

Perceived Stigma Associated with Tuberculosis (TB) among Patients and Attitude of Caregivers Towards Affected Person in Selected areas of Surat District, Gujarat

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Abstract

Introduction: Tuberculosis (TB), caused by *Mycobacterium tuberculosis*, primarily affects the lungs and is a leading cause of global mortality, total of 1.25 million people died from tuberculosis (TB) in 2023 (including 161 000 people with HIV). The disease disproportionately impacts low- and middle-income countries, with a significant burden among men. TB spreads through airborne transmission, but most exposed individuals do not develop active disease. Stigma plays a crucial role in shaping societal attitudes towards TB, affecting patients and their families through fear of discrimination and exclusion. This study examines perceived TB stigma among patients and their household contacts.

Methodology: This cross-sectional study employed a quantitative approach to assess perceived stigma associated with tuberculosis (TB) among patients and evaluate caregivers' attitudes towards affected individuals in Bardoli taluka. Using the Raosoft sample size calculator, 148 TB patients undergoing DOT therapy were recruited through non-probability purposive sampling. Inclusion criteria were patients over 18 who understood Gujarati, Hindi, or English, while those with deafness and dumbness and mentally challenged were excluded. Data collection involved socio-demographic and medical information, as well as the Modified Explanatory Model Interview Catalogue (MEMIC) stigma scale for patients and the Explanatory Model Interview Catalogue (EMIC) for caregivers. Data were collected via face-to-face interviews from May 28 to July 3, 2024, each lasting 15-20 minutes.

Result: The study finds that most TB patients are young, male (56.1%), married (77.0%), and Hindu (88.5%), with many laborers earning Rs. 5001-10,000 (42.6%). Nearly all have pulmonary TB (98.6%) and high treatment compliance (89.2%). Stigma is prevalent, with 35.8% hiding their condition, 46.6% feeling a loss of self-respect, and 38.5% experiencing shame. Caregivers, mostly females (58.8%), share similar concerns. The mean stigma score is 20.76 (SD = 6.41), with a moderate positive correlation ($r = 0.587$) between stigma and caregiver attitudes. While stigma is not linked to patient demographics, caregiver attitudes significantly vary with income.

Conclusion: Based on the findings of the study, it was concluded that the stigma negatively impacts family dynamics and employment. Stigma level linked to care giver's perceptions of TB care.

Key words: Perceived, Stigma, Attitude, Tuberculosis, Care givers

Introduction

Tuberculosis (TB), caused by *Mycobacterium tuberculosis*, primarily affects the lungs and is a leading cause of global mortality. Total of 1.25 million people died from tuberculosis (TB) in 2023 (including 161 000 people with HIV). Worldwide, TB has probably returned to being the world's leading cause of death from a single infectious agent, following three years in which it was replaced by coronavirus disease (COVID-19). It was also the leading killer of people with HIV and a major cause of deaths related to antimicrobial resistance. In 2023, an estimated 10.8 million people fell ill with TB worldwide, including 6.0 million men, 3.6 million women and 1.3 million children. TB is present in all countries and age groups. TB is curable and preventable. Multidrug-resistant TB (MDR-TB) remains a public health crisis and a health security threat. Only about 2 in 5 people with drug resistant TB accessed treatment in 2023. US\$ 22 billion is needed annually for TB prevention, diagnosis, treatment and care to achieve the global target by 2027 agreed at the 2023 UN high level-meeting on TB¹.

The disease disproportionately impacts low- and middle-income countries, with a significant burden among men⁴. TB spreads through airborne transmission, but most exposed individuals do not develop active disease. Stigma plays a crucial role in shaping societal attitudes towards TB, affecting patients and their families through fear of discrimination and exclusion.

Objectives

1. To assess perceived stigma associated with TB among patients diagnosed with the same.
2. To find out attitude of caregivers towards affected patients diagnosed with TB.
3. To find correlation between the level of stigma and attitude of caregivers.
4. To find the association of level of stigma and attitude of caregivers with their selected sociodemographic variables.

Need for The Study

Existing literature indicates a high prevalence of stigma among TB patients in India. For instance, a study conducted in Puducherry reported that 69.3% of TB patients experienced some form of stigma, with 52.6% reporting participation restriction due to stigma¹⁵. Similarly, research in Delhi revealed that 45.5% of TB patients perceived stigma from family and friends, and 58.2% faced stigma at the workplace.

In Surat district, there is a dearth of data on the prevalence and impact of TB-related stigma. Given the region's unique cultural and socioeconomic landscape, it is imperative to assess the extent of stigma and its associated factors among TB patients. Moreover, understanding the attitudes of caregivers towards TB patients is crucial, as their support and perceptions can influence treatment adherence and patient well-being¹⁹.

Therefore, this study aims to assess the perceived stigma associated with TB among patients and evaluate the attitudes of caregivers towards affected individuals in selected areas of Surat district, Gujarat. The findings will provide valuable insights to inform targeted interventions and policies aimed at reducing stigma and improving the quality of care for TB patients in the region.

Methodology

This cross-sectional study employed a quantitative approach to assess perceived stigma associated with tuberculosis (TB) among patients and evaluate caregivers' attitudes towards affected individuals in Bardoli taluka. Using the Raosoft sample size calculator, 148 TB patients undergoing DOT therapy were recruited through non-probability purposive sampling at 95% confidence level and 5% margin of error. Inclusion criteria were patients over 18 who understood Gujarati, Hindi, or English, while those with deafness and dumbness and mentally challenged were excluded. Data collection involved socio-demographic and medical information, as well as the Modified Explanatory Model Interview Catalogue (MEMIC) stigma scale for patients and the

Explanatory Model Interview Catalogue (EMIC) for caregivers. The EMIC demonstrated high reliability, with Cronbach's alpha coefficients of 0.74 for patients and 0.90 for caregivers. Data were collected via face-to-face interviews from May 28 to July 3, 2024, each lasting 15-20 minutes. Statistical analysis included range, mean, standard deviation, median, and mean percentage to evaluate stigma levels and caregiver attitudes.

Result

The study finds that most TB patients were under 30, predominantly male (56.1%), married (77.0%), and Hindu (88.5%), with many working as laborers

earning Rs. 5001-10,000 (42.6%). Nearly all have pulmonary TB (98.6%) and exhibit high treatment compliance (89.2%). Caregivers are mostly aged 31 to 40 (30.4%) and female (58.8%). Stigma is significant, with 35.8% of patients wanting to hide their condition, 46.6% feeling a loss of self-respect, and 38.5% experiencing shame. Additionally, 42.6% believe their community would show less respect, and 34.5% worry about their children's social standing. Caregivers also express concerns, with 43.9% believing individuals with TB prefer to conceal their status. Overall, the data highlights the pervasive stigma and social anxiety surrounding TB, impacting both patients and their families.

Table 1. Item wise analysis of Explanatory Model Interview Catalogue (EMIC) stigma scale, adapted for TB affected people N=148

SL. No.	ITEMS	YES		POSSIBLY		UNCERTAIN		No	
		f	%	f	%	f	%	f	%
1	If possible, would you prefer to keep people from knowing about TB?	53	35.8	31	20.9	16	10.8	48	32.4
2	Have you discussed this problem with the person you consider closest to you, the one whom you usually feel you can talk to most easily?	28	18.9	15	10.1	59	39.9	46	31.1
3	Do you think less of yourself because of this problem? Has it reduced your pride or self-respect?	19	12.8	50	33.8	41	27.7	38	25.7
4	Have you ever been made to feel ashamed or embarrassed because of this problem?	18	12.2	43	29.1	30	20.3	57	38.5
5	Do your neighbours, colleagues or others in your community have less respect for you because of this problem?	16	10.8	33	22.3	36	24.3	63	42.6

Continue....

6	Do you think that contact with you might have any bad effects on others around you even after you have been treated?	34	23.0	40	27.0	28	18.9	46	31.1
7	Do you feel others have avoided you because of this problem?	36	24.3	35	23.6	30	20.3	47	31.8
8	Would some people refuse to visit your home because of this condition even after you have been treated?	19	12.8	52	35.1	35	23.6	42	28.4
9	If they knew about it would your neighbors, colleagues or others in your community think less of your family because of this problem?	19	12.8	48	32.4	31	20.9	50	33.8
10	Do you feel that your problem might cause social problems for your children in the community?	51	34.5	53	35.8	22	14.9	22	14.9
11A	Do you feel that this disease has caused problems in getting married? (Unmarried only)	20	13.5	9	6.1	4	2.7	115	77.7
11B	Do you feel that this disease has caused problems in your marriage? (Married only)	26	17.6	43	29.1	12	8.1	67	45.3
12	Do you feel that this disease makes it difficult for someone else in your family to marry?	35	23.6	50	33.8	35	23.6	28	18.9
13	Have you been asked to stay away from work or social groups?	35	23.6	28	18.9	35	23.6	50	33.8
14	Have you decided on your own to stay away from work or social group?	29	19.6	32	21.6	28	18.9	59	39.9
15	Because of TB people think you also have other health problems	21	14.2	55	37.2	20	13.5	52	35.1

Table 2. Item wise analysis of Explanatory Model Interview Catalogue (EMIC) stigma scale for the care givers, adjusted for TB. N=148

SL. No.	ITEMS	YES		POSSIBLY		NO/DON'T KNOW	
		f	%	f	%	f	%
1	Would a person with TB keep others from knowing, if possible?	65	43.9	49	33.1	34	23.0
2	If a member of your family had TB, would you think less of yourself, because of this person's problem?	28	18.9	67	45.3	53	35.8
3	In your community, does TB cause shame or embarrassment?	22	14.9	37	25.0	89	60.1
4	Would others think less of a person with TB?	25	16.9	42	28.4	81	54.7
5	Would knowing that someone has TB have an adverse effect on others?	42	28.4	75	50.7	31	20.9
6	Would other people in your community avoid a person affected by TB?	51	34.5	48	32.4	49	33.1
7	Would others refuse to visit the home of a person affected by TB?	35	23.6	61	41.2	52	35.1
8	Would people in your community think less of the family of a person with TB?	36	24.3	63	42.6	49	33.1
9	Would TB cause problems for the family?	83	56.1	34	23.0	31	20.9
10	Would a family have concern about disclosure if one of their members had TB?	46	31.1	63	42.6	39	26.4
11	Would TB be a problem for a person to get married?	59	39.9	57	38.5	32	21.6
12	Would TB cause problems in an on-going marriage?	54	36.5	61	41.2	33	22.3
13	Would having TB cause a problem for a relative of that person to get married	37	25.0	68	45.9	43	29.1

Continue....

14	Would having TB cause difficulty for a person to find work?	40	27.0	79	53.4	29	19.6
15	Would people dislike buying food from a person affected by TB?	23	15.5	85	57.4	40	27.0

Table 3 provides details on the perceived stigma associated with tuberculosis (TB) among 148 patients. The dataset, which spans a range from 3 to 35, reveals a mean of 20.76, indicating the average value is relatively central within this range. The standard deviation of 6.40 suggests a moderate level of variability among the data points. The median, at 22.0, further supports the central tendency of the dataset, showing that half of the values fall below this point. Additionally, a mean percentage of 46.1 reflects the overall proportionate representation of the data, highlighting its significant variability in the level of stigma perceived by the patients.

Table 3. Range, mean, standard deviation, median and mean percentage of perceived stigma associated with TB among TB affected patients

N = 148

Range	Mean	Standard deviation	Median	Mean percentage
3-35	20.76	6.40	22.0	46.1

Table 4 provides a summary of the caregivers' attitudes towards TB. The scores for caregivers' attitudes range from 2 to 28. The average score is 14.74, with a standard deviation of 4.57, indicating a moderate level of variability in attitudes among caregivers. The median score is 15.0, which is close to the mean, suggesting that the data is fairly

symmetrically distributed around the average score. The mean percentage, which represents the average attitude score as a percentage of the maximum possible score, is 49.1%. This percentage reflects that, on average, caregivers' attitudes are about halfway between the minimum and maximum possible scores, indicating a generally moderate attitude towards TB.

Table 4. Range, mean, standard deviation, median and mean percentage of care giver's attitude

N = 148

Range	Mean	Standard deviation	Median	Mean percentage
2-28	14.74	4.57	15.0	49.1

Table 5 describes the relationship between stigma experienced by TB patients and the attitudes of their caregivers. The mean stigma score is 20.76 with a standard deviation of 6.41, while the correlation coefficient (r value) between stigma and caregiver attitude is 0.587. This indicates a moderate positive correlation, meaning that as stigma levels increase, caregivers' attitudes tend to become more positive. The p-value is less than 0.001, suggesting that this correlation is statistically significant. The data reveal a significant moderate positive relationship between the stigma experienced by TB patients and the attitudes of their caregivers.

Table 5. Correlation between stigma associated with TB affected patients and care giver's attitude

N = 148

Variables	Mean	Standard deviation	Coefficient of correlation (r value)	Type of correlation	p value
Stigma	20.76	6.41	0.587	Moderate positive	<0.001***
Care giver's attitude	14.74	4.57			

Table 6. Association of level of stigma with selected socio-demographic variables among TB affected patients

N = 148

Sl. No	Demographic variables	Patient Stigma score		Total	χ^2 test
		≤Median (≤22.0)	>Median (>22.0)		
1	Age in years				$\chi^2=3.270$, df=4, p=0.514(NS)
	≤30	28	16	44	
	31-40	19	20	39	
	41-50	13	12	25	
	51-60	17	10	27	
	>60	9	4	13	
2	Gender				$\chi^2=0.170$, df=1, p=0.680(NS)
	Male	47	36	83	
	Female	39	26	65	
	Transgender				
3	Marital status				$\chi^2=3.022$, df=2, p=0.221(NS)
	Married	64	50	114	
	Unmarried	15	11	26	
	Widower/widow	7	1	8	
4	Religion				$\chi^2=4.242$, df=2, p=0.120(NS)
	Hindu	75	56	131	
	Muslim	11	4	15	
	Christian				
	Others	0	2	2	
5	Educational qualification				$\chi^2=4.373$, df=4, p=0.358(NS)
	No formal Education	12	11	23	
	Primary	58	33	91	
	Secondary	2	1	3	
	Higher secondary	12	16	28	
	Under graduate and above	2	1	3	
6	Occupation				$\chi^2=7.945$, df=4, p=0.094(NS)
	Self Employed	20	21	41	
	Govt. Job	0	1	1	
	Private job	12	14	26	
	Laborer	44	19	63	
	Farmer	10	7	17	
7	Monthly income				$\chi^2=0.121$, df=3, p=0.989(NS)
	Rs. 3000 to 5000	21	15	36	
	Rs. 5001 to 10,000	37	26	63	
	Rs. 10,001 to 15,000	26	19	45	
	Rs. 15000 and above	2	2	4	

Continue....

8	Diet				$\chi^2=2.416$, df=1, p=0.120(NS)
	Vegetarian	28	13	41	
	Mixed	58	49	107	
10	Diagnosis of Tuberculosis (To be recorded from medical records)				
10.1	Type of Tuberculosis				$\chi^2=1.462$, df=1, p=0.227(NS)
	Pulmonary	84	62	146	
	Extra Pulmonary	2	0	2	
10.2	Duration				$\chi^2=3.249$, df=3, p=0.355(NS)
	<1 Month	19	17	36	
	1 to 3 Months	35	17	52	
	3.1 to 6 Months	24	23	47	
	6.1 Months and above	8	5	13	
10.3	Treatment				$\chi^2=0.026$, df=1, p=0.873(NS)
	First line	81	58	139	
	Second line	5	4	9	
10.4	Compliance to treatment				$\chi^2=1.519$, df=1, p=0.218(NS)
	Yes	79	53	132	
	No	7	9	16	
10.5	Drug resistance				-
	MDR				
	XDR				
	No drug resistance	86	62	148	
11	History of suffering from any disease (Any Comorbidity).				$\chi^2=1.523$, df=1, p=0.217(NS)
	Yes, then please specify_____.	7	2	9	
	No	79	60	139	
12	History of taking any medication.				$\chi^2=2.300$, df=1, p=0.129(NS)
	Yes, then please specify_____.	6	1	7	
	No	80	61	141	

NS- Not Significant

Table 7. Association of caregiver attitude score with selected socio-demographic variables

N= 148

Sl. No	Demographic variables	Caregiver attitude score		Total	χ^2 test
		\leq Median (≤ 15.0)	$>$ Median (> 15.0)		
1	Age in years				$\chi^2=4.750$, df=4, p=0.314(NS)
	≤ 30	21	11	32	
	31-40	23	22	45	
	41-50	19	24	43	
	51-60	14	8	22	
	> 60	4	2	6	
2	Gender				$\chi^2=0.770$, df=1, p=0.380(NS)
	Male	36	25	61	
	Female	45	42	87	
3	Marital status				$\chi^2=0.337$, df=1, p=0.562(NS)
	Married	70	60	130	
	Unmarried	11	7	18	
4	Religion				$\chi^2=0.140$, df=1, p=0.709(NS)
	Hindu	74	60	134	
	Muslim	7	7	14	
5	Educational qualification				$\chi^2=4.753$, df=4, p=0.314(NS)
	No formal Education	13	9	22	
	Primary	56	43	99	
	Secondary	1	1	2	
	Higher secondary	7	13	20	
	Under graduate and above	4	1	5	
6	Occupation				$\chi^2=3.557$, df=4, p=0.469(NS)
	Self Employed	23	28	51	
	Govt. Job	4	4	8	
	Private job	10	8	18	
	Laborer	33	21	54	
	Farmer	11	6	17	
7	Monthly income				$\chi^2=13.720$, df=3, p=0.003**
	Rs. 3000 to 5000	18	18	36	
	Rs. 5001 to 10,000	46	20	66	
	Rs. 10,001 to 15, 000	12	25	37	
	Rs. 15000 and above	5	4	9	
8	Relationship with client.				$\chi^2=2.169$, df=3, p=0.538(NS)
	Parents	18	22	40	
	Brother/sister	5	3	8	
	Spouse	45	33	78	
	Others	13	9	22	

NS- Not Significant, **- Significant at 0.01 level

There was no significant association found between stigma of patients affected with TB with their selected sociodemographic variables while there is a significant association between caregiver attitudes and monthly income found, indicating that attitudes vary with income levels.

Discussion

The present study result reveals that most are under 30 which is supported by study done by Swarna S. K. Kallepalliet al, Anand et al (30.51±11.3years)¹⁸ and Kamble et al (31.5±11.5 years),^(15, 16) predominantly male (56.1%) which is supported by studies by Kamble et al, Sunil et al and Aryal et al.^(15,17), married (77.0%) which is supported by study done by Kamble et al, and Aryal et al.^(15,17), and Hindu (88.5%) supported by study done by Swarna S. K. Kallepalliet al.¹⁸ A significant portion has completed primary education (61.5%) and works as labourers (42.6%), with most earning between Rs. 5001 and 10,000 (42.6%) which is similar to study done by Swarna S. K. Kallepalliet al.¹⁸ Clinically, 98.6% have pulmonary TB, with high treatment compliance (89.2%) and no drug resistance reported. Caregivers, mainly aged 31 to 40 (30.4%) and female (58.8%), share similar demographic traits, with many also being labourers or self-employed. The EMIC stigma scale data represents that patients prefer to keep their status hidden, experiencing feelings of shame and diminished self-respect. The EMIC stigma scale analysis reveals that (43.9%) believe individuals with TB prefer to hide their condition. While 45.3% wouldn't judge a family member with TB. Community views are largely negative, with 60.1% acknowledging shame and 54.7% believing others would judge affected individuals. This stigma affects family dynamics, marriage prospects, and employment, highlighting an urgent need for intervention. The perceived stigma among patients shows positively correlating with care giver's attitude ($r = 0.587$). However, stigma levels do not significantly relate to socio-demographic factors, except for a notable association between caregiver attitudes and monthly income, indicating that income influences perceptions and attitudes towards TB care.

Limitations

- This study is limited to selected areas within Surat district, Gujarat. Therefore, the findings may not be generalizable to patients with Pulmonary Tuberculosis in other regions of Gujarat or in different states or countries.
- The study includes a specific sample size of 148 patients. Participants are selected from certain health facilities or communities within Surat district, which may not represent the entire population of TB patients in the district.
- The focus is exclusively on patients diagnosed with Tuberculosis. Other respiratory diseases are excluded from the study.
- The study assesses the stigma and care giver's attitude at a single point in time or over a limited duration. Long-term impacts of TB or changes in stigma score or care giver's attitude over time are not addressed.

Recommendations

- The study can be repeated on the large-scale sample to validate and for better generalization of the findings.
- Comparative study can be done in urban, rural and tribal areas to assess level of stigma and care giver's attitude towards TB adjusted patient.
- Ongoing research and policy implementation for care and counselling should be integrated into health centres to raise TB awareness, reduce stigma, and eliminate barriers to care.
- Enhancing public knowledge about the effectiveness of anti-TB treatment can help diminish stigmatizing attitudes, prevent delays in diagnosis and treatment, and ultimately reduce TB-related morbidity and mortality.
- Comprehensive health education aimed at changing attitudes through community involvement is essential. Planning initiatives like family sensitization, community awareness campaigns, and emotional support for TB patients are crucial for reducing stigma and improving patient compliance.
- Support from community members, recovered patients, and others can aid in de-stigmatizing TB.

Conclusion

Based on the findings of the study, it was concluded that the stigma negatively impacts family dynamics and employment. Stigma level linked to care giver's perceptions of TB care.

Conflict of Interest: There was no conflict of interest reported.

Source of Funding: This study was self-funded.

Ethical Consideration: The permission was obtained from the CDHO, Surat, Gujarat with ref No. 1578. Study was approved by Institute ethics Committee with ref No. MBNC/231/2024-25. The Researcher had taken consent from the patients with Tuberculosis and their caregivers meeting the inclusion criteria.

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