

## A SOCIOLOGICAL STUDY ON STIGMA AMONG TB PATIENTS IN DELHI\*

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### Summary

**Setting :** The study was carried out at Delhi State, New Delhi.

**Objectives :** 1. To assess the effect of social stigma in TB patient's treatment, their personality, emotions, feelings, changes in their thinking process and behaviour of their family members, friends.

2. To study the relationship of gender and to what extent social stigma affects their lives.

**Design :** It was a prospective study. A total of 1977 newly diagnosed and registered cases under Revised National TB Control Programme for treatment during the period of March 2009 to May 2009 were included in the study. Out of a total population of 170 lacs, a proportion of 31 lacs of Delhi, distributed among five chest clinics of Delhi, comprised the study population. All the patients were interviewed according to a pre-designed & pre-tested questionnaire after taking informed consent of the patients. The data was collected and analysed after processing into MS excel sheets for statistical analysis.

**Results :** There was an immense stigma observed at society level with 60% of the patients hiding their disease ( $p < 0.05$ ) from friends and neighbours. Stigma was observed more among middle and upper middle class when compared to lower middle class and lower class ( $p < 0.05$ ). Gender-wise further it was observed that stigma was more among females ( $p < 0.05$ ) than in males.

**Conclusion :** The study has demonstrated that despite good performance of Revised National TB Control Programme the stigma in tuberculosis still remains a problem and we need to supplement the efforts in advocacy, communication and social mobilization for reducing the stigma problem among TB patients in effective control of tuberculosis.

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**Key words :** Stigma, tuberculosis, gender.

## INTRODUCTION

Tuberculosis (TB) is one of India's most important public health problems. India accounts for nearly one fifth of the global TB burden. Every day in India more than 20,000 people develop the disease, and more than 1000 die from TB<sup>1</sup>. TB is a classical example of a disease with both medical and social dimensions, characterized by its close relation to poor socio-economic conditions<sup>2</sup>. TB patients experience psychological and social sufferings and their basic rights may be negated. Amongst problems met by TB patients, social stigma has been increasingly recognized. Social stigma is "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society"<sup>3</sup> India lags far behind developed countries in managing tuberculosis (TB)

because of social stigma attached to it. The stigma attached to TB adds to the burden of disease for both men and women, and even more so if they are of marriageable age. While men have to deal with the stigma at their work place and at the community level, women are faced with ostracism within the household and in the immediate neighbourhood. They are also inhibited in discussing their illness and participating in social functions due to fear of becoming an outcast<sup>4</sup>.

Implementation of Directly Observed Treatment Short Course (DOTS) under Revised National TB Control Programme, improved IEC activities, ACSM, continuing medical education programmes, community meetings, public health messages and increased dissemination of knowledge about the transmission of tuberculosis has certainly

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made a considerable difference in overcoming the stigma among TB patients. Nevertheless in India the stigma to TB is still rampant and is an important factor which not only delays the initiation of treatment but is also a major factor in hindering adherence to treatment.

A study was carried out at New Delhi Tuberculosis Centre to define the problem of social stigma among TB patients in the domiciliary area covered under Revised National TB Control Programme in Delhi.

### OBJECTIVES

1. To assess the effect of social stigma in patient's treatment, their personality, emotions, feelings, changes in their thinking process and behaviour of their family members, friends etc.
2. To study the relationship of gender and to what extent social stigma affects their lives.

### MATERIAL AND METHODS

Study population comprised 31 lacs population of Delhi out of a total population of 170 lacs distributed among five chest clinics of Delhi namely Gulabi Bagh, R.K. Mission, LNJP, Jhandewalan and Pili Kothi. Almost all chest clinics had representation of slum population as well.

A total of 2196 patients diagnosed and registered under the Revised National TB Control Programme for treatment during the period of three months i.e. March 2009 to May 2009 were included in the study. All these patients were subjected to personal detailed interview according to a pre-designed semi-structured questionnaire after taking informed consent of the patients. The questionnaire contained various questions formed to elicit requisite information about the knowledge of tuberculosis action taken by the patients, their experience at work place and their family response. Before conducting the study, the proforma was pre-tested and evaluated for proper conduct of the study. The interviews

were conducted by two properly trained health visitors having diploma in TB Health Visitor's course and who had been specially trained for the purpose. The investigators had taken special interest and supervision during these interviews. The interviews were conducted in the intensive phase of treatment.

The information was elicited from TB patients regarding 'problems faced in their homes, attitudes of neighbours, friends and co-workers. Interview included questions regarding data on socio-economic and awareness of TB and the nature of their disclosure of their disease to family members, relatives, neighbours, friends and employers. The information was also elicited regarding behavioural changes such as maintaining appropriate personal distance and avoiding close contact activities with family members neighbours, friends and other fellow employees.

The data was scrutinized and analysed after processing into MS excel sheets in computer for statistical analysis and chi square test and proportion tests were used to assess significance. A value of  $p < 0.05$  was taken as significant.

### RESULTS

Out of a total of 2196 patients registered for treatment in the three months period, 20 had expired and 53 children below 14 years of age were excluded, leaving 2123 for interview. Out of these remaining 2123 patients, 1977 (93.1%) could be interviewed. The various reasons of those who could not be interviewed (6.9%) were patients on non-DOTS treatment (49), defaulters (38), left locality (9) or taking treatment from covered services like ESI (11) and therefore not available for personal interview at the DOT Centres.

Five chest clinics which were selected for the study are Gulabi Bagh where 478 patients interviewed formed 24.2% of total study length, R.K. Mission 527 patients had 26.6% representation, Jhandewalan had 385 patients 19.5% representation, LNJP had 286 patients 14.5% representation and Pili Kothi had 15.2% representation 301 patients who were interviewed in the study.

**Table 1:** The stigma at family level

S.No.		No.	Percentage	Significance
1.	Total No. of patients interviewed.	1977	100.00	----
	Disclosure of their disease in their family.	1961/1977	99.2	No Stigma
	• Male	1131/1144	98.9	No Stigma
	• Female	830/833	99.6	(P>0.05)
2.	Disclosure of their disease with diagnosis as			
	• Pulmonary TB(+)	904/914	98.9	No Stigma
	• Pulmonary TB(-)	287/291	98.6	(P>0.05)
	• EP TB	770/772	99.7	
3.	Number of patients who were unmarried and between age 18-38 years.	456/888	51.3	
	• Male	330/456	72.4	
	• Female	126/456	27.6	
4.	The patients who were unmarried and not worried about marriage after having disease			
	• Male	241/330	73.0	No Stigma
	• Female	80/126	63.5	P>0.05
5.	First reaction of the family members after disclosure of disease.			
	• Supportive	1870	94.6*	Significant
	• Shocked	47	2.4	P<0.05
	• No reaction	41	2.0	
6.	No any change in the behavior of spouse in married patients.	1002	92.0	Significant
	• Male	599/634	94.5	Z=5,
	• Female	403/455	88.6	P<0.05
7.	The sharing of information about disease with the family members.	1178/1977	59.6	
	• Male	743/1144	64.9	Significant
	• Female	435/833	52.2	Z=5.93
				P<0.05

**Table 2:** The stigma at work level

S.No.		No.	Percentage	Significance	
1.	Total number of patients interviewed.	1977	100.00	----	
	Employed.	773	39.1		
	• Males	723/773	93.5		
	• Females	50/773	6.5		
2.	Disclosure of their disease among				
	Males	Colleagues	595/723	82.3*	Z=3.93 P<0.05* Z=4.6 P<0.05**
		Employers	576/723	79.6**	
	Females	Colleagues	30/50	60.0*	Significant
		Employers	26/50	52.0**	
Total	Colleagues	625/773	80.8	No Stigma	
	Employers	602/773	77.9		
3.	No change in behaviour.			Significant Z=2.76 P<0.05	
	• Males	573/723	79.9		
	• Females	28/50	56.0		
4.	Continuing with the same jobs.			Significant Z=2.76 P<0.05	
	• Males	679/723	93.9		
	• Females	42/50	84.0		
5.	Allowed to attend the clinic for treatment of disease				
	• Yes	35	4.5		
	• N.A.	738	95.5		

If we see the sex wise distribution, then we can say that males were more than females, 1144 (57.8%) / 833 (42.2%) females formed the ration 1:1.37. Out of total number, 1413 (71.3%) were literate and 567 (28.7%) were illiterate. As far as marital status is concerned, 1089 patients were married and 888 were unmarried. Further we have bifurcated total strength in six different heads of occupation i.e. Employed (773), Unemployed (185), Students (422), Retired (47), Housewives (412) and others (138).

Out of total 1977 patients who were interviewed, 1144 were newly diagnosed males and

833 were females. They were further categorised in three categories as per the RNTCP recommendations, 914 were pulmonary smear positive, 219 were pulmonary smear negative and 772 were extra-pulmonary. Most of the patients belonged to Category I (1237) rest of 424 belonged to Category II and 316 in Category III. 79.3% (1568) patients had no history of ATT, 81.6% (1613) did not have any TB patients in the family. Almost every patient was given initial motivation.

No stigma at family level was observed in the present study and the family members by large were found supportive to the patients (P<0.5). This

**Table 3:** The stigma at society level

S.No.			No.	Percentage	Significance
1.	Number of interviewed patients belonged				
	1. Upper Class Upper Middle Class		203	10.3	
	2. Lower Middle Class Upper Lower		905	45.8	
	3. Lower		869	43.9	
2.	Number disclosed their disease among Friends – F, Neighbourers - N				Significant Z= 5.97 P<0.05
	◆ 1 Upper Class	F	120/203	59.1*	
		Upper Middle Class	N	121/203	
	◆ 2 Lower Middle Class	F	583/905	64.4	
		N	602/905	66.5	
	◆ 3 Upper Lower Class	F	688/869	76.8*	
		N	666/869	76.6	
	3.	Patients disclosed their disease at society level.			
• Yes			788	39.9	
	• No		1189	60.1	
4.	Number disclosed their disease among				Significant Z=8.5 P<0.05 Significant Z=7.0 P<0.05
	Male	Friends	876/1144	76.5	
		Colleagues	869/1144	75.9	
	Female	Friends	495/833	59.4*	
Colleagues		520/833	64.4**		
5.	Number of patients who have been invited for social ceremonies after disclosure of their disease				No Stigma  No Stigma
	Male	Friends	534/876	60.9*	
		Colleagues	524/869	60.2**	
	Female	Friends	338/495	68.2*	
Colleagues		338/520	63.7**		

◆ Classification based on Socio economic criterion of Kuppaswamy's socio-economic status scale modified for 2007.

could have been the result of efficiently running DOTS programme in the area for over 10 years. Sharing of information with family however was significantly less among female patients ( $P < 0.5$ ) as compared to males.

At the work level also, the study did not find any significant stigma with 80.8% having disclosed their disease to their colleagues and 77.9% to their employers. However when analysed according to sex, less female patients shared their disease with colleagues as well as their employers as compared to males and this was found significant statistically ( $Z = 3.93$ ,  $P < 0.5$  and  $Z = 4.6$ ,  $P < 0.5$ ). Patients were allowed by their employees to attend the chest clinic for treatment and 93% were continuing the same jobs and continuing treatment.

There was an immense stigma observed at society level with 60% of the patients hiding their disease ( $P < 0.5$ ) from the friends or neighbours and this was found to have statistically significant difference with more stigma among middle and upper middle class when compared to lower middle class and lower class. Moreover the stigma was observed to be more among females ( $P < 0.5$ ).

## DISCUSSION

The consequences of stigma can be seen affecting care-seeking behaviours, as patients have been known to hesitate or choose not to disclose their TB status to family or friends out of fear of being socially avoided. Stigma has also been shown to hinder adherence to treatment. Research has demonstrated that in some cases personal rejection occurs as a result of the strong stigma surrounding TB. Understanding patient's perception about tuberculosis will enable better design of a client-oriented comprehensive programme for tuberculosis<sup>5</sup>. By identifying both the sources and consequences of stigma, social science research has illustrated the need for effective intervention strategies<sup>6</sup>.

Stigma in tuberculosis patients is usually of two types<sup>7</sup> – one i.e. a fear of the patient about other's behaviour to him and a sense of inferiority due to

development of tuberculosis i.e. **perceived stigma**; and other due to actual discrimination or being actually avoided by the people since the patient has now tuberculosis i.e. **enacted stigma**. Patient often tries to hide his/her disease from others due to stigma resulting in further delay in diagnosis and treatment and thus increase chances of transmission to healthy community.

In a study by K. Jaggarajamma<sup>2</sup> *et al*, among both male and female TB patients enrolled under Revised National TB Control Programme, perceived stigma was more than enacted stigma in the context of personal, family, community and work place interactions. One third of the TB patients were reluctant to attend social functions due to their illness. About 10-25% of the patients experienced negative reactions from the family members. Problems related to marriage prospects were expressed by 63% of unmarried patients from this study. Uplekar *et al*<sup>8</sup> also reported that parents of the young women don't want to reveal their daughter's illness or don't want to send them to DOTS due to difficulties that may arise in marrying them. However the present study did not substantiate this. Compared to the study by Jaggarajamma *et al*<sup>7</sup>, the present study revealed more supportive attitudes of the family for the patients & more tolerance by the colleagues at the work place. But at society level 60% of patients preferred to hide their disease ( $P < 0.5$ ) from friends & neighbours & this stigma at society level was observed to be significantly higher among females and also among high middle and upper class. However, it may be mentioned here that the number of patients in their study was 350 and only 79% (276) of the patient included could be interviewed whereas in the present study 1977 (i.e. 93.1%) could be interviewed.

Though the RNTCP has improved the stigma situation regarding tuberculosis, but still enough needs to be done to change the mind set of the patients and the society. Reducing stigma about TB can only break the barrier of having undisclosed TB patients who keep on spreading the disease. Once stigma is removed, these patients will volunteer themselves at the TB Centre for DOTS treatment and once effective treatment is started these patients



will turn non-infectious within two weeks of start of DOTS therapy. Fear of infection had been identified as the main reason for the stigmatization attitudes and behaviour of both health professionals and community members towards those with TB. A study conducted in Ghana<sup>9</sup> found that the activities of health professionals could be a basis of stigmatization of those suffering from TB in society. The use of isolation wards by most hospitals, and the observation that some doctors and nurses use mask and gloves when dealing with TB patients can lead to stigmatization of TB in the eyes of the community members. Besides, the humiliating attitudes and behaviour of health professionals and open avoidance of TB patients could send a message to the community members that TB is a shameful disease.

Another study was conducted in Thailand<sup>10</sup> to assess social stigma, knowledge and belief about TB/HIV co-infected patients. Out of 769 enrolled, 500 (65%) reported high TB stigma, 177 (23%) low TB knowledge and 379 (49%) low HIV knowledge. Patients with low TB knowledge were more likely to have severe TB disease.

DOTS programme has been in operation in Delhi since 1997 and total coverage had been achieved in March 2006 and a desirable change in the stigma against TB has been felt. Macq Jean *et al* from rural Nicaragua<sup>11</sup> also demonstrated that perceived stigma among TB patients is significantly reduced when a package of interventions including TB clubs, patient's centered home visits is successfully implemented.

**To conclude, the study has demonstrated that despite the excellent performance of Revised National TB Control Programme for over more than a decade in Delhi and the excellent results of success rates over 82% and case detection of over 70%, the stigma in TB still remains a problem and we need to supplement our efforts in Advocacy, Communication and Social Mobilization for reducing the stigma problem among TB patients which will pay dividends towards effective TB control and to achieve millennium development goal.**

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