Original Research Article

A HOSPITAL BASED CROSS-SECTIONAL STUDY ON ASSESSMENT OF STIGMA AMONG TUBERCULOSIS PATIENTS IN RURAL TAMIL NADU

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ABSTRACT

Background: Tuberculosis (TB), the world health problem has been a dreadful disease that kills about 1.5 million every year while causing illness to around 10 million. Despite TB being a treatable and curable disease by proper diagnosis and medical treatment, stigma stands as a barrier from achieving complete elimination of TB. **Objectives:** 1) To assess the pattern of stigma present in tuberculosis patients. 2) To correlate stigma pattern with their socio-demographic data for significance.
Materials and Methods: Institution based cross sectional study. Sample size was calculated as 80 for the prevalence of 73%. Participants of the study were assessed for stigma using semi-structured, pre-coded and pre-tested questionnaire on the basis of Explanatory Model Interview Catalogue (EMIC). Simple descriptive statistical analysis was done.
Results: Almost 76 (95%) shares about their illness to their family seeking an emotional support. Only 24 (30%) were asked to stay away from work or social groups, while 69(86.25%) decided themselves to stay away from work or social groups. These results prove the dominance of self-stigma perceived by the patients over social stigma. 58 (72.5%) answered that their sudden and significant loss of weight made people think that they have other health problems along with TB.
Conclusion: Tuberculosis affects the person not only medically, but also psychologically. Therefore, in addition to appropriate medical treatment, psychological support and counselling is also essentioal for better outcome.
Keywords: Tuberculosis, Stigma, EMIC scale.

INTRODUCTION

Tuberculosis (TB), the world health problem that kills about 1.5 million every year while causing illness to around 10 million.[1] stigmatising a disease has been in society for a long period. It is the most common chronic infectious disease affecting all age groups and socioeconomic strata. It is associated with several complications due to various organ involvement. The disease is associated with significant stigma since a long time, which is still persisting.

The commonest cause of stigmatisation is the perceived fear of contacting the disease,[2]Stigma impacts seeking medical care and adherence to treatment. Also, patients isolate themselves and internalise stigma.[3]They also suffer depression and anxiety, also affecting them financially.[4,5]

Despite being curable, stigma stands as a barrier, whose effect is often left unaddressed. So, it is important to improvise policies that focuses more upon stigma to eliminate TB.

Objectives

1. To assess the stigma among patients with Pulmonary Tuberculosis using the Explanatory Model Interview Catalogue (EMIC) scale.

2. To study the socio-demographic details of the tuberculosis patients and correlate it with the pattern of stigma.

MATERIAL AND METHODS

Institution based cross sectional study was undertaken from January – February of 2022, in a Government Medical College and Hospital in the district headquarters, in departments of Chest and Thoracic Medicine and Community Medicine

Sample Size

In previous study by Beena E. Thomas et al,[6]the prevalence of stigma was 73%. Calculating from the prevalence obtained from the earlier study,[6] using the formula, $4pq \div l^2$ the sample size was calculated to be 80.

Where, p is prevalence, q is (100-p) and l is allowable error or precision

Study Population

Eighty patients with Pulmonary Tuberculosis (PTB) who were either confirmed microbiologically or clinically by physician and were currently on treatment or follow up or patients who were declared cured within the past 6 months were included in the study. Patients with extra-pulmonary TB were excluded and those who were declared cured earlier than 6 months were also excluded. Patients with other comorbid conditions such as HIV infection, malignancy and diagnosed psychiatric illnesses were excluded from the study to eliminate their contribution towards stigma.

Data collection tool: Participants of the study were assessed for stigma using semi- structured, pre-coded and pre-tested interview schedule on the basis of Explanatory Model Interview Catalogue stigma scale (EMIC),[7]EMIC has 15 questions graded from 0 to 3 for No, Uncertain, Possibly, Yes respectively for every question. Question 2 has reverse scoring. The score for each question is added and the sum is calculated. Higher total score implies higher stigma.[8]The EMIC scale was adapted and modified for score in the study population.

Pilot testing was done with 10% of sample size and then the scale was administered to the study participants by the principal investigator and the answers are recorded in MS Excel. EMIC scale has been used previously for assessment of various other health related stigma like in leprosy, psychiatric illnesses and also in TB. It is easy to administer and it's applicable for the cultural setting of India.[8] "Yes" and "Probably" are considered as accepting the question in EMIC scale, similarly "Uncertain" and "No" are considered as denying the question in EMIC scale. The questions were subcategorized into various domains. The questions 1 and 2 are assessing self-stigma concerning disclosure of the disease, self-esteem (questions 3 and 4), community behaviour (questions 5,6,7,8 and 9), family life (questions 10, 11A, 11B, 12), work life (questions 13 and 14) and medical condition (questions 15).

Questions 1, 2, 3, 6, 9, 10, 11A, 12, 14 are concerned with perceived stigma and questions 4, 5, 7, 8, 11B, 13, 15 are concerned with enacted stigma. Data analysis: Data was entered into MS excel, missing data and incomplete data were corrected before and imported into the Epi info software package. Simple descriptive statistical analysis was performed for mean, standard deviation, frequencies and percentages. Chi square test and t-test were applied for the test of significance.

Ethics statement

The study was reviewed by the Scientific Research Committee and approved by the Institutional Ethics Committee of the Government Medical College and Hospital.

Privacy of the study participants was ensured during the interview. Abiding the Declaration of Helsinki, an informed and written consent was obtained from the study participants in their regional language. Illiterate participants were explained verbally about the study procedure and signature was obtained from them along with a witness.

The study was conducted only from consented individuals by a trained Principal Investigator. No compensation was provided to the patient in terms of cash.

RESULTS

The socio demographic details of the study participants as mentioned in Table-1. Out of 80 participants 67 (83.7%) were male and 13 (16.3%) were female. The mean years of age of the study participants were 45.8 +13.2. Majority of them were literate with 60 (80%). Based on the Modified Dr. B. G. Prasad classification, about 9 (11.3%) belong to class 1, 19 (23.7%) belong to Class 2, 23 (28.7%) belong to class 3 and 29 (36.2%) belong to Class 4. Regarding the Type of family, 58 (72.5%) live as a Nuclear Family, 10 (12.5%) live as a joint family and 12 (15%) live as a Three Generations family. About smoking habit, around 32 (40%) were smokers in past or current smokers. [Table 1]

As seen in table 2, the association of tuberculosis patients and environmental determinants were explained. Regarding housing type, 18 (22.5%) lives in Kutcha house, 13 (16.2%) lives in Semi pucca house and 49 (61.3%) lives in pucca house. Around 36 (45%) of the study participants lived in inadequate ventilated houses. Regarding the lighting 31 (38.7%) were living with inadequate lighting. About 43 (53.7%) lived in overcrowded housing. Regarding the usage of cooking fuel, 14 (17.5%) were using Firewood, 3 (3.7%) were using Kerosene and , 63 (78.7%) of them were using LPG. About 18 (22.5%) had family contacts of tuberculosis and 8 (10%). [Table 2]

Table 3 shows the results obtained for each question in the EMIC scale, majority of the participants of the study 73 (91.3%) were keen about keeping people from knowing about their disease. But,

almost everyone 76 (95%) shared about their illness to their family. On questions regarding self-esteem [question 3, question 4] 27(33.8%) people said yes and 31 (38.8%) said probably making it 58 (72.6%) people feel less of themselves because of their illness. But only 28 (35%) accepted that they were made to feel ashamed. Again only 24 (30%) were asked to stay away from work or social groups, while 69 (86.25%) decided themselves to stay away from work or social groups. These results prove the dominance of perceived stigma over enacted stigma. On a positive note 68 (85%) were aware that they don't spread their illness to people around them after they are cured. And 70 (87.5%) felt that their illness will not cause problems for their children in the community. Concerning marriage and Tuberculosis, of the18 respondents who were unmarried, 14 felt that Tuberculosis has caused problems in them getting married. But for participants who were already married, 48 (75%) do not face any problem in their married life. But in an Indian rural setting these results must be taken with caution as most of the study participants are male and usually women have less say in matters of sexual life in rural India, which could also be a reason for many not having any issues in their married life. When patients were asked about what people around them think when they know they have TB, almost 58 (72.5%) answered that their sudden and significant loss of weight made people think that they have other health problems along with TB. This change in physical appearance too made into a factor that has caused them to avoid social groups in the office or neighbourhood. [Table]

As seen in table 4, it explains the correlation between age of patients and education with their mean EMIC score. In patients with TB of age more than 60 had mean EMIC score as 14.3+ 5.2 while patients with TB of age less than 60 had mean EMIC score as 20.8 +6.7. Stigma among the young and working population is significantly (p value = 0.043) greater than old people. But the level of education had no significant impact on Tuberculosis Stigma (p value = 0.061) as for graduates, the Mean EMIC score was 22.7+7.8 and in other literates, the mean score was 19.5+6.7. [Table 4]
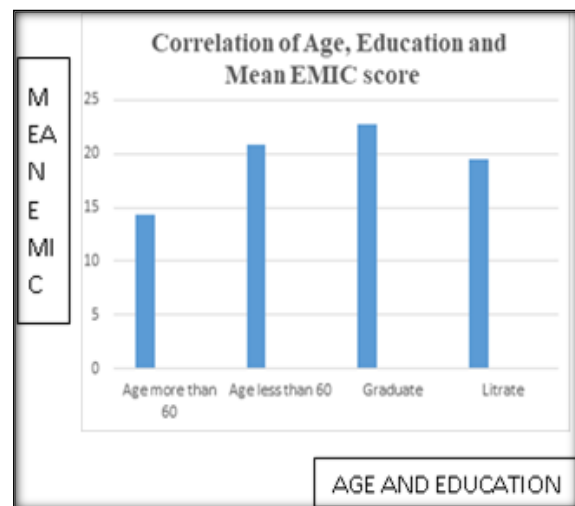

Figure 1

Table 1: Socio demographic details of the study participants with Tuberculosis

Sex	**Male**	**67 (83.7%)**
	Female	**13 (16.3%)**
Age group	Mean years of age	45.8 ± 13.2
Literacy	Illiterate	16 (20%)
	Literate	64 (80%)
Employment status	Employed	55 (68.7%)
	Unemployed	25 (31.3%)
Socio economic status	Class 1	9 (11.3%)
(B.G.Prasad Classification)	Class 2	19 (23.7%)
	Class 3	23 (28.7%)
	Class 4	29 (36.2%)
Type of Family	Nuclear family	58 (72.5%)
	Joint family	10 (12.5%)
	Three Generation family^	11 (13.7%)
Smoking	Current/Past	32 (40%)

Table 2: Association of Tuberculosis patient and Environmental determinants

Housing	**Kutcha**	**18 (22.5%)**
	Semi pucca	**13 (16.2%)**
	Pucca	**49 (61.3%)**
Ventilation	Inadequate	36 (45%)
Lighting	Inadequate	31 (38.7%)
Overcrowding	Present	43 (53.7%)
Cooking fuel	Firewood	14 (17.5%)
	Kerosene	3 (3.7%)
	LPG	63 (78.7%)
Contact	Family history	18 (22.5%)
	Work place exposure	8 (10%)

Table 3: Explanatory Model Interview Catalogue (EMIC) questionnaire

Q. No	Questions	Yes	Probably	Uncertain	No
	DISCLOSURE:				
1	Keep people from knowing about your illness?	57	16	4	3
		71.30%	20%	5%	3.70%
2	Share with closed one or family	76	0	0	4
		95%	0%	0%	5%
	SELF ESTEEM				
3	Reduced pride or self esteem	27	31	17	5
		33.80%	38.80%	21.30%	6.30%
4	Made to feel ashamed or embarrassed	7	21	24	28
		8.80%	26.20%	30%	35%
	COMMUNITY BEHAVIOUR				
5	Respected less by neighbours	10	38	21	11
		12.50%	38.70%	35%	13.70%
6	Disease spreads even after treatment	0	4	8	68
		0%	5%	10%	85%
7	Avoided by others	9	33	29	9
		11.30%	41.30%	36.20%	11.30%
8	Refusal of people to visit your home	9	19	17	35
		11.30%	23.80%	21.30%	43.80%
9	If known, neighbours, colleague or community will think less of you	13	25	36	6
		16.30%	31.30%	45%	7.50%
	FAMILY LIFE				
10	Social problems to your children due to your illness	2	8	21	49
		2.50%	10%	26.30%	61.30%
11.A	Problem in getting married (Unmarried)	10	3	2	1
		62.50%	18.80%	12.50%	6.30%
11.B	Problem in marital life (Married)	5	11	9	39
		7.80%	17.20%	14.10%	60.90%
12	Difficulty for others in your family to marry	3	7	18	52
		3.80%	8.80%	22.50%	65%
	WORK LIFE				
13	Asked to stay away from work or social groups	9	15	37	19
		11.30%	18.80%	46.30%	23.80%
14	Decided on your own to stay away	51	18	7	4
		63.70%	22.50%	8.80%	5%
	MEDICAL CONDITION				
15	Do people assume that you have other illnesses	25	33	16	6
		31.30%	41.30%	20%	7.50%

DISCUSSION

Health related stigma is defined as a 'social process or related personal experience characterised by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem.[9]'. This study was conducted in a rural population with many differences in their level of education, occupation and income. The majority of the study population were male (83.8%) like that in the previous studies conducted in India..[8,10,11] The mean age is 45.8+13.2, proving again that TB is more prevalent in working age group.[12] 68.7% were employed and 31.3% were unemployed, among them the majority being unemployed either totally or left the job was mainly due to their illness, causing increase in financial burden. 40% of the total study participants were smokers either in the past or at present.[13] 45% reported inadequate ventilation and 53.7% reported overcrowding at their home. These two environmental factors are prevalent despite knowledge about the mode of spread of TB, this could be attributed to their financial status, where they couldn't afford to have a separate room or emotional attachment of not wanting the patient to feel left out. Both factors that play an important role in communicability of this disease are yet prevalent and require attention to avoid spread. Even 22.5% had contracted TB from their family and 10% reported contact at workplace.

The major results of this study pointed towards perceived stigma being more of a menace than enacted stigma to patients with tuberculosis. This finding is in accordance with the previously conducted study by Jaggarajamma K et al.[10] Comparing the level of stigma among different age groups (Table 3), stigma is significantly higher in people less than 60 years than in people older than 60. This could be because young populations are more concerned about their health, their career and especially more concerned about their economy to run their family. Tuberculosis affecting them physically by sudden weight loss is also causing body image issues among young patients. Any question about their physical appearance makes them apprehensive to attend social gatherings. But education did not significantly influence stigma as it's almost the same among all groups. This is in

contrast with the popular opinion of less stigma in highly educated people, who are thought to have more awareness about the disease than the uneducated. Complete knowledge about the disease course and cure is necessary along with counselling in these patients to reduce their perceived stigma.

In this study, 91.25% of patients did not want others to know about their illness. They hide their reason of visit to hospital to everyone except their immediate family. But 95% seek affection and care of their family and trust to share it with them. Majority of the patients stated that it was their family's constant advice that led them to visit hospital after they developed symptoms.72.5% of people said "yes" or "probably" as the answer for if the disease reduces their pride or self-respect. They restrain themselves from attending social gatherings. These results are similar to that of Shivapujimath R Et al. Study conducted in Udupi,[11]and Jaggarajamma K et al,[10] conducted in Tamil Nadu. The manifestation of the disease as a symptom in public like cough, sputum production, sudden loss of weight etc., are the major reasons patients usually avoid interaction with people other than their family. Also 72.6% said that people around them think they have other health problems because they have TB. And the commonly associated was HIV infection and malnutrition, which is similar to previous studies.[14,15]

In contrast to this scenario, only 35% said they were made to feel embarrassed about the disease.70.1% chose to stay away from social gatherings while only 30.1% were actually asked to stay away. This peculiar finding is in contrast with the previous study where people admitted that they were not invited to the social gatherings.[8]Also present study shows 72.6% people reported lowered self-esteem which is higher than the previous studies.[10,11]It proves that perceived stigma forms the major part of the disease stigma rather than the enacted stigma. Patients are more concerned about their status in the society that makes them feel discriminated while in real case the percentage of discrimination for their illness is less than that's enacted.

On a positive side, this study shows that almost 95% were aware that they don't transmit infection to people around them if they are cured by treatment with Anti Tubercular drugs. This is against the popular thought that lack of awareness about the disease is the cause of persistence of stigma. Stigma is persistent even in people who have enough knowledge on TB and its transmission routes. Hence, it isn't the lack of knowledge rather it is the fear of infection, which is the root cause of stigma among healthy individuals.[2]But this increased awareness has also encouraged symptomatic individuals to seek medical care and TB patients to adhere to treatment. So, an effective doctor patient relationship with initial and follow up counselling in order to keep their mental status in check and helping them to seek psychiatric help when necessary is an important part of tuberculosis treatment plan. This also requires government intervention via policies and help from social groups for tuberculosis that can aid in reducing stigma and pave a path for eradication of Tuberculosis.

CONCLUSION

This study reports there is a presence of stigma among TB patients of rural Tamil Nadu. Tuberculosis affects the person psychologically as much as physically. TB is treated intensively with drug therapy to eliminate the bacteria from the body. The same way it must be treated psychologically by providing support and counselling to them. These measures will further enhance the rate of reporting and patient compliance. Addressing stigma and combating it, is yet another giant leap towards eradication of Tuberculosis.

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