 50–59 years wherein it was significantly higher for females. The reasons for not starting TB treatment were broadly similar for females and males, and were reported as money-related, provider-related, access-related, and having no TB symptoms (Appendix Figure 3).

TB treatment status

Among the 262 deceased females who were reported to have started TB treatment, 144 (55%) were on TB treatment at the time of death, 103 (39.3%) had completed TB treatment, and 14 (5.3%) had discontinued TB treatment (Table 2). The proportion of being on TB treatment at the time of death decreased and that of having completed TB treatment increased with increasing age at death ($p < 0.001$), and there was a significant difference in the TB treatment pattern for females by wealth index quartile ($p = 0.030$) and state ($p = 0.004$). No significant difference was seen by the other variables shown in Table 2. A distinct difference was seen in the TB treatment pattern for deceased females between years 2019–20 and 2021–22 (Fig. 2), with the proportion of those who had completed TB treatment being significantly higher in the latter (45.9%) than in the former (32.8%; $p = 0.013$). Among the 754 deceased males who were reported to have started TB treatment, 444 (58.9%) were on TB treatment at the time

Variable	Variable categories	Coverage of TB treatment (95% confidence interval)	
		Females	Males
Overall		81.4 (76.7–85.3)	82.4 (79.8–84.7)
Place of residence	Rural	80.2 (74.7–84.7)	82.0 (78.9–84.7)
	Urban	85.7 (75.1–92.3)	83.7 (78.3–88.0)
Wealth index quartile	Q1	75.0 (78.3–88.0)	82.3 (77.7–86.0)
	Q2	83.1 (73.8–89.6)	78.5 (72.6–83.5)
	Q3	83.1 (72.4–90.2)	82.6 (76.5–87.4)
	Q4	86.4 (75.7–92.8)	87.2 (81.4–91.3)
Year of TB diagnosis	2015 or earlier	85.7 (74.6–92.5)	89.9 (48.9–80.7)
	2016–2018	94.9 (81.3–98.7)	89.9 (80.9–94.9)
	2019	84.0 (81.3–98.7)	88.8 (84.3–92.1)
	2020	82.9 (68.0–91.7)	83.6 (75.9–89.2)
	2021	75.7 (59.2–87.0)	72.2 (63.0–79.9)
	2022	66.7 (48.9–80.7)	74.8 (65.4–82.2)

CI denotes confidence interval.

Table 1: **Coverage of Tuberculosis (TB) treatment by select variables in deaths who were reported to be diagnosed with TB ever.**

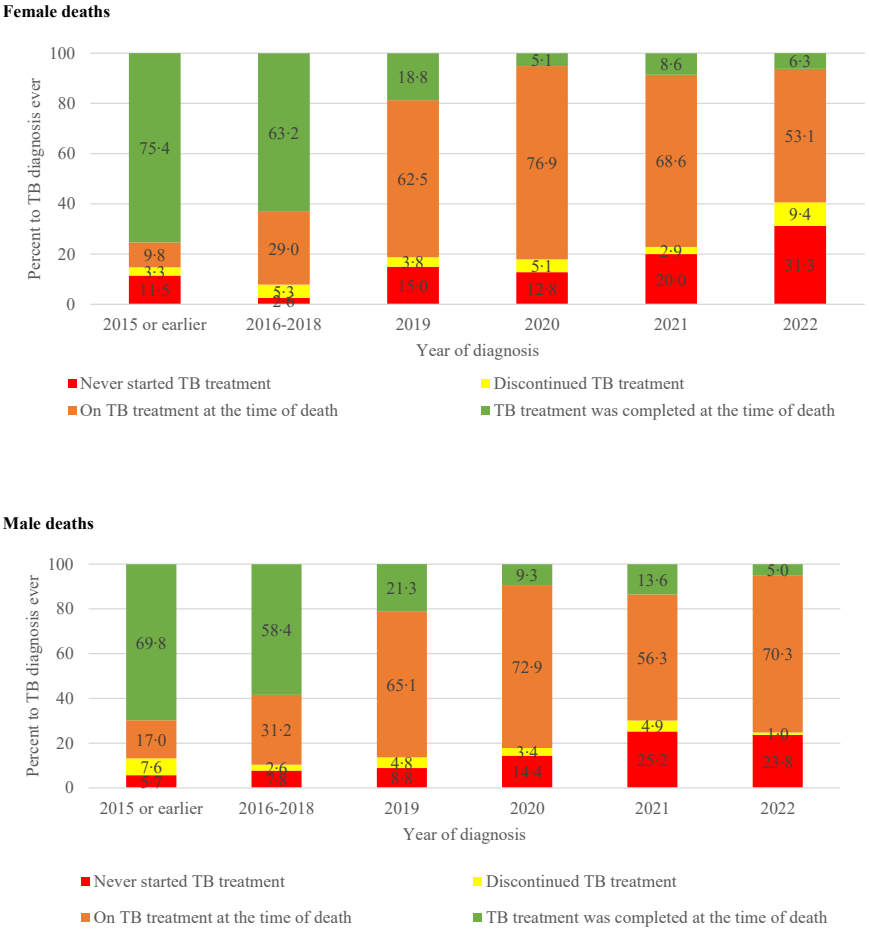

Fig. 1: **Distribution of Tuberculosis (TB) treatment status among deaths who were ever diagnosed with TB, by the year of TB diagnosis.**

Variable	Variable categories	Total deaths reported to have started TB treatment	TB treatment status				Chi-square test of significance, p-value
			Discontinued TB treatment (% of N; 95% CI)	On TB treatment at the time of death (% of N; 95% CI)	TB treatment was completed before death (% of N; 95% CI)	TB treatment started but status unknown (% of N; 95% CI)	
Overall		262	14 (5.3; 3.2–8.8)	144 (55.0; 48.9–60.9)	103 (39.3,33.5–45.4)	1 (0.4; 0.1–2.7)	
Age group (in years)	0–19	11	0	10 (90.9; 46.3–99.1)	1 (9.1; 0.9–53.7)	0	<0.001
	20–39	41	1 (2.4; 0.3–16.6)	28 (68.3; 52.0–81.1)	12 (29.3; 17.0–45.5)	0	
	40–59	81	2 (2.5; 0.6–9.6)	57 (70.4; 59.3–79.4)	22 (27.2; 18.4–38.1)	0	
	60–79	103	8 (7.8; 3.9–14.9)	42 (40.8; 31.6–50.7)	52 (50.5; 40.8–60.2)	1 (1.0; 0.1–6.8)	
	80+	26	3 (11.5; 3.5–32.1)	7 (26.9; 12.7–48.3)	16 (61.5; 40.7–78.9)	0	
Place of residence	Urban	60	3 (5.0; 1.6–14.8)	34 (56.7; 43.6–68.9)	22 (36.7; 25.2–49.9)	1 (1.7; 0.2–11.5)	0.313
	Rural	202	11 (5.4; 3.0–9.6)	110 (54.5; 47.5–61.3)	81 (40.1; 33.5–47.1)	0	
Wealth index quartile	Q1	72	6 (8.3; 3.7–17.6)	49 (68.1; 56.2–78.0)	17 (23.6; 15.0–35.0)	0	0.030
	Q2	74	3 (4.1; 1.3–12.1)	42 (56.8; 45.0–67.8)	29 (39.2; 28.6–51.0)	0	
	Q3	59	1 (1.7; 0.2–11.7)	29 (49.2; 36.4–62.1)	28 (47.5; 34.8–60.5)	1 (1.7; 0.2–11.7)	
	Q4	57	4 (7.0; 2.6–17.7)	24 (42.1; 29.7–55.6)	29 (50.9; 37.7–63.9)	0	
Type of TB	Pulmonary	217	11 (5.1; 2.8–9.0)	113 (52.1; 45.4–58.7)	92 (42.4; 35.9–49.1)	1 (0.5; 0.1–3.2)	0.147
	Extra-pulmonary	45	3 (6.7; 2.1–19.4)	31 (68.9; 53.5–81.0)	11 (24.4; 13.8–39.6)	0	
State	Assam	23	1 (4.3; 0.5–28.4)	7 (30.4; 14.3–53.4)	15 (65.2; 42.6–82.6)	0	0.004
	Gujarat	27	1 (3.7; 0.5–24.5)	14 (51.9; 32.5–70.7)	12 (44.4; 26.2–64.3)	0	
	Haryana	36	3 (8.3; 2.6–23.9)	16 (44.4; 28.6–61.5)	17 (47.2; 31.0–64.0)	0	
	Jharkhand	25	2 (8.0; 1.8–29.1)	13 (52.0; 31.8–71.6)	10 (40.0; 22.0–61.2)	0	
	Kerala	11	0	4 (36.4; 11.7–71.2)	6 (54.5; 22.6–83.2)	1 (9.1; 0.9–53.7)	
	Maharashtra	27	2 (7.4; 1.7–27.2)	13 (48.1; 29.3–67.5)	12 (44.4; 26.2–64.3)	0	
	Odisha	24	0	19 (79.2; 56.8–91.7)	5 (20.8; 8.3–43.2)	0	
	Tamil Nadu	14	0	8 (57.1; 28.4–81.7)	6 (42.9; 18.3–71.6)	0	
	Uttar Pradesh	75	5 (6.7; 2.7–15.3)	50 (66.7; 55.0–76.6)	20 (26.7; 17.7–38.0)	0	

CI denotes confidence interval.

Table 2: **Basic descriptive data by Tuberculosis (TB) treatment status for female deaths with a history of ever diagnosis of TB who were reported to have started TB treatment.**

of death, 264 (35%) had completed TB treatment, and 39 (5.2%) had discontinued TB treatment (Table 3). The proportion of being on TB treatment at the time of death decreased whereas and that of having completed TB treatment increased with increasing age at death for males (p = 0.001). There was a significant difference in the TB treatment pattern for deceased males by state, wealth index quartile, and type of TB (Table 3). Variations were seen in the reasons between females and males for discontinuing TB treatment with the provider-related reasons and Covid-19 lockdown reported as reasons higher for the former than the latter (Appendix Figure 3).

Access to health care during COVID-19 pandemic

A total of 647 (52.3%) deceased were alive during the Covid-19 pandemic of whom 42 (6.5%) had completed TB treatment for both sexes combined. Among the 157 females and 448 males who were alive during the Covid-19 pandemic, 119 (75.8%) females and 341 (76.1%) males were reported to have TB symptoms during COVID-19 pandemic and 108 (68.9%) females and 335 (74.8%) males were on TB treatment at that time. Among those with TB symptoms, 103 (86.5%) females and 294 (86.2%) males had accessed health care for symptoms, 12 (10.1%) females and 35 (10.3%) males did not access health care, and 4 (3.4%) females and 12 (3.5%) males died before accessing health care for TB symptoms, respectively. Deceased who never started TB treatment (6 females and 19 males) and those on TB treatment at the time of death (6 females and 16 males) accounted for the cases who did not seek health care for their symptoms. Some variation was seen in the pattern of reasons for not accessing health care for TB symptoms by treatment status and by sex (Appendix Figure 4). Pandemic social norms and fear of quarantine were reported for the majority, and these were reported more for females than males.

Type of TB treatment provider

Among the 262 and 754 deceased females and males for whom TB treatment was reported, 191 (72.9%) females and 573 (76.0%) males had taken TB treatment from public sector provider, respectively. Overall irrespective of the year of diagnosis, the proportion of private sector provider utilization for TB treatment was similar by

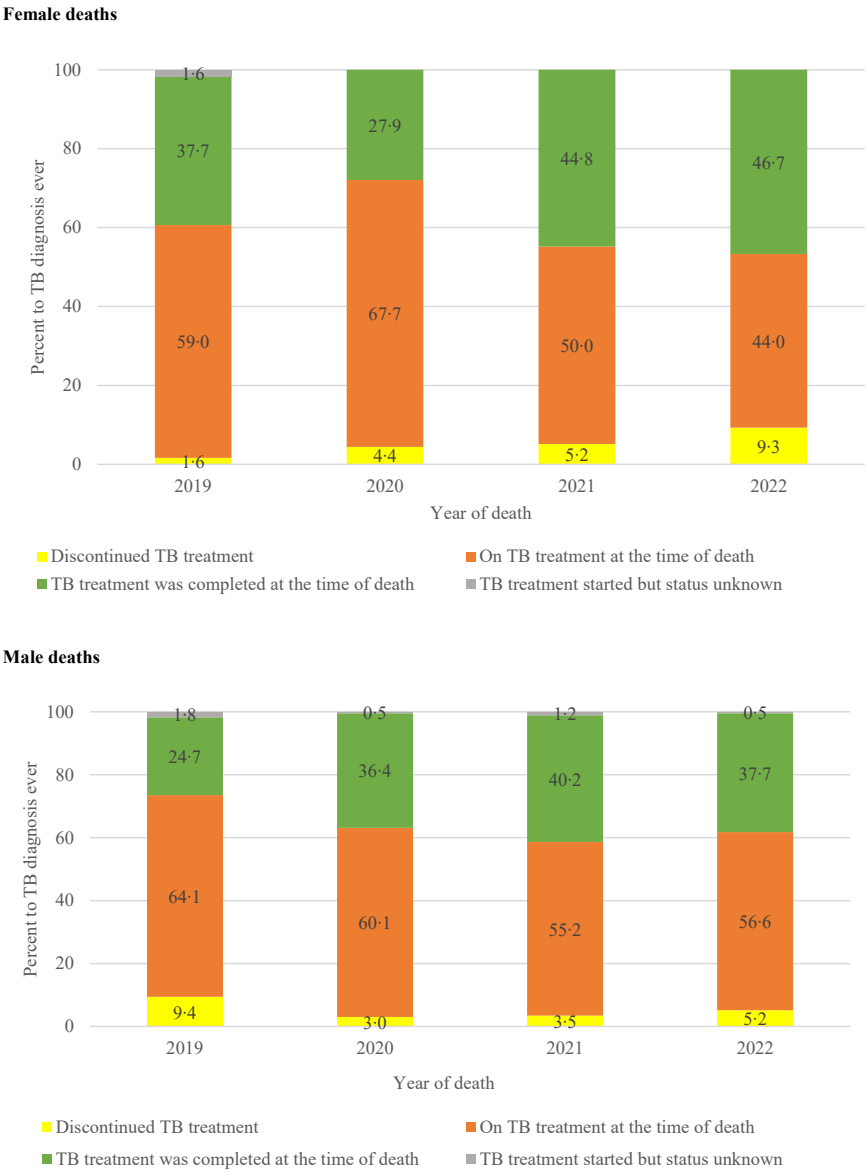

Fig. 2: **Distribution of Tuberculosis (TB) treatment status among deaths who were reported to have started TB treatment, by the year of death.**

females (21.8%) and males (20.2%; Appendix Figure 5). For females, the proportion of private sector utilization was higher though not statistically significant in those diagnosed between the years 2020 and 2022 (29.3%) as compared with those diagnosed in years 2018–2019 (17.9%; p = 0.107). The proportion of private sector provider utilization for TB treatment in urban areas was higher in females (39.3%) as compared with males (23.6%; p = 0.128) though not significant. The proportion of private sector provider utilization for TB treatment increased with increasing wealth index quartile among females in urban area and for males in rural area though not statistically significant (Fig. 3). The utilization of private sector provider by wealth index quartile 4 females and males was higher by 24.1% (95% CI –79.5 to 127.7) and 37.8% (95% CI –18.1 to 93.7%) as compared with those in wealth index quartile 1 in the rural areas, respectively.

The proportion of females on treatment at the time of death was similar between the public sector (56.5%) and private sector (54.4%) provider (Appendix Figure 6). The proportion of females who had discontinued TB treatment was nearly 5 times higher among those with private sector provider (12.3%) as compared with the

Variable	Variable categories	Total deaths reported to have started TB treatment	TB treatment status				Chi-square test of significance, p-value
			Discontinued TB treatment (% of N; 95% CI)	On TB treatment at the time of death (% of N; 95% CI)	TB treatment was completed before death (% of N; 95% CI)	TB treatment started but status unknown (% of N; 95% CI)	
Overall		754	39 (5.2; 3.8–7.0)	444 (58.9; 55.3–62.4)	264 (35.0; 31.7–38.5)	7 (0.9; 0.4–1.9)	
Age group (in years)	0–19	7	0	6 (85.7; 25.7–99.0)	1 (14.3; 1.0–74.3)	0	0.001
	20–39	97	6 (6.2; 2.8–13.3)	73 (75.3; 65.5–82.9)	16 (16.5; 10.3–25.4)	2 (2.1; 0.5–8.1)	
	40–59	263	12 (4.6; 2.6–7.9)	166 (63.1; 57.1–68.8)	84 (31.9; 26.6–37.9)	1 (0.4; 0.1–2.7)	
	60–79	331	18 (5.4; 3.4–8.5)	176 (53.2; 47.8–58.5)	133 (40.2; 35.0–45.6)	4 (1.2; 0.5–3.2)	
	80+	56	3 (5.4; 1.7–15.8)	23 (41.1; 28.7–54.6)	30 (53.6; 40.2–66.5)	0	
Place of residence	Urban	190	14 (7.4; 4.4–12.1)	103 (54.2; 47.0–61.2)	73 (38.4; 31.7–45.6)	0	0.089
	Rural	564	25 (4.4; 3.0–6.5)	341 (60.5; 56.4–64.4)	191 (33.9; 30.1–37.9)	7 (1.2; 0.6–2.6)	
Wealth index quartile	Q1	269	12 (4.5; 2.5–7.7)	179 (66.5; 60.7–72.0)	75 (27.9; 22.8–33.6)	3 (1.1; 0.4–3.4)	0.036
	Q2	172	13 (7.6; 4.4–12.6)	102 (59.3; 51.7–66.5)	56 (32.6; 25.9–40.0)	1 (0.6; 0.1–4.1)	
	Q3	157	6 (3.8; 1.7–8.3)	84 (53.5; 45.6–61.2)	65 (41.4; 33.9–49.3)	2 (1.3; 0.3–5.0)	
	Q4	156	8 (5.1; 2.6–10.0)	79 (50.6; 42.8–58.5)	68 (43.6; 35.9–51.6)	1 (0.6; 0.1–4.5)	
Type of TB	Pulmonary	663	36 (5.4; 3.9–7.4)	401 (60.5; 56.7–64.1)	222 (33.5; 30.0–37.2)	4 (0.6; 0.2–1.6)	0.005
	Extra-pulmonary	91	3 (3.3; 1.0–9.9)	43 (47.3; 37.1–57.7)	42 (46.2; 36.0–56.6)	3 (3.3; 1.0–9.9)	
State	Assam	71	6 (8.5; 3.8–17.9)	33 (46.5; 35.0–58.3)	32 (45.1; 33.7–57.0)	0	<0.001
	Gujarat	52	3 (5.8; 1.8–17.0)	30 (57.7; 43.6–70.7)	19 (36.5; 24.3–50.8)	0	
	Haryana	109	8 (7.3; 3.7–14.1)	50 (45.9; 36.6–55.4)	50 (45.9; 36.6–55.4)	1 (0.9; 0.1–6.4)	
	Jharkhand	113	2 (1.8; 0.4–6.9)	76 (67.3; 58.0–75.4)	35 (31.0; 23.0–40.2)	0	
	Kerala	33	2 (6.1; (1.4–2.6)	7 (21.2; 10.0–39.4)	24 (72.7; 54.3–85.7)	0	
	Maharashtra	82	5 (6.1; 2.5–14.1)	54 (65.9; 54.7–75.5)	21 (25.6; 17.2–36.4)	2 (2.4; 0.6–9.5)	
	Odisha	63	0	35 (55.6; 42.9–67.6)	28 (44.4; 32.4–57.1)	0	
	Tamil Nadu	41	3 (7.3; 2.3–21.2)	24 (58.5; 42.5–73.0)	14 (34.1; 20.9–50.4)	0	
	Uttar Pradesh	190	10 (5.3; 2.8–9.6)	135 (71.1; 64.1–77.1)	41 (21.6; 16.3–28.1)	4 (2.1; 0.8–5.5)	

CI denotes confidence interval.

Table 3: **Basic descriptive data by Tuberculosis (TB) treatment status for male deaths with a history of ever diagnosis of TB who were reported to have started TB treatment.**

public sector provider (2.6%; z test p = 0.003). There was no significant difference in treatment status by type of treatment provider for males (Appendix Figure 6).

Survival post TB diagnosis

The mean age at death and the mean gap between TB diagnosis and death in years by select variables is shown

Fig. 3: **Distribution of private sector Tuberculosis (TB) treatment provider among deaths who had taken treatment for TB, by place of residence and wealth index quartile.**

in Table 4. The mean age at death was 56.8 years (95% CI 54.6–58.9) for females and 57.3 years (95% CI 56.2–58.3) for males. The mean age at death was significantly lower for males belonging to wealth index quartiles 1 or 2 as compared with those in quartile 4, and for those who never started TB treatment or were on TB treatment at the time of death as compared with those who had completed TB treatment (Table 4).

Overall, the mean gap between TB diagnosis and death in years was not significantly different between females (5.7 years; 95% CI 4.5–6.9) and males (4.4 years; 95% CI 3.9–5.0). The highest mean gap was documented for those who had completed TB treatment at the time of death, and was similar for females (12.8 years; 95% CI 10.0–15.5) and males (10 years; 95% CI 8.5–11.4). Similarly, the least mean gap was documented for those who had discontinued TB treatment for both females (5.5 years; 95% CI 0–12.4) and males (6.7 years; 95% CI 3.4–10.0).

The mean gap between TB diagnosis and death ranged from <1 to 60 years for females. A total of 225 (76.5%) females survived for 5 years or less, 16 (5.4%) for >5–9 years, and 53 (18.0%) for 10 years or more post TB diagnosis. There was no significant difference in mean gap by place of residence, wealth index quartile, and year of death for females. The highest mean gap was documented in the state of Kerala for females (9.3 years) but was not significantly different from the other states. Survival in years post TB diagnosis ranged from <1 to 62 years for males. A total of 660 (78.8%) males survived for 5 years or less, 45 (5.4%) for >5–9 years, and 133 (15.9%) for 10 years or more post TB diagnosis. The mean gap between TB diagnosis and death for males was significantly higher in those belonging to the wealth index quartile 4 (6.6 years; 95% CI 4.8–8.5) as compared with those belonging to the wealth index quartile 1 (3.3 years; 95% CI 2.6–4.0). The highest mean gap for males was also

Variable	Variable categories	Mean age at death in years (95% CI)		Mean gap between TB diagnosis and death in years (95% CI)	
		Female	Male	Female	Male
Overall		56.8 (54.6–58.9)	57.3 (56.2–58.3)	5.7 (4.5–6.9)	4.4 (3.9–5.0)
Place of residence	Urban	57.0 (51.8–62.2)	56.5 (54.4–58.7)	6.5 (3.5–9.5)	5.5 (4.2–6.9)
	Rural	56.7 (54.4–59.1)	57.5 (56.3–58.7)	5.5 (4.2–6.8)	4.1 (3.4–4.7)
Wealth index quartile	Q1	52.6 (49.2–56.0)	54.0 (52.2–55.7)	4.4 (2.6–6.1)	3.3 (2.6–4.0)
	Q2	54.1 (49.9–58.4)	57.1 (55.0–59.2)	3.5 (1.9–5.2)	3.9 (3.0–4.9)
	Q3	62.8 (58.3–67.3)	57.5 (55.2–59.9)	6.9 (4.0–9.9)	5.0 (3.6–6.3)
	Q4	60.0 (54.9–65.1)	63.3 (61.1–65.5)	9.3 (6.0–12.7)	6.6 (4.8–8.5)
Year of death	2019	54.3 (49.5–59.1)	56.5 (54.3–58.6)	6.1 (3.4–8.7)	4.4 (3.1–5.7)
	2020	55.4 (51.3–59.4)	57.1 (55.0–59.2)	3.7 (2.1–5.4)	4.4 (3.2–5.6)
	2021	59.9 (56.4–63.3)	56.8 (54.6–59.1)	7.3 (4.3–10.3)	4.8 (3.6–6.0)
	2022	57.4 (52.8–61.9)	58.4 (56.5–60.4)	5.9 (3.7–8.0)	4.2 (3.2–5.2)
Type of TB	Pulmonary	57.7 (55.3–60.0)	57.2 (56.1–58.4)	5.9 (4.6–7.2)	4.1 (3.5–4.7)
	Extra-pulmonary	52.7 (47.6–57.7)	57.6 (54.7–60.4)	4.8 (1.8–7.8)	6.6 (4.5–8.7)
State	Assam	56.6 (50.7–62.5)	58.0 (55.1–60.9)	4.5 (1.7–7.3)	4.0 (2.6–5.4)
	Gujarat	54.6 (46.7–62.6)	53.9 (50.3–57.6)	6.8 (2.9–10.7)	3.9 (2.0–5.8)
	Haryana	62.9 (57.0–68.7)	59.1 (56.1–62.0)	7.4 (3.9–11.0)	5.8 (3.7–7.8)
	Jharkhand	56.0 (49.6–62.4)	52.9 (50.1–55.6)	6.1 (2.9–9.3)	3.7 (2.3–5.1)
	Kerala	67.3 (56.6–78.0)	68.2 (65.0–71.4)	9.3 (0–22.0)	10.0 (5.7–14.4)
	Maharashtra	57.1 (49.8–64.3)	55.0 (51.5–58.5)	6.4 (1.6–11.1)	4.2 (2.6–5.8)
	Odisha	53.7 (48.3–59.1)	59.5 (55.6–63.5)	3.3 (0–7.7)	6.2 (4.3–8.1)
	Tamil Nadu	60.9 (54.1–67.6)	60.6 (57.2–64.1)	8.8 (2.3–15.3)	3.7 (1.9–5.5)
	Uttar Pradesh	53.4 (49.1–57.7)	56.9 (54.8–59.0)	4.5 (2.7–6.4)	3.2 (2.2–4.2)
TB treatment status	Never started TB treatment	57.2 (51.1–63.3)	55.9 (52.3–59.5)	3.6 (1.4–5.8)	1.7 (0.8–2.6)
	Discontinued TB treatment	67.6 (56.3–78.8)	57.5 (52.0–63.0)	5.5 (0–12.4)	6.7 (3.4–10.0)
	On TB treatment at the time of death	51.0 (47.9–54.1)	54.8 (53.3–56.3)	1.7 (0.9–2.5)	1.7 (1.3–2.2)
	TB treatment completed before death	62.6 (59.3–66.0)	61.8 (60.1–63.6)	12.8 (10.0–15.5)	10.0 (8.5–11.4)
	TB treatment started but status unknown	68.0	57.3 (44.5–70.1)	5.2 (0–11.0)	3.8 (0–10.3)
	Do not know about TB treatment	59.9 (50.9–68.8)	58.3 (54.4–62.2)	–	6.2 (2.5–10.0)

CI denotes confidence interval.

Table 4: **Average age at death and gap between Tuberculosis (TB) diagnosis and death in years among deaths who were reported to have been diagnosed with TB ever by select variables.**

in Kerala state (10 years; 95% CI 5.7–14.4), which was significantly higher than in Assam (4.0 years; 95% CI 2.6–5.4), Jharkhand (3.7 years; 95% CI 2.3–5.1), Tamil Nadu (3.7 years; 95% CI 1.9–5.5), and Uttar Pradesh (3.2 years; 95% CI 2.2–4.2).

Discussion

The sex-disaggregated findings on TB coverage by wealth index, place of residence, state, and type of TB treatment provider from a nationally representative sample of deaths in India allows for a more recent understanding of gender issues that may be needed to effectively address TB in India.

The history of TB diagnosis was significantly higher in males than in females though variations were seen by the age group for the two sexes.[2,9,18] Overall, TB treatment coverage was fairly high at over 80% for both females and males with not much gender-differential seen in TB treatment coverage. However, by the year of diagnosis, there was a 57%–70% increase in not starting TB treatment among those diagnosed with TB in 2021/22 as compared with 2020/19, and a significant drop in TB treatment coverage for males and of borderline significance for females diagnosed in 2021/22 as compared with 2019. It is now well established that the COVID-19 pandemic has had and continues to have damaging impact on access to TB treatment slowing down the progress made up to 2019 with the global TB targets being off track.[26] Previously published modelled estimates indicate a drop from 88% to 25% in TB treatment initiation as a result of stock-outs and supply interruptions in India during the COVID-19 lockdown.[15,27] Data from this study also indicate a drop in treatment coverage but potentially for both males and females. However, this study does not allow us to comment on the extent of reduction in TB notification rate as a result of COVID-19 pandemic in India or what proportion of people diagnosed with TB in 2021/22 were part of the backlog of people who developed TB in previous years whose diagnosis was delayed by COVID-related disruptions.[1] Important to note is that India is among the two countries that have made the biggest contributions to the global rebound in the reported number of people newly diagnosed with TB in 2022 between 2021 and 2022.[27] Extrapolating this trend, it is likely that the TB treatment initiation has also had a rebound in India since the COVID-19 pandemic. Additionally, most deceased who were reported to have TB symptoms during the COVID-19 pandemic in this study also accessed health care during that time with no significant gender-differentials reported in this access. We are unable to comment on whether the health care access was sought for TB or for COVID-19 given the similarity of symptoms but this finding suggests an increase in health seeking behaviour during the pandemic.[28–32]

The public sector was the predominant TB treatment provider for both females and males in this study, however, distinct variations were seen when disaggregated by wealth index, place of residence, and year of death. A higher preference for the private sector in this study was reported for females in the urban areas, and its higher utilisation both by females and males belonging to the highest wealth index quartile. Increase in the private sector utilisation was seen for females diagnosed with TB in 2020–22 as compared with 2016–19 but not for males. The finding of preference for the private sector for TB services among deceased females is similar to that reported in India among the alive which is due to various reasons, including stigma and gendered health care services poor at addressing the needs of women.[9,33–35] Our study adds to the literature indicating that it is likely that COVID-19 further increased utilisation of private sector as the public sector was occupied with COVID-19 pandemic services.[36,37] Additionally in this study, more females in the private sector discontinued TB treatment as compared with those in the public sector. Over the last five years, significant progress has been made under the NTEP to expand the coverage of and to involve more private sector providers in TB care.[2] The National TB prevalence survey 2019–21 estimated that half of the people with TB symptoms sought care from the private sector in India but with considerable variations across the states. With a large number of people with TB being managed by the private sector, there are concerns about the suboptimal quality of care; lack of systems for ensuring treatment adherence, patient support, and contact screening and investigations; and high lost to follow-up rate, eventually raising the risk of drug resistance to TB.[38–41] These data suggest that the gendered aspects of utilisation of private sector during the pandemic needs further exploration as it would be relevant for other future public health emergencies on national efforts to control TB; and also strengthening of gender lens in the service delivery in private sector for TB services in particular due to the finding of increased loss to follow-up among the deceased women.[9,33]

The barriers for not starting or discontinuing TB treatment were largely similar for deceased females and males in our study, and are similar to those reported previously among alive population.[5,9,12,33,42] The continued reporting of similar barriers over time across the various studies and among the deceased indicate that these barriers have to be addressed specifically to increase the uptake and adherence of TB treatment. Even though the types of barriers cited were similar for females and males, it is important to note that gender has a marked effect on TB epidemiology across the life course, as females and males follow different pathways to seek diagnosis and treatment.[9,33,43] For females, gender roles can also negatively affect health seeking

behaviour, treatment adherence and experiences of stigma, hence, interventions to reduce diagnostic delay and improve engagement with care for males are likely to look quite different to those suitable for females.[3,9,33,44,45] It is noted that healthcare services dominated by a traditionally masculine, authoritarian approach may be unable to adequately meet the needs of men, and may be even poorer at addressing the needs of women.[9,33,46] Therefore, as also indicated in the national gender-responsive approach to TB in India, gender-responsive development of policy and services is required both with regard to the gender-related needs of patients, and the gendered behaviour of service providers to systematically and adequately address the barriers towards the uptake and adherence of TB treatment.[7,9,33,46]

The mean age at death among those diagnosed with TB was still lower than the life expectancy at birth of 70.8 years in India in 2019,[47] highlighting the disparity in years of potential life lost for those suffering with TB. Though the mean age at death was similar between females and males, there were significant differences for mean age at death by wealth index quartile and treatment status for males. Interpretation of the mean gap between TB diagnosis and death should be done with caution as this is reported only from those who have died, and hence could be an underestimation of actual mean survival post TB diagnosis. With this mean gap being the highest for those who had completed TB treatment and the least for those who had discontinued TB treatment, it further substantiates the efforts of TB program in TB case finding, initiating TB treatment and facilitating adherence to TB treatment.[2] Furthermore, we did not find gender differentials in the mean gap, but distinct differences were seen for males by wealth index and state. This disproportionate risk of premature mortality in those with TB can be alleviated through the delivery of better and more accessible targeted services, and through engagement with TB survivors for advocacy. The NTEP strategy 2025 envisages to actively engage with and work through the community for ensuring community driven response to end TB by 2025.[2] These data highlighting the lower age at death and better mean survival on completing TB treatment can be used to tailor specific messages and interventions for community engagement, in particular to target vulnerable populations.[2]

Use of sex-disaggregated data at various stages of the TB care cascade is a key resource for the design and evaluation of gender-responsive programming.[7,8] Application of gender lens is recommended for the NTEP as part of the National framework for a gender-responsive approach to TB.[9,33] Importantly, the key indicators for the priority programmatic areas and the targets indicated in NSP 2020–25 are not sex-disaggregated.[2] It would be imperative for the NSP and NTEP to generate and monitor sex-disaggregated data including among the deceased to ensure that the objectives of the gender-responsive approach to TB are met.

The major strength of this study is that it is a representative sample of deaths in India between 2019 and 2022, which is a value-add as this population is typically not covered in routine service coverage surveys. The last nationally representative survey of deaths in India was undertaken for deaths in years 1998–2014.[48] In addition to good participation, data on TB cases diagnosed from 1960s to 2022 provide a reasonable understanding of trend over time. The limitations of the study include possible recall bias in terms of reporting of TB diagnosis or treatment status, in particular for those who were diagnosed of TB much earlier and if treatment was taken from various providers over a period of time. There could also be under-reporting of TB diagnosis due to stigma associated with TB.

We have utilized a mortality survey designed to estimate TB mortality to capture sex-disaggregated TB treatment coverage and outcomes among the deceased. The majority of the data on gender-specific issues in TB programming is available for those who are currently on treatment or who were lost to follow-up. This study offers a unique perspective in understanding gender-specific issues among those who have died, a population missed in most assessments. We believe that this approach complements the insights available from TB program data, thereby, leading to a more nuanced and comprehensive understanding of TB services and outcomes at the population level. Though triangulation of the data from this survey with other data sources was beyond the scope for this analysis, such a triangulation can benefit programmatic action and decision-making especially in high TB burden countries to address TB treatment coverage and improve treatment outcomes.

In conclusion, India is committed to achieve the Sustainable Development Goals related to ending TB by 2025, five years ahead of the global target. The sex-disaggregated findings from this nationally representative sample of deaths are a value-add to effectively address TB in India as majority of such understanding towards gender-responsive strategies is available from those who are alive.

Contributors

RD, LD, GAK, VR, BV, AS and RR conceptualised the study. RD, LD, GAK, KS, VC, KR and RR designed the study methods. RD wrote the first draft of the manuscript. GAK, SSPD and SG performed the data analysis with contributions from RD, MA, MM and LD. All authors contributed to the interpretation and agreed with the final version of the paper. GAK, SSPD, RD and RR verified the data underlying this study. All the named authors have contributed to the interpretation, agreed with the final version of the paper, accept responsibility to submit for publication. RD and RR are the guarantors for the overall content of the paper.

Data sharing statement

All data and materials relevant to the study are included in the article or uploaded as supplementary information.

Declaration of interests

VR and YNP are employees of TIFA India, and AS and BV are employees of USAID/India. Other authors declare no completing interests.

Acknowledgements

The authors acknowledge the support of staff of the State and District Tuberculosis Units in the nine states for facilitation of the field work and support in data collection.

Funding: This study is made possible by the support of the American people through the United States Agency for International Development (USAID). The contents do not necessarily reflect the views of USAID or the United States Government. The funder had no role in study design, data collection, data analysis, data interpretation, or writing of the manuscript.

Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.lansea.2024.100448.

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