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Study of Social Factors for Persistence of Stigma among Tuberculosis Patients

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ABSTRACT

Background: *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.* ***Aim:*** *Thus this study was planned to study the social factors behind persistence of stigma among tuberculosis patients in our society.* ***Methods:*** *Study subjects were randomly selected and interviewed when they visited the DOTS center. Pre-structured, pretested questionnaire was used for data collection. The questionnaire consisted of questions related to: Socio-demographic profile, Treatment history and Social stigma among TB patients attending DOTS centre.* ***Results:*** *Forty-four subjects were afraid of disclosing disease to friends. Seventy percent disclosed their disease to friends. Over ninety percent of friends behaved normal to them. Over fifty percent of them were afraid to disclose the status at their workplace. 56.6% subjects disclosed their ailment at their workplace. 50 percent of co-workers avoided them after knowing the disease status whereas a few isolated themselves.27% of the subjects felt bad about others behavior towards them. 25% of participants blamed themselves guilty for this. 14% of the families reacted in the form of isolation. 78% of unmarried subjects were worried about their marriage in the future.* ***Conclusions:*** *Keeping factors behind such stigma in mind, we found scope to improve various aspects like motivate patient's family to provide family support, reducing negative reactions of the family.*

1. Introduction

Tuberculosis is one of India's major public health problems. According to WHO estimates, India has the world's largest tuberculosis epidemic.[1] Many research studies have shown the effects and concerns revolving around TB, especially in India; where social and economic positions are still in progression.[2,3] Those listed are all the bodily and personal causes of acquiring TB, but decreases in tuberculosis in India incidence are correlated with improvements in social and economic determinants of health more so than with access to quality treatment.

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."[4] It is also "a social process to be understood in relation to the concept of power, domination and difference. It is a process worsening already existing inequalities and exclusions."[5]

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.[6]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. Thus this study was planned to study the social factors behind persistence of stigma among tuberculosis patients in our society.

2. Materials and methods

Department of sociology, psychology and community medicine conducted this cross-sectional study jointly during in year 2018. Tuberculosis patients taking treatment at DOTS centers in the study area formed the study population. Information about DOTS centers in the study area was fetched from the office of civil surgeon. Based on that information, five DOTS centers were selected randomly. Purposive sampling technique was adopted. Twenty eligible patients were interviewed at each DOTS center. Thus sample size was 100. Patients diagnosed with tuberculosis, seeking treatment at these DOTS centers and patients of age more than 18 years formed the inclusion criteria.

DOTS centers were approached around 10.30am. Study subjects were randomly selected and interviewed when they visited the DOTS center. Four to five interviews were conducted in a single day. One DOTS center was covered in one such visit. A single interviewer conducted all the interviews to keep sense of uniformity. It took an average of 20 minutes to complete one interview.

Pre-structured, pretested questionnaire was used for data collection. The questionnaire consisted of questions related to: Socio-demographic profile, Treatment history and Social stigma among TB patients attending DOTS centre. Written informed consent was obtained in the local language from every study subject before conducting each interview. They were explained about the nature and purpose of study and requested to participate. To obtain consent, he read the contents of the consent information sheet out loud to each respondent, who was given the opportunity to ask the

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questions. They were assured privacy and confidentiality of the information provided.

The collected data was entered in Microsoft Excel. Coding of the variables was done. The analysis was done by Statistical Package for the Social Sciences (SPSS) version 21. Interpretation of the collected data was done by using appropriate statistical methods.

3. Results

Majority of study subjects were in the age group of 18-37 years (53%) followed by in the age group of 38-57 years (32%). Most (59%) of subjects were married whereas 40% were not married at the time of study. Seventy five percent subjects were staying in nuclear families. Gender wise males outnumbered females. Majority of participants belonged to Hindu religion. Most of subjects belong to upper lower (46%) followed by lower middle (31%) class of socio-economic scale as per Revised kuppuswamy scale. (Table 1)

Table 1. Baseline characteristics of the study participants

Variable	Category	Number (%)
Age group	18-37 years	53 (53)
	38-57 years	32 (32)
	58-77 years	15 (15)
Marital Status	Married	59 (59)
	Unmarried	40 (40)
	Divorced	01 (01)
Family Type	Nuclear	75 (75)
	Joint	25 (25)
Gender	Male	58 (58)
	Female	42 (42)
Religion	Hindu	84 (84)
	Muslim	13 (13)
	Jain	01 (01)
	Buddhist	01 (01)
	Sikh	01 (01)
SES (Revised kuppuswamy scale 2014)	Upper	03 (03)
	Upper middle	16 (16)
	Lower middle	31 (31)
	Upper lower	46 (46)
	Lower	04 (04)

Majority of subjects fall in cat I of treatment category. Most of the participants were diagnosed with having pulmonary type of tuberculosis. While conducting this interview, most of subjects were in intensive phase of treatment. (Table 2)

Table 2. Treatment profile of the study subjects

Variable	Category	N (%)
Treatment category	Category I	73 (73)
	Category II	22 (22)
	Category IV	05 (05)
Type of TB	Pulmonary TB	71 (71)
	Extra Pulmonary TB	29 (29)
Phase of treatment	Intensive phase	65 (65)
	Continuous phase	35 (35)

Forty-four subjects were afraid of disclosing disease to friends. Seventy percent disclosed their disease to friends. Over ninety percent of friends behaved normal to them. Over fifty percent of them were afraid to disclose the status at their workplace. 56.6% subjects disclosed their ailment at their workplace. 50 percent of co-workers avoided them after knowing the disease status whereas a few isolated themselves. (Table 3)

Table 3: Social stigma perceived by the patients with friends and at workplace

Variable	Category	o.(%)
Afraid of disclosing disease to friends (N=100)	Yes	44 (44)
	No	56 (56)
Disclosed their disease to friends (N=100)	Yes	70 (70)
	No	30 (30)
Reactions of Friends (n=72)	Avoidance	07 (9.7)
	Normal	65 (90.3)
Afraid to disclose at their workplace (n=65)	Yes	36 (55.4)
	No	29 (44.6)
Disclosed at their workplace (n=60)	Yes	34 (56.6)
	No	26 (43.3)
Reaction at work place (n=60)	No change in behavior	21 (35)
	Isolation	08 (13.3)
	Avoidance	30 (50)
	Leave job	01 (1.7)

27% of the subjects felt bad about others behavior towards them. 25% of participants blamed themselves guilty for this. 14% of the families reacted in the form of isolation. 78% of unmarried subjects were worried about their marriage in the future. (Table 4)

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Table 4. Perceived stigma by the patients and family reaction

Variables	Category	N (%)
Perceived Stigma*	Delayed Treatment Seeking	09 (09)
	Feel Inferior	14 (14)
	Feel Burden to the family	20 (20)
	Feel Alone	15 (15)
	Feel Guilty	25 (25)
	Feel Bad About others Behavior	27 (27)
Reactionof the family*	Supportive	46 (46)
	Shocked	09 (09)
	Isolation	14 (14)
Marriage worry in unmarried (n=32)	Yes	25 (78.1)
	No	7 (21.9)
*Multiple responses permitted		

4. Discussion

Stigma is perceived as an important social determinant of health. Tuberculosis is a social disease with medical manifestations in true sense. When diseases are stigmatized, individuals show reluctance in seeking medical care and non-adherence to treatment probably due to fear of the social and economic consequences following diagnosis. Another study from Thailand,which shows that stigma is present on patients perspective towards TB.[7] Another study from Delhi is also in concordance with our observations.[8] Understanding patient's perception about tuberculosis will enable better design of a client-oriented comprehensive programme for tuberculosis. By identifying both the sources and consequences of stigma, social science research has elucidated the need for effective intervention strategies.[9]

We observed that forty-four subjects were afraid of disclosing disease to friends. Seventy percent disclosed their disease to friends. Over ninety percent of friends behaved normal to them. Over fifty percent of them were afraid to disclose the status at their workplace. 56.6% subjects disclosed their ailment at their workplace. 50 percent of co-workers avoided them after knowing the disease status whereas a few isolated themselves.A similar finding was recorded by Rajeswari R et al in her study on perceptions of tuberculosis patients about their physical, mental and social well-being. She observed that 6.7% of patients gave wrong names and addresses to avoid being exposed as TB patients to their acquaintances.[10]These results are cohort with others.[11,12]It could be due to feeling of insecurity, less autonomy and power, feeling of loosing the job perceived by the patients.

It was observed in this study that 27% of the subjects felt bad about others behavior towards them. 25% of participants blamed themselves guilty for this. 14% of the families reacted in the form of isolation. It is a common myth among people that the food/utensil gets contaminated on being used by a person who eats from it, if he or she is having some disease like tuberculosis. TB patients are often subjected to such unnecessary sanctions at home. Fears about getting infected with TB, often lead to isolating experiences such as forcing a TB patient to use a separate utensil. Other forms of isolation included washing clothes separately, giving separate room, neglect by the families and not being permitted to attend the social functions with more male patients reporting this.[13]

Not surprisingly our study shows that 78% of unmarried subjects were worried about their marriage in the future. Another study 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.[14] It was also noted that unmarried females deliberately looked for health care center for her treatment far away from home because they had apprehension that disclosure of the diagnosis could cause them harm in searching a partner for her marriage. The impact of TB-related stigma on marriage was also noted in few other investigations. Many of these found that TB-related stigma affected the marriage prospects of both genders, with men having a slightly more difficult time finding a wife in areas with a low female/male ratio.[15,16] Another author from Sialkot[17] observed divorce as a direct consequence of TB to be more likely to affect females and TB-infected females were more likely than TB-infected males to face difficult marital prospects.

5. Conclusions

On the basis of findings of this study it can be concluded that stigma among tuberculosis patients still remains a problem. Keeping factors behind such stigma in mind, we found scope to improve various aspects like motivate patient's family to provide family support, reducing negative reactions of the family. Such client centered tailored approach to reduce TB stigma is expected to pay dividends towards effective tuberculosis control.

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