

Navigating the Stigma Terrain: Insights from Individuals with Pulmonary Tuberculosis and Healthcare Delays in India

Mohd Kaif¹, Qurratul Ain Ali², Wajahat Ali³

^{1,2}Department of Social Work Aligarh Muslim University, Aligarh, 202002, India,

³Department of Statistics and Operations Research, Aligarh Muslim University, Aligarh, 202002, India,

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Abstract:

Pulmonary tuberculosis (PTB) is a significant health issue in India, with millions of new cases reported annually. The persistence of PTB is attributed to factors such as poverty, overcrowding, and limited healthcare access. Comprehensive strategies are needed to address this public health concern, as efforts to control PTB face challenges such as drug resistance and social stigma.

This study investigates the stigmatization experienced by individuals undergoing treatment for pulmonary tuberculosis (PTB) in Aligarh, Uttar Pradesh, India. A sample of 99 participants from Jawaharlal Nehru Medical College, Aligarh Muslim University (AMU), was selected using stratified and simple random sampling techniques. Statistical analysis comprised of Kruskal-Wallis tests, regression analysis, and goodness-of-fit tests. The regression analysis identified several significant stigmatization predictors, including age, family size, rural residence, and access to TB healthcare services. The results revealed gender differences in on-time/delay behaviors, with females exhibiting higher median ranks, study also identified that, the stigma is relatively higher for the married group, similarly, illiterates experience the most stigma and rural individuals perceive more stigma compared to urban individuals means patient belongs to the rural areas where the medical facility is at distance feel hesitant to seek the treatment and have fear for the disease as if the community will ostracized by their community after knowing their TB status. This stigma acts as a barrier to healthcare access, resulted delays in seeking medical assistance, leading to diagnostic delays and worsening health issues. Targeted interventions are crucial in addressing TB risk factors, especially among the most vulnerable population.

Keywords: Tuberculosis, Pulmonary tuberculosis, stigmatization,

Introduction:

Pulmonary tuberculosis (PTB) is a significant health issue in India, with millions of new cases reported annually. The persistence of PTB is attributed to factors such as poverty, overcrowding, and limited healthcare access. Comprehensive strategies are needed to address this public health concern, as efforts to

control PTB face challenges such as drug resistance and social stigma (Aggarwal, 2019; Chawla et al., 2021). This communicable disease, caused by Mycobacterium tuberculosis, primarily impacts the respiratory system, particularly the lungs, and remains a persistent concern in the Indian subcontinent

(Singh et al., 2022). When it affects the lungs, it's called pulmonary TB (PTB). TB outside of the lung is called extrapulmonary TB.

India, with its vast and diverse population, grapples with a noteworthy burden of tuberculosis (TB), consistently reporting a high incidence of cases that significantly contribute to the global TB challenge (Dye et al., 1999). The prevalence of PTB is intricately linked with socio-economic determinants, such as poverty, substandard housing, and limited healthcare accessibility (Nidoi et al., 2021). Vulnerable populations residing in densely populated urban areas and impoverished rural communities face elevated risks of TB transmission and encounter delays in accessing healthcare services (Nyasulu et al., 2016). Despite strides in medical science in India, challenges persist in the prompt diagnosis and treatment of PTB, with issues like diagnostic delays, inadequate healthcare infrastructure, and the enduring stigma associated with TB complicating disease management (Harries & Kumar, 2018; Getnet et al., 2020). The prevalence of PTB is further exacerbated by its coexistence with other health issues, such as malnutrition and HIV, adding layers of complexity to the healthcare landscape (Osman, 2021). Notably, the stigma attached to TB plays a substantial role in impeding timely healthcare-seeking (Alema et al., 2019).

There are strong stigma prevailed in Indian society for the TB and these stigma of tuberculosis (TB) poses a significant challenge to TB control because it leads to delayed diagnosis and non-adherence (Thomas & Stephen, 2021).

As many study suggested that the Stigma is directly related to the delay in treatment. Keeping in mind the stigma associated with the TB, this study investigate the nature (like gender, family size, age, literacy, marital status, Rural urban community etc.) of the population with more delays in treatment and follow-ups because of the stigma associated with this disease.

Global Burden of Pulmonary Tuberculosis:

PTB imposes a significant global burden, with an estimated 9.9 million new cases worldwide in 2020, predominantly affecting the lungs. TB remains a leading cause of mortality, with 1.5 million deaths annually, primarily in low- and middle-income countries. Challenges include drug resistance, limited access to diagnostics and treatment, and socioeconomic factors exacerbating its spread. Efforts to combat TB involve strengthening healthcare systems, improving access to care, and investing in research for better diagnostics and treatments.

India alone accounts for about a quarter of the global TB burden with an estimated incidence of 2,590,000 TB cases and 124,000 MDR/RR-TB cases as of 2020. TB kills approximately 480,000 Indians every year, i.e., more than 1,400 every day. India also has more than a million 'missing' cases every year that are either not notified or remain undiagnosed or unaccountably and inadequately diagnosed and treated in the private sector. (India Stop TB Partnership, 2021)

Pattern and Factors in TB Incidence:

Highest proportion of TB disease and deaths attributable to *smoking among high-TB burden countries*. This underscores the urgency of implementing tobacco control measures in countries with a high TB burden to address both TB incidence and mortality. (Amere et al., 2018)

Sarkar et al., (2017) examined the epidemiology, clinical features, mechanisms, and management of chronic obstructive pulmonary disease linked to TB. Emphasized the significance of risk factors beyond smoking, including *exposure to biomass fuel, childhood lower-respiratory tract infections, chronic asthma, outdoor air pollution, and a previous history of PTB in the onset of chronic obstructive pulmonary disease*.

Individuals often defer seeking medical assistance because of perceived social exclusion and bias (Marrone & Golowka, 1999). This delay not only jeopardizes individual health but also perpetuates the spread of TB within communities (Mason et al.,

2016). So spread of this infection is because of the dealy and associated stigma in seeking health checkups/treatment.

Nezenega (2020), identified more tha factors that influence adherence to TB treatment in Ethiopia, demonstrating that it is a complex problem that is affected by the interplay of multiple factors.

They have found major additional factors for TB medication non-adherence or default or loss to follow up. These were

- social support from families and neighbors such as food support, reminders, and encouragement;
- being busy with work;
- being away from home;
- perceived and experienced stigma and discrimination;
- beliefs such as perceived wellness/cure,
- perceived risk;
- economic constraints for having adequate food and medication cost other than anti-TB medication;
- poor healthcare provider-patient relationships such as:
 - communication gaps,
 - disrespecting patients,
 - quality healthcare service, and
 - patient satisfaction,
- health information/education,
- pill burden,
- the persistence of symptoms after treatment initiation; and
- use of substances.

Healthcare managers, providers, and researchers need to address these underlying factors when they design and implement adherence interventions.

The Intersection of Stigma and Pulmonary Tuberculosis in India:

In the world of health-related stigma, people often face discrimination, stereotypes, and bias, making it hard for them to get the healthcare they need (Pescosolido & Martin, 2015; Carvalho et al., 2021). Stigma acts as a barrier to healthcare access (Bayer, 2008), causing people to delay seeking

medical assistance, leading to diagnostic delays and worsening health issues (Stangl et al., 2019). This is especially true for conditions already stigmatized by society, as individuals struggle to manage their health while navigating societal judgment (Madsen et al., 2023), as in the case of TB. In India, stigma intersects with PTB exacerbating the disease burden. PTB carries social stigma due to misconceptions about its transmission and association with poverty. Stigmatization can lead to delayed diagnosis, treatment non-compliance, and social isolation, hindering public health efforts. People facing stigma may hesitate to disclose their health conditions to healthcare providers, fearing judgment and discrimination (Modak et al., 2023). This reluctance can hinder accurate diagnoses, impede the development of effective treatment plans, and create an environment where people are not fully honest about their health concerns. Addressing healthcare-related stigma requires a comprehensive approach (Ramos et al., 2023). Public health campaigns and advocacy efforts are crucial in reshaping societal attitudes and empowering individuals to seek medical care without fear of judgment (Bayer, 2008). This need to understand the patient's perspective of health seeking behavior, particularly patients with the TB.

The quality of healthcare is one of the paramount factor intrinsically tied to its alignment with patient perspectives (Sofaer & Firminger, 2005). By acknowledging patients' subjective experiences within the healthcare system, practitioners can identify areas for improvement, enhance communication, and elevate overall care quality (Motamedi et al., 2021). This is particularly crucial in addressing healthcare disparities and ensuring equitable access to services for diverse patient populations. Trust forms the cornerstone of the patient-provider relationship (Natale-Pereira et al., 2011). Understanding patient perspectives fosters trust and rapport, creating an environment where patients feel valued and respected (Dayton & Henriksen, 2007; Pratt et al., 2021).

Methodology:

In this study, researcher used semi-structured questionnaires, ensuring validity through a rigorous back-translation process. A sample of 99 PTB patients from the different Rural and Urban location/centers governed by Jawaharlal Nehru Medical College, AMU, was selected using simple random sampling techniques. Additionally, in-depth interviews were conducted with 25 individuals. Statistical analyses comprised Kruskal-Wallis tests to explore gender differences in on-time versus delayed behavior. Furthermore, regression analysis was employed to identify predictors of stigmatization, with model robustness evaluated through goodness-of-fit tests. Diagnostic analyses were undertaken to identify any anomalous observations necessitating further investigation. This methodology ensured a comprehensive exploration of the intersection between stigma and PTB in the Indian context, enhancing the validity and reliability of our findings.

Data collection:

A survey instrument was designed based on insights from an extensive literature review and used to collect quantitative data systematically. A semi-structured questionnaire was also crafted based on the literature review and inquiries emerging during interviews to prompt participants for detailed or concealed information. The initial drafts of both questionnaires were prepared in English and later translated into Hindi. The translated versions underwent a back-translation verification process overseen by three bilingual experts. An original set of questions about TB stigmatization from a patient perspective, including 12 items, was previously validated with Cronbach's alpha ranging from 0.88 to 0.91 (Kipp et al., 2011).

Additionally, a series of questions translated into Hindi were validated, with Cronbach's alpha ranging from 0.86 to 0.90 subsequently, all participants were provided with the Hindi questionnaire and asked to record their responses on a *four-level Likert scale: strongly disagree (1), disagree (2), agree (3), and strongly agree (4).*

Higher scores, which were obtained by summing up the scores from each of the 12 Likert items, indicated higher levels of perceived stigmatization. This extensive investigation utilized a combination of research methods and included individuals, some below the age of 18, who had been undergoing treatment for PTB for over a month. The study concentrated on patients receiving care at Jawaharlal Nehru Medical College, AMU, and its various locations in rural and urban settings in Aligarh, Uttar Pradesh, India. It was determined through a formula designed to estimate the sample size in a cross-sectional analytical study involving a finite population (Feldman & McKinlay, 1994; Nundy et al., 2022). Ninety nine participants were sampled from various centers affiliated with Jawaharlal Nehru Medical College, AMU.

Participants were selected through simple random sampling techniques to engage in questionnaire surveys. Data collection was concluded when no new themes emerged, indicating data saturation. (Guest et al., 2020) interviews were conducted privately after establishing rapport with patients waiting for their appointments.

Result Findings

Table 1. Kruskal-Wallis Test: health seeking delay versus Gender

Gende r	N	Media n	Mean Ran k	Z- Valu e
F	6 1	1	53.6	1.58
M	3 8	0	44.2	-1.58
Overall	9 9		50.0	

Table 1 presents the results of a Kruskal-Wallis Test assessing the relationship between the variable "On time/delay" and gender. The table includes three distinct categories: "F" (presumably representing females), "M" (presumably

representing males), and "Overall" (the combined data for both genders). For the female group (F), consisting of 61 observations, the median value of the "On time/delay" variable is 1, and the mean rank is 53.6. The Z-Value of 1.58 suggests a positive deviation from the mean, indicating a potential difference in the distribution of on-time/delay values for females. Conversely, the male group (M), comprising 38 observations, exhibits a median of 0 and a mean rank of 44.2, with a corresponding Z-Value of -1.58, implying a negative deviation. The Overall row provides a summary, indicating a total of 99 observations and a median rank of 50.0. The Z-values for both gender groups suggest a divergence in the distribution of on-time/delay values, warranting further examination to determine the statistical significance of these differences.

The finding indicates that health seeking delay associated with pulmonary tuberculosis (PTB) manifests differently between genders. While both

males and females were delay in seeking TB treatment, and have some stigma associated with the PTB, the data suggests that females exhibit higher health seeking delay. Therefore, while stigma affects both genders, females may experience relatively higher levels of stigma associated with PTB (as general health seeking behavior of females are poorer so in this case as well).

After the detailed discussions with the respondents, it has been identified that majority of them were afraid and were so stigmatized in coming to seek checkups and treatment for the PTB, according to them, in their community there are many stigma associated with this disease. They were afraid that they may not be seen by any from their community while receiving treatment. Moreover, it has been further identified that the patients who shown more delay were actually more stigmatized and have fear for the isolation and community ostracized

. Regression equation

P (1)	=	$\exp(Y') / (1 + \exp(Y'))$
Y'	=	88 + 0.0 gender_F 32.6 gender_M + 0.0 Age_8 - 99 Age_12 - 1 Age_13 + 16 Age_14 - 30 Age_15 + 28 Age_16 + 81 Age_17 + 16 Age_18 - 42 Age_19 + 13 Age_20 + 13 Age_22 + 88 Age_23 - 61 Age_24 + 44 Age_25 - 32 Age_26 + 123 Age_27 + 13 Age_28 - 24 Age_29 + 12 Age_30 - 62 Age_31 - 52 Age_32 - 3 Age_33 + 85 Age_34 + 36 Age_35 + 40 Age_37 - 83 Age_38 + 58 Age_39 + 8 Age_40 + 48 Age_42 + 100 Age_43 + 41 Age_44 - 14 Age_45 + 39 Age_46 + 85 Age_50 - 83 Age_51 + 88 Age_52 + 63 Age_53 + 44 Age_54 - 22 Age_55 - 49 Age_58 - 25 Age_60 - 59 Age_70 + 27 Age_71 + 29 Age_72 + 117 Age_85 + 0.0 Marital status_M - 99 Marital status_married - 67 Marital status_unmarried - 156 Marital status_widowed + 0.0 Education level_graduate + 25 Education level_illiterate + 18 Education level_primary - 11 Education level_secondary - 86 Education level_under graduate + 0.0 family size_2 + 91.7 family size_3 + 33.2 family size_4 + 44.4 family size_5 + 21.7 family size_6 - 12 family size_7 + 35.2 family size_8 - 51.0 family size_9 + 67 family size_10 + 40 family size_11 + 0.0 Residence location type_rural - 14 Residence location type_rural - 21.1 Residence location type_urban + 0.0 Are healthcare services for TB_no - 44.4 Are healthcare services for TB_yes + 9 Are healthcare services for TB_yes

This regression equation predicts the probability (P) of an event (on-time/delay) based on various predictor variables. It includes coefficients for each predictor variable, such as gender, age, marital status, education level, family size, residence

location type, and access to TB healthcare services. The equation calculates the predicted probability using a logistic function, allowing for the assessment of the impact of each predictor on the likelihood of the event occurring.

Table 4. Coefficients

Term	Coef	SE Coef	Z-Value	P-Value	VIF
Constant	88	458	0.19	0.848	
Gender					
M	-32.6	28.2	-1.15	0.248	9.12
Age					
12	-99	349	-0.28	0.777	8.50
13	-1	328	-0.00	0.997	23.39
14	16	346	0.05	0.964	8.37
15	-30	3849	-0.01	0.994	1.01
16	28	319	0.09	0.930	1408.30
17	81	21421	0.00	0.997	1.00
18	16	330	0.05	0.962	83.45
19	-42	327	-0.13	0.899	77.78
20	13	324	0.04	0.967	347.90
22	13	324	0.04	0.968	93.38
23	88	180	0.49	0.624	4.52
24	-61	329	-0.19	0.853	25.52
25	44	323	0.14	0.891	407.11
26	-32	342	-0.09	0.924	8.19
27	123	332	0.37	0.710	30.95
28	13	320	0.04	0.967	1769.37
29	-24	323	-0.07	0.941	257.32
30	12	322	0.04	0.970	538.31
31	-62	323	-0.19	0.848	231.29
32	-52	707111	-0.00	1.000	35003920.56
33	-3	335	-0.01	0.992	12.31
34	85	332	0.25	0.799	31.76
35	36	321	0.11	0.910	1038.08
37	40	330	0.12	0.903	25.40
38	-83	344	-0.24	0.808	16.57
39	58	326	0.18	0.858	774.18
40	8	346	0.02	0.981	8.38
42	48	345	0.14	0.890	8.35
43	100	387	0.26	0.797	10.49
44	41	344	0.12	0.906	7.62
45	-14	328	-0.04	0.967	26.77

46	39	344	0.11	0.911	8.30
50	85	332	0.25	0.799	23.86
51	-83	344	-0.24	0.808	8.29
52	88	180	0.49	0.624	4.52
53	63	330	0.19	0.848	22.11
54	44	176	0.25	0.803	2.16
55	-22	322	-0.07	0.945	83.97
58	-49	707111	-0.00	1.000	35003920.51
60	-25	343	-0.07	0.942	8.24
70	-59	347	-0.17	0.864	8.44
71	27	343	0.08	0.937	8.26
72	29	346	0.09	0.932	8.39
85	117	707111	0.00	1.000	35003922.33
Marital status					
Married	-99	183	-0.54	0.590	639.30
Unmarried	-67	181	-0.37	0.710	619.79
Widowed	-156	472	-0.33	0.741	15.58
Education level					
Illiterate	25	266	0.09	0.926	1511.73
Primary	18	272	0.07	0.947	598.16
Secondary	-11	264	-0.04	0.968	1451.40
Undergraduate	-86	707111	-0.00	1.000	69950636.11
family size					
3	91.7	87.4	1.05	0.294	15.14
4	33.2	67.0	0.49	0.621	81.80
5	44.4	71.6	0.62	0.535	78.49
6	21.7	66.4	0.33	0.744	64.23
7	-12	300	-0.04	0.969	38.69
8	35.2	45.0	0.78	0.435	15.65
9	-51.0	43.9	-1.16	0.245	12.28
10	67	707111	0.00	1.000	1.04840E+08
11	40	115	0.35	0.729	2.41
Residence location type					
Rural	-14	345	-0.04	0.967	16.61
Urban	-21.1	24.6	-0.86	0.391	7.19
Are healthcare services for TB					
Yes	-44.4	33.5	-1.32	0.186	16.99
YES	9	413	0.02	0.982	11.95

Residence location type			
Rural	Rural	0.0000	(0.0000, 1.42706E+287)
Urban	Rural	0.0000	(0.0000, 6.01635E+11)
Urban	Rural	0.0009	(0.0000, 1.88799E+288)
Are healthcare services for TB			
Yes	No	0.0000	(0.0000, 1.86499E+09)
YES	No	12830.6503	(0.0000, *)
YES	Yes	2.45372E+23	(0.0000, *)

Table 4 presents regression coefficients for predictor variables in a statistical model assessing the likelihood of tuberculosis (TB) occurrence. The coefficients represent the estimated impact of each variable on TB prevalence. Standard errors provide a measure of uncertainty around these estimates. Significance of each coefficient is determined by Z-Values and P-Values. Values below 0.05 are generally considered statistically significant. To assess multicollinearity between predictors, we use the Variable Inflation Factor (VIF). The results show that age, family size, and access to TB healthcare services are significant contributors to TB prevalence. The coefficients for age_27, family size_10, and unavailability/distant healthcare services for TB_ are higher, and the p-values are significant, indicating that increasing age and larger family sizes are associated with higher odds of TB occurrence. TB prevalence rates are significantly affected by access to TB healthcare services. Targeted interventions are crucial in addressing TB risk factors, especially among older individuals, those from larger families, and those with limited access to TB healthcare services. Public health efforts can effectively reduce TB transmission and improve outcomes in affected communities. This can be achieved by focusing on key determinants and implementing preventative measures tailored to high-risk populations. It is important to prioritize enhancing access to TB

healthcare services and addressing the specific needs of vulnerable groups to combat TB effectively.

- The p-value for the married group was 0.590, which is closer to 0.500 than the values for the unmarried and widowed groups, which were 0.710 and 0.741, respectively. This indicates that the stigma is relatively higher for the married group.
- Similarly, illiterates experience the most stigma, in terms of education level, with a p-value of 0.936, while undergraduates experience the least stigma.
- Additionally, rural individuals perceive more stigma compared to urban individuals, with p-values of 0.967 and 0.391, respectively.
- The coefficients for age_27, family size_10, and unavailability/distant healthcare services for TB_ are higher, and the p-values are significant, indicating that increasing age and larger family sizes are associated with higher odds of TB occurrence.

More prevalence rates of PTB are also identified in the joint family(as per this small data), Distance also matters in health seeking behaviour ,more delays has been identified among the patient living far from the health facilities

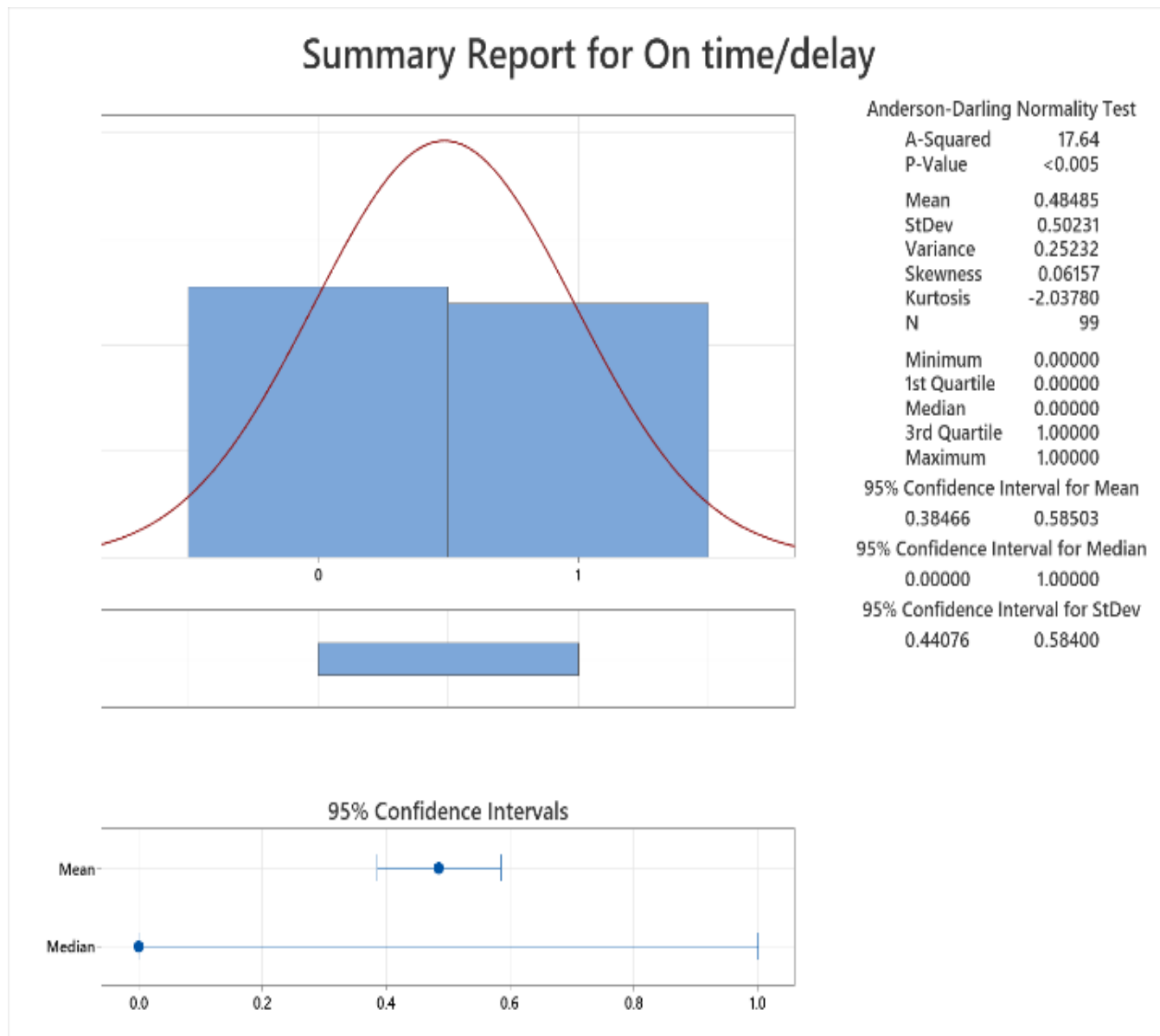


Fig 3. Represent the summary report of on-time/delay

Figure 3 represents the summary report of on-time/delay about tuberculosis (TB). It suggests that individuals who were on time had a lower incidence of TB compared to those who experienced delays. It indicates a potential correlation between timeliness in seeking healthcare and lower rates of TB infection. Thus, the figure underscores the importance of prompt medical attention in mitigating the risk of TB transmission and infection. And suggests that people who promptly seek medical attention when they have symptoms of TB feel less embarrassed or judged about having TB. On the other hand, those who wait to see a doctor might feel more stigma or shame about it. This highlights the importance of

seeking medical attention promptly, not only for physical health but also for reducing the negative feelings associated with TB.

Discussion and Future direction

The study reveals the widespread stigma experienced by PTB patients in Aligarh, Uttar Pradesh, India, with significant gender disparities. Females experienced higher levels of perceived stigmatization than males, indicating the necessity for targeted interventions to address these disparities. Regression analysis has identified several socio-demographic factors as significant predictors of stigmatization, highlighting the intricate interplay of individual and structural

determinants. Although the regression model demonstrated exceptional fit and discriminatory power, further research is necessary to investigate potential outliers and influential data points identified through diagnostic analysis. Future research directions include qualitative exploration to understand the underlying mechanisms of stigma, intervention development to mitigate stigma and improve access to TB healthcare services, longitudinal studies to track changes in stigma perceptions, intersectional analysis to examine multiple dimensions of stigma, and advocacy for policy changes to address structural determinants of stigma. Advancing our understanding of stigma and its impacts can inform targeted strategies to alleviate the burden of stigma on patients with PTB and improve their overall well-being.

Conclusion and Suggestions:

The study reveals notable gender disparities in on-time/delay behavior among PTB patients, with females displaying higher levels of perceived stigmatization. Regression analysis identified age, family size, rural residence, and access to TB healthcare services as significant predictors of stigmatization. The study revealed that, patient belongs to rural areas perceive more stigma compared to urban individuals means patient belongs to the rural areas where the medical facility is at distance feel hesitant to seek the treatment and have fear for the disease as if the community will ostracized them after knowing their TB status. This study highlighted the fact that, the individuals who were on time had a lower incidence of TB compared to those who experienced delays. It indicates a potential correlation between timeliness in seeking healthcare and lower rates of TB infection. A good number of the respondent belongs to the joint family this indicated that the chances of the spread is more in joint family. Married people are more worried and show delay just to avoid any bad news and fear of losing the earning.

This stigma acts as a barrier to healthcare access, resulted delays in seeking medical assistance, leading to diagnostic delays and worsening health issues. A comprehensive policy is needed, taking all the factors of the stigma and delays on priority basis to minimize this problem. However, it is necessary to conduct further research to investigate the impact of potential outliers and influential data points that were identified through diagnostic analysis. In general, these findings enhance our comprehension of stigmatization in PTB patients and emphasize the significance of targeted interventions to alleviate its adverse effects.

Addressing PTB-related stigma requires:

Very Comprehensive strategies that encompass public awareness campaigns is required to address the stigma.

- Awareness generation/Education, (for e.g., using Information Education and Communication tools)
- Community engagement, (by using Group counselling, sessions etc.)
- De-stigmatization campaigns (by using IEC techniques, social action and counselling etc.)
- Behavior changes of general community and specifically family suffering from this problem (by applying Social Behavior Change communications, SBCC tools)
- Foster supportive environment (by engaging Community in large, creating supportive and welcoming health services)
- Policy interventions promoting inclusivity and reducing discrimination.
- More and more researches are needed on different factors and on different perspective of this issue.

Competing Interests:

We would like to declare that we have no conflicts of interest that could potentially influence the publication of this research work.

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Author contributions:

W. Ali and M. kaif designed the study and obtained finding. M. kaif wrote the initial draft of

the manuscript, and all authors contributed to revisions and editing. Q. Ali developed the mathematical regression model and created the figures and supervised this research. The final paper was read and approved by all the authors.

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