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Study of social stigma among tuberculosis patients from western Uttar Pradesh

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Abstract

Background: Understanding tuberculosis-related perceived stigma will enable us to provide programmatic inputs for effective intervention strategies. Aim of this investigation was to assess the social stigma among the tuberculosis patients attending DOTS centers and to find out the factors related to social stigma perceived by them.

Methods: Three hundred subjects diagnosed with tuberculosis seeking treatment at DOTS centers were interviewed using a structured questionnaire. Patients aged >18 years diagnosed with tuberculosis, seeking treatment at these DOTS centers were included in this study. Study subjects were randomly selected and interviewed when they visited the DOTS center.

Results: Out of total, >65% subjects experienced stigma. 42% (n=126) revealed that they had fear of disclosing illness to his or her friends. About 31% (n=92) did not disclose their illness to friends. 20.3% (n=52) subjects faced a negative reaction in the form of avoidance by their friends after knowing about their illness. 40 (37%) females compared to 50 (26%) males felt bad about behavior of others towards them after knowing their illness. 37% of females and 19.8% of male subjects were shocked and upset by reaction of family members.

Conclusion: TB stigma is still deep rooted in our society. Study provided a fair idea about factors behind the stigma and gave us the direction for making improvements. Patient centric tailored approach to reduce TB stigma is expected to pay dividends towards effective tuberculosis control.

Keywords: Tuberculosis, social stigma, community

1. Introduction

Tuberculosis (TB) is one of chronic infectious disease and is a leading cause of morbidity and mortality worldwide including India. This disease still accounts for nearly one fifth of the global TB burden [1]. TB kills approximately 480,000 Indians every year i.e. more than 1,400 every day and continues to be India's severe health crisis [2]. TB brings physical sufferings apart from lot of psychological trauma and a wide range of social consequences. Tuberculosis is truly a social disease with medical manifestations, characterized by its close relation to poor socio-economic conditions [3]. Recently social stigma has increasingly been recognized in tuberculosis patients.

Stigma stands as decreasing attribute which arises from social interaction and is related to the power dominance and difference [4]. Social (enacted) stigma refers to 'an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society [3] while perceived stigma refers to the shame and expectation of discrimination that prevents people from talking about their experiences and sense of unworthy and guilty. TB is already a highly stigmatized disease. It is known that stigma in TB is perpetrated and reinforced by health staff, family, neighbours, and other groups [5, 6].

Perceived stigma renders patients to refuse disease and medical services that leads to distortion of health condition making difficult to treat. This increases the infectivity and communicability of the disease. Understanding tuberculosis-related perceived stigma will enable us to provide programmatic inputs for effective intervention strategies. Therefore this study aimed to assess the social stigma among the tuberculosis patients attending DOTS centers and to find out the factors related to social stigma perceived by them.

Materials and Methods

This cross-sectional observational study was planned and conducted by Department of sociology and community medicine during August 2017- February 2018. Study area was DOTS centers in the Aligarh district. Tuberculosis patients visiting the DOTS centers in the study area to take the medicines, served as study population. Location and address of these centers was obtained from office of civil surgeon of the district. Of total DOTS centers, ten were selected randomly. Purposive sampling technique was used in this study. Thirty eligible patients were interviewed at each DOTS center. Thus sample size was 300. Patients aged >18 years diagnosed with tuberculosis, seeking treatment at these DOTS centers were included in this study.

Investigators visited study centers around 11 am. Study subjects were randomly selected and interviewed there after obtaining informed consent. Ten subjects were interviewed in a single day. One DOTS center was covered in one such visit. Investigators took half an hour on an average to complete one interview. A structured questionnaire was used for data collection. Study tool included a structured interviewer administered questionnaires on socio-demographic characteristic that mainly focused on age, sex, education, occupation, marital status, religious view of the study participants, and others. The questionnaire also consisted of questions related to Treatment history and Social stigma among TB patients attending DOTS center. 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 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. We used SPSS version 22 to analyze the data. Results were expressed by percentages and proportions. Interpretation of the collected data was done by using appropriate statistical tests like chi-square test wherever applicable. A two-tailed $P < 0.05$ was considered statistically significant.

Results

Data of 300 subjects was included and analyzed in this study. Majority of study subjects ($n=160$, 53.4%) were in the age group of 20-40 years followed by 36.0% ($n=108$) in the age group of 40-60 years. Male participants outnumbered females. Most ($n=184$, 61.3%) of the subjects were married. 72.0% ($n=216$) subjects were staying in nuclear family. (Table 1) Out of total, 98 (65.3%) subjects experienced stigma.

Table 1: Socio-demographic profile of the study subjects

| Variables | Category | Number | Percentage |
|----------------|-------------|--------|------------|
| Age group | <20 years | 10 | 3.3% |
| | 20-40 years | 160 | 53.4% |
| | 40-60 years | 108 | 36.0% |
| | >60 years | 22 | 7.3% |
| Sex | Male | 192 | 64.0% |
| | Female | 108 | 36.0% |
| Religion | Hindu | 210 | 70.0% |
| | Muslim | 90 | 30.0% |
| Marital Status | Married | 184 | 61.3% |
| | Unmarried | 116 | 38.7% |
| Type of family | Nuclear | 216 | 72.0% |
| | Joint | 84 | 28.0% |

Majority of participants (224, 74.7%) were beneficiary of the treatment category I of DOTS. 84.7% ($n=254$) of the participants were diagnosed having pulmonary tuberculosis. Most (60.7%) of participants (cases) were receiving intensive phase of treatment. 74.7% of the cases were newly registered cases. (Table 2)

Table 2: Treatment profile of the study participants

| Variable | Category | Number | Percentage |
|--------------------|-------------------------|--------|------------|
| Treatment category | Category I | 224 | 74.7% |
| | Category II | 76 | 25.3% |
| Type of TB | Pulmonary TB | 254 | 84.7% |
| | Extra Pulmonary TB | 46 | 15.3% |
| Phase of treatment | Intensive phase | 182 | 60.7% |
| | Continuous phase | 118 | 39.3% |
| Type of patient | New | 224 | 74.7% |
| | Relapse | 30 | 10.0% |
| | Treatment after default | 22 | 7.3% |
| | Transfer in | 14 | 4.7% |
| | Failure | 10 | 3.3% |

On questioning about disclosing illness to friends, 42% ($n=126$) revealed that they had fear of disclosing illness to his or her friends. About 31% ($n=92$) did not disclose their illness to friends. 20.3% ($n=52$) subjects faced a negative reaction in the form of avoidance by their friends after

knowing about their illness. About 64% revealed that they had fear of disclosing illness at place of work. Almost 34% of study subjects did not disclose their illness at workplace. (Table 3)

Table 3: Perceived social stigma with friends and at workplace

| Variables | Category | No. (%) |
|---|----------|------------|
| Perceived stigma with friends | | |
| Fear of disclosing illness to friends (N=300) | Yes | 126 (42.0) |
| | No | 174 (58.0) |
| Disclosed their illness to friends (N=300) | Yes | 208 (69.3) |
| | No | 92 (30.7) |

| | | |
|--|-----------------------|------------|
| Reactions of friends (N=256) | Avoidance | 52 (20.3) |
| | Normal | 204 (79.7) |
| Perceived stigma at workplace | | |
| Fear of disclosing illness at their workplace (N=166) | Yes | 106 (63.9) |
| | No | 60 (36.1) |
| Disclosed their illness at workplace (N=130) | Yes | 86 (66.1) |
| | No | 44 (33.9) |
| Reaction at work place (N=86) | No change in behavior | 42 (48.8) |
| | Isolation | 18 (20.9) |
| | Avoidance | 18 (20.9) |
| | Leave job | 8 (9.3) |

Out of total 192 male and 108 female study subjects involved in the study, 40 (37%) females compared to 50 (26%) males felt bad about behavior of others towards them after knowing their illness (p value = 0.04). 37% of females and 19.8% of male subjects were shocked and upset by

reaction of family members and this observation was found to be statistically highly significant. About half of the males and females were worried about their marriage, if his/her ailment becomes public. (Table 4)

Table 4: Perceived stigma by the patients and family reaction.

| Variables | Sex | | P-value |
|---|--------------------------------|--------------|-----------|
| | Male N (%) | Female N (%) | |
| Perceived stigma* | Feel liability to the family | 52 (27.1) | 0.03 |
| | Feel bad about others behavior | 50 (26.0) | 0.04 |
| | Feel guilty | 42 (21.9) | 0.02 |
| | Feel inferior/degraded | 30 (15.6) | 0.04 |
| | Feel alone | 28 (14.9) | 0.008 |
| | Delayed treatment seeking | 20 (10.4) | 0.16 |
| Reaction of the family* | Sympathetic and concerned | 156 (81.2) | 0.25 |
| | Shocked and upset | 38 (19.8) | 0.001 |
| | Isolation | 19 (9.3) | 0.0005 |
| Concern about marriage among unmarried (n=58) | Yes | 36 (51.4) | 0.93 |
| | No | 24 (52.2) | 22 (47.8) |

*Multiple responses permitted

Discussion

TB is highly stigmatized disease that can be experienced and felt at a different social setting like home, workplace, and community thus 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. Many scientists have tried to analyze the effects of stigma and discrimination associated with TB. The key effects in developing countries are social isolation of patients, both outside the family, where the person may be avoided by former friends and acquaintances, and inside the family where the patient may be forced to eat and sleep separately [7, 8].

In the current study, more than sixty five percent of participants experienced one or other forms of the stigma. Our findings confirm the results of another study from Vietnam, which shows that stigma is present on patient's perspective towards TB [9]. Another study from Delhi, also observed similar results [10]. Comprehensive programme for control of tuberculosis can not succeed unless it considers clear understanding of patient's perception about the disease and such concept becomes really important while designing a client-oriented preventive programme. By identifying both the sources and consequences of stigma, social science research has revealed the need for effective intervention strategies.

In this study more than forty percent subjects had fear of disclosing illness to his or her friends. Almost 31% did not

disclose their illness to friends. These observations are similar to another study by an author who studied socio-economic impact of tuberculosis on patients and family in India [11]. She observed that 6.7% of patients gave wrong names and addresses to avoid being exposed as TB patients to their acquaintances. Similar observations were made by others [12, 13]. A possible explanation can be given as they were feeling insecure or had fear of losing job if the ailment was disclosed.

Study finds that 37% of females and 19.8% of males were shocked and upset by reaction of family members. TB patients are often face unnecessary sanctions and harassments due to a variety of myths prevalent among the society members. One of such myth is 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. People have fear that if by any chance its open in society that he has TB then his or her utensils will be separated and no one will give him even glass of water. 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 [14].

It is observed that those having poor knowledge of Tb suffer from severe forms of the disease. Sirinapha X from Thailand assessed perceptions of subjects with TB/HIV co-infection [15]. In that study, 65% reported high TB stigma, 23% had low TB knowledge and 49% were having low HIV knowledge. A lot of negative reactions of the family members were noted down. This provides us an idea about the direction of work, involvement of community DOTS

providers in order to reduce the stigma, and motivation of patient's family to provide family support.

The ability to arrange marriage was a key feature of stigma for this study sample. We observed that a big proportion of unmarried females were worried about their marriage in case ailment is disclosed. Community members anticipated an adverse impact on marriage, not only for people with TB, but also for their family members. Uplekar MW *et al.* observed 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 [16]. 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. Furthermore, anticipation of problems in ongoing marriage for the male vignette counters a cultural stereotype that women with TB are more vulnerable to marital problems. 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 [17, 18]. However, it also reflects woman's own value judgment of looking after family and her culturally sanctioned role of supporting her husband in a close-knit rural community. Findings also suggest that strong family bonding and community support can have a positive implication for stigma reduction. Another author from Pakistan [19] 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.

Conclusions

On the basis of findings of this study, it can be said that TB stigma is still deep rooted in our society. Study provided a fair idea about factors behind the stigma and gave us the direction for making improvements. There is definitely a wide scope to improve various aspects like motivate patient's family to provide family support, involvement of community DOTS providers in order to reduce negative reactions of the family. Patient centric tailored approach to reduce TB stigma is expected to pay dividends towards effective tuberculosis control.

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