Original Research Article

Burden of stigma among tuberculosis patients: a cross-sectional study

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ABSTRACT

Background: Tuberculosis (TB) is a significant public health problem in populous countries like India. Despite having effective treatment, social stigma still exists and it manifest as social exclusion (enacted stigma) or perception of it (felt stigma). The main causes of stigma are fear of TB and the terrible effects the disease will have on affected people and their family's health, finances, personal lives, and social standing. Delay in diagnosis and treatment are brought on by stigma, resulting in adverse treatment outcomes and thus prevent TB from being eliminated. The objectives of the study were to (a) estimate the burden of stigma experienced by tuberculosis patients; and (b) identify the factors associated with stigma.
Methods: A cross-sectional analytical observational study was carried out among 100 TB patients above 18 years of age in the months of September - November 2022. Multistage random sampling was used to select the study participants from different peripheral health institutes. Data was collected using predesigned, pretested proforma from explanatory model interview catalogue developed by WHO. Data was collected after obtaining informed consent and analysed by using SPSS 21.
Results: Majority of patients (59%) perceived stigma. Many (73%) revealed that they desire to keep others from knowing about their condition, felt that others would think less of patient's family (66%) and avoided them (69%) due to disease.
Conclusions: Patients with TB still experience greater stigma at home, among friends, and at work. Sensitization of family and awareness among the public is essential to combat stigma.

Keywords: Burden, Stigma, Tuberculosis

INTRODUCTION

Tuberculosis (TB) is one of the oldest and stigmatised diseases affecting mankind. Globally, an estimated 10.0 million people fell ill with TB in 2018 and an estimated 1.2 million TB deaths among HIV-negative people.[1] India takes almost 25% of the global TB burden among HIV-negative people.[2] Limited general knowledge about TB may lead to the stigmatized nature of TB. Limiting the transmission and improving patient knowledge of TB is an important component and a major goal of the End TB strategy.[3] TB is considered as a social disease with many socio-cultural factors contributing to the disease burden.[4] Some studies have suggested that TB stigma could lead to

delays in patients seeking appropriate medical care.[5] This can result in greater morbidity and mortality for the patient and increased transmission of Mycobacterium TB in the community.[6] A TB patient can experience stigma within the household, at workplace and in the immediate neighbourhood and society.[7] People who experienced this stigma and discrimination develop poor psychosocial health and are less likely to recover from disease because of less self-motivation towards treatment.[8] Amongst all the problems met by TB patients, social stigma has been increasingly recognized and remains an important and neglected aspect, which leads to under-reporting of TB cases and taking treatment from unqualified persons. There are a smaller number of studies focusing on this important

aspect of TB. The true prevalence of stigma among TB patients and its role in delaying health-seeking behaviour, however, are unclear.[9] Thus, the present study was done to assess the burden of stigma and its associated factors among the TB patients.

Objectives

The objective of the study were to (a) estimate the burden of stigma experienced by TB patients; and (b) identify the factors associated with stigma experienced by TB patients.

METHODS

The study was a cross-sectional, observational study conducted in different peripheral institutes which comes under District TB Center (DTC) of Kakinada District, Andhra Pradesh in the months of September - November 2022.

The study population included TB patients aged more than 18 years who were diagnosed with TB as per National TB Elimination Program (NTEP) and availing treatment from the peripheral health institutes and who were willing to participate in the study. Patients with debilitating illness and HIV-TB coinfection patients were excluded from the study. Sample size was calculated using the prevalence of social stigma among TB patients- 52% from the previous study [9] and absolute precision of 10% was taken. Using the formula:

$$N = \frac{1.96 \times 1.96pq}{d^2}$$

The sample size arrived was 96. The present study included a sample of 100.

Permission was obtained from District Program officer. Multistage random sampling was used. DTC of Kakinada consists of 9 TB units (TU). Of these, three TU's were selected randomly in first stage. Based on the population, 20 peripheral health institutes (PHIs) were selected in the second stage, 7 from 2 TU's and 6 from 1 TU. In next step, five TB patients were interviewed at each PHI. Data was collected using predesigned, pretested proforma from explanatory model interview catalogue developed by WHO through direct interviews at the health facility and through telephonic interviews. The interview schedule consists of socio demographic profile, illness related questions, and stigma related questionnaire.

The stigma related questionnaire consisted of 17 items. Responses were coded on a 0-3 ordinal scale (0= no, 1= uncertain, 2= possibly and 3= yes). Items were scored on 4-point Likert scale (3-0 with 3= yes, 2= possibly, 1= uncertain and 0= no). Two out of 17 item-number 2 and 12 were reverse scored as these are negatively formulated so that the higher the score the more positive the reading, as with the positively formulated items. Maximum obtainable score was 51 and minimum score was 0. Score of more than or equal to 26 was considered as perceived stigma.

Data was analysed using Statistical Package for Social Sciences (SPSS IBM) version 21.0. Chi-square test was applied and p value of <0.05 was considered to be significant. Ethical clearance was obtained from the Institutional Ethics Committee. Study participants were explained about the purpose of the study and after obtaining informed written consent, data was collected. Confidentiality of the patient was maintained.

RESULTS

In the present study, a total of 100 TB patients from five peripheral health institutes were studied, the mean age of patients was 42.6 years (SD±15.07). Majority of the patients (44%) were in the age group of 31–50 years. Males were more (64%) as compared to females (36%) and many (72%) of them were Hindu by religion. Majority were married (76%) followed by unmarried (13%). Most (72%) of the patients belonged to the nuclear family and residing in rural area (60%). Educational status revealed that 60% were literates and nearly half of them (41%) were financially dependent.

Socioeconomic status showed that almost all (92%) patients were in middle class with mean total family income per month (INR) 16,800 (±7,557). In relation to disease, family history of TB was seen in 25% and previous history of having TB was 8%. Majority (71%) of them had pulmonary TB while 29% had extrapulmonary TB and about two third (66%) of patients were on intensive phase of treatment.

More than half (59%) of TB patients perceived stigma with a score of 31.1±3.25 (Table 1]). Most of the patients (73%) revealed that they don't want others to know about the disease. About 46% of patients felt shamed or embarrassed and thought low of themselves (Table 2). The factors associated with stigma experienced by TB patients showed that 72.7% of the respondents, aged 31-50 years, who were occupationally independent (67.8%), unmarried (69.2%) and living separately (90.9%) had experienced stigma (p<0.05) (Table 3). Patients who had family history of TB experienced high stigma (76%) when compared to their counterparts (p<0.05) (Table 4).

Among 100 patients, 92% with drug sensitive TB and 11% were afraid to go to visit health centre. Regarding knowledge related to disease 61% know that TB is a contagious disease and more than half (53%) of them know the route of transmission and most of them (76%) believe that TB is curable. However, patients with poor knowledge about contagiousness (71.8%), mode of transmission (76.6%) and curability (87.5%) of the disease were found to experience more stigma and those who have experienced stigma (90.9%) were less likely to visit TB clinic (p<0.05) (Figure 1).

Table 1: Distribution of study subjects based on stigma (n=100).

Perceived stigma	Frequency (%)	Median score	Mean score±SD
Stigma not experienced	41 (41)	19	17.6±5.71
Stigma experienced	59 (59)	31	31.1±3.25

Table 2: Distribution of study subjects according to EMIC stigma questionnaire (n=100).

Variables	No N (%)	Uncertain N (%)	Possibly N (%)	Yes N (%)
Desire to keep others from knowing	20 (20)	7 (7)	31 (31)	42 (42)
Did not disclose to confident	51 (51)	26 (26)	16 (16)	7 (7)
Think less of yourself	31 (31)	23 (23)	38 (38)	8 (8)
Shamed or embarrassed	36 (36)	23 (23)	33 (33)	8 (8)
Others would think less of you	17 (17)	20 (20)	51 (51)	12 (12)
Adverse effect on others	24 (24)	25 (25)	32 (32)	19 (19)
Others have avoided you	21 (21)	10 (10)	57 (57)	12 (12)
Others refuse to visit	21 (21)	9 (9)	54 (54)	16 (16)
Others would think less of patients family	17 (17)	17 (17)	53 (53)	13 (13)
Problems for your children	35 (35)	13 (13)	37 (37)	15 (15)
Problem getting married despite cure	87 (87)	5 (5)	6 (6)	2 (2)
Did not expect support from spouse	70 (70)	2 (2)	5 (5)	23 (23)
Other problem in marriage after cure	86 (86)	6 (6)	7 (7)	1 (1)
Problem for the relative to marry	66 (66)	23 (23)	10 (10)	1 (1)
Asked to stay away from work	27 (27)	25 (25)	27 (27)	21 (21)
Decided to stay away from work groups	25 (25)	12 (12)	17 (17)	46 (46)
Presumed other health problems	42 (42)	30 (30)	17 (17)	11 (11)

Table 3: Distribution of study subjects based on socio-demographic characteristics and stigma (n=100).

Socio-demographic characteristics		No stigma N (%)	Stigma present N (%)	Total	Chi square, DF; p value
Age (years)	18-30	16 (59.3)	11 (40.7)	27	7.324, df-2; p value=0.026*
	31-50	12 (27.3)	32 (72.7)	44	
	>50	13 (44.8)	16 (55.2)	29	
Gender	Male	23 (35.9)	41 (64.1)	64	1.884, df-1; p value=0.171
	Female	18 (50)	18 (50)	36	
Occupation	Dependent	22 (53.7)	19 (46.3)	41	4.603, df-1; p value=0.032*
	Independent	19 (32.2)	40 (67.8)	59	
Education	Illeterate	15 (37.5)	25 (62.5)	40	0.338, df-1; p value=0.361
	Literate	26 (43.3)	34 (56.7)	60	
Marital status	Unmarried	4 (30.8)	9 (69.2)	13	6.467, df-2; p value= 0.039*
	Married	36 (47.4)	40 (52.6)	76	
	Living separately	1 (9.1)	10 (90.9)	13	
Religion	Hindu	28 (38.9)	44 (61.1)	72	0.578, df-2; p value=0.749
	Christian	11 (47.8)	12 (52.2)	23	
	Muslim	2 (40)	3 (60)	5	
Family income rs/month	≤15000	24 (39.3)	37 (60.7)	61	0.177, df-1; p value=0.674
	>15000	17 (43.6)	22 (56.4)	39	
Type of family	Nuclear	29 (40.3)	43 (59.7)	72	2.418, df-2; p value=0.299
	Joint	4 (28.6)	10 (71.4)	14	
	Three generation	8 (57.1)	6 (42.9)	14	
SES	I	4 (50)	4 (50)	8	0.752, df-3; p value=0.861
	II	13 (37.1)	22 (62.9)	35	
	III	20 (40.8)	29 (59.2)	49	
	IV	4 (50)	4 (50)	8	
Residence	Rural	23 (38.3)	37 (61.7)	60	0.441, df-1; p value=0.507
	Urban	18 (45)	22 (55)	40	

*Significant at p<0.05.

Table 4: Distribution of study subjects based on disease characteristics and stigma (n=100)

| Disease related information		No stigma N (%)	Stigma present N (%)	Total	Chi square, DF; p value
Family history of TB	Yes	6 (24)	19 (76)	25	3.982, df-1; p value=0.046*
	No	35 (46.7)	40 (53.3)	75	
Previous history of TB	Yes	3 (37.5)	5 (62.5)	8	0.044, df-1; p value=0.834
	No	38 (41.3)	54 (58.7)	92	
Site of involvement	Pulmonary	28 (39.4)	43 (60.6)	71	0.247, df-1; p value=0.619
	Extra-pulmonary	13(44.8)	16(55.2)	29	
Treatment category	Drug sensitive	39 (42.4)	53 (57.6)	92	0.920, df-1; p value=0.337
	Drug resistant	2 (25)	6 (75)	8	
Treatment phase	IP	31 (47)	35 (53)	66	2.860, df-1; p value=0.091
	CP	10 (29.4)	24 (70.6)	34	

*Significant at p<0.05.
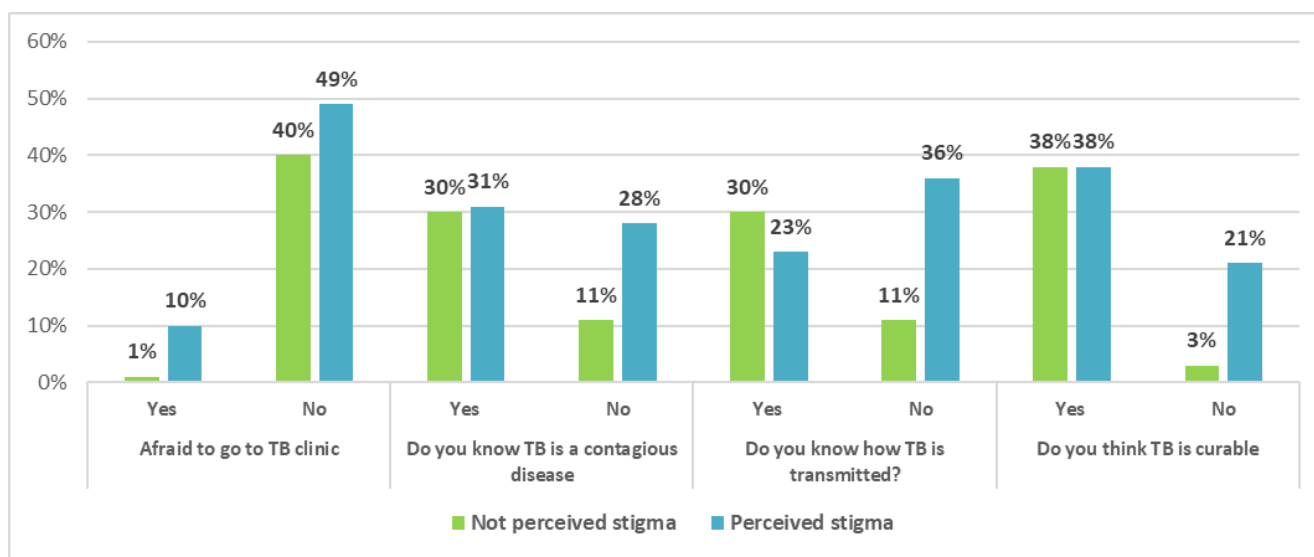
Figure 1: Distribution of study subjects based on knowledge regarding disease (n=100).

DISCUSSION

Beyond dealing with the burden of the disease, feeling stigmatized about having TB contributes to great social and mental distress. When stigmatized, patients show reluctance in seeking health care and treatment non-adherence. Hence stigma should be considered as an important social health determinant. In the present study, the mean age in the present study was 42.6±15.07 years which is higher than other studies, Anand et al (30.51±11.3 years) and Kamble et al (31.5±11.5 years).[10,11] The majority of study participants (44%) belonged to 31-50 years of age which is similar to the study by Atre et al where 62% were below 45 years of age and Kamble et al, 56.7% belonging to 18-37 years of age.[10,11]

Males were more (64%) in our study which is similar in studies by Kamble et al, Sunil et al and Aryal et al.[12,13] 76% were married, 40% were illiterate in the present study, these findings are similar in study by Aryal et al.[10-13] In the present study, 59% perceived stigma which was lower than study done by Sunil et al (65.3%) and study done by Aryal et al (63.3%).[13] Most of the patients (73%) revealed that

they do not want others to know about the disease. About 46% of patients felt shamed or embarrassed and thought low of themselves. This finding was similar to the studies done by Aryal et al and Atre et al.[11] Nearly 23% of respondents did not disclose to confident. Similar finding was observed in study by Sunil et al, where 42% had fear of disclosing illness to friends and study done by Somma et al where 35% did not disclose to confident in Malawi country.[12,14] Nearly 69% of respondents thought that others have avoided them. This finding was consistent with study done by Somma et al where they found this finding was common among all members with TB in four countries, they studied.[14] Stigma was observed more among illiterates and those having family income less than 15000 Rs/month. This finding was consistent with a study done by Datiko et al where stigma was lower in patients with higher education and higher family income.[15] Study participants with previous history and family history of TB had more stigma, which is similar in a study by Aryal et al where stigma was high among participants with the previous history of TB.[13] Participants with pulmonary TB experienced stigma (60.6%) higher than participants with other forms of TB. Participants in the continuous phase

(70.6%) experienced stigma higher than in the intensive phase of treatment (53%). A higher number of participants without knowledge about TB experienced stigma which was statistically significant. Lack of awareness about TB and pre-existing taboos related to the disease may be the reason for stigma. A patient-centred care approach would be effective in addressing TB. The role of the primary care physician is vital in combating stigma from the point of diagnosis in order to deliver patient-centred treatment. By identifying stigma and resolving it for improved compliance in drug treatment, we can enhance the effectiveness of the program and stop the spread of disease.

CONCLUSION

One major barrier to achieve goal of TB control program is the stigma attached to the disease. The findings from this study showed that 59% of the patients were stigmatized which is high. Factors more associated with stigma are economically productive age group, male gender, occupationally independent, unmarried people and those with poor knowledge related to disease. The obvious cause of discrimination and stigma is fear of being infected and incomplete knowledge regarding disease.

Recommendations

Goal of achieving TB elimination needs intersectoral approach. By reducing stigma associated with TB and by improving access to information about the disease, diagnosis and treatment of TB would be successful. Continuing research and implementation of policies for care and counselling should be integrated in health centres to provide TB awareness, decrease TB stigma and ultimately eliminate barriers to care. Improving general awareness related to TB about the effectiveness of anti-TB treatment could help to reduce stigmatizing attitudes, prevent delayed diagnosis and treatment, ultimately reducing TB related morbidity and mortality. Extensive health education directing towards attitudinal change by community involvement is needed. Active planning such as sensitization of family, community awareness about the disease, and emotional support by family/friends to TB patients are deemed necessary for reducing stigma against TB and improve the compliance of the patient. Health care providers should ensure that patients and their families understand the benefits of treatment and the duration of infectiousness after the start of treatment. Support to patients from community members, recovered patients and others may also facilitate de-stigmatization of TB. Hence, TB-related stigma has a direct impact on TB control and national TB control programs must incorporate stigma-reduction strategies in their future plan.

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