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Case Report

## To study the awareness level and psycho-social impact of Tuberculosis on a Patient's life

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### **Abstract**

**Background:** Tuberculosis (TB) is a major health problem worldwide, not only because of current cases of active disease and emergence of drug resistant TB (DR-TB) but also because of the threat of latency and co infection with HIV. The major reason behind this is the lack of proper knowledge about the disease among patients and people in general. They are unaware about adhering to the treatment, mode of transmission of the disease and as such are prone to transmit it to others. Lack of knowledge about treatment plan leads to relapse. An important aspect of TB is its socio-psychological effect on the patient.

**Methods:** The work set-up was a prospective questionnaire based study from Feb 2016 to July 2016 conducted by third year undergraduate medical student in TB patients registered under RNTCP center of defined King George's Medical University, UP, Lucknow (KGMU-RNTCP) for Directly Observed Treatment Short course regimen (DOTS). This study was carried out on 150 TB patients. The rationale of our work was to understand the level of awareness about TB disease.

**Results:** The study results clearly show that a large number of patients suffering from TB don't have knowledge about its etiology, mode of transmission, methods of prevention. Many patients have reported considerable decrease in their social life and many have received negative treatment from friends and society. Majority of patients are getting full support and cooperation of the family but few patients claim of ill treatment by family members.

**Conclusion:** Awareness programs and psychological workshops can be organized to give proper knowledge about the disease to the patients and attendants and the nature of treatment so as to remove fear, misconceptions about TB and minimize relapse cases.

Keywords: Tuberculosis, RNTCP, Social life, Drug-resistance, Mode of transmission.

### 1. Introduction

TB is a common and deadly infectious disease caused by the *Mycobacterium tubercuolsis* (Mtb). It is one of the oldest recorded, most prevalent microbial human infections. One of the most remarkable features of Mtb is it's capacity to cause both symptomatic disease and asymptomatic infection in human. Emergence of drug resistant TB; rise in HIV infection levels and the neglect of TB control programs have lead to the resurgence of TB [1]. Some studies have reported depression, anger, loneliness, suicidal ideation and suicidal behaviour in TB patients [2,3].

Behaviour of society towards them is often full of prejudice and most of the time patients feel lonely and disheartened. Families also often disown the patient as a TB patient is considered burden in the family since it affects his /her working capacity. Physical recovery from TB is affected by patient's psychological problems such as feeling insecure, fear of isolation, fear of spreading disease to children and the lack of support at family as well as community level. A number of factors have been identified to be associated with better health-related quality of life in TB patients relating to

younger age [4], higher household income [5], no stigma [6], less depression and family support [7].

### 2. Methods

### 2.1 Study design

The present work was a prospective questionnaire based study among TB patients registered under RNTCP center of King Georg's Medical University, UP, Lucknow (KGMU-RNTCP) for Directly Observed Treatment Short course regimen (DOTS).

### 2.2 Study participants and sampling procedures

This study was carried out on 150 TB patients. All recruited TB patients were consecutively interviewed. The interviews were conducted by trained external research assistants for a period of 6 months from Feb 2016 to July 2016. The study was performed on patients receiving combination of anti tubercular therapy (ATT) for the management of TB. Patients who were above 18 years of age and gave written consent for participating in the study were included; whereas patients below 18 years of age were excluded from the study. The questionnaire was related to:

- Patient's knowledge about disease- its etiology, prevention of transmission and importance of taking complete treatment course.
- Psychosocial impact of disease on patients: which includes
- > Depressive episodes- Panic episodes
- > Suicidal tendencies- Substance abuse
- > Social problems-Family support

The collected data has been presented in form of the percentage of people out of 150 for each respective disorder.

#### 3. Results

### 3.1 Demographic and Socioeconomic characteristics

This study consists of 150 TB patients. They were selected through purposive sampling from the outpatient department of Respiratory Medicine, KGMU, UP, Lucknow. A researcher-designed questionnaire was used to record information about participant's age, gender, educational level, marital status, income, employment status, dwelling characteristics and residential status.

### 3.2 The description of the patients

The study group includes age group as follows: 17 patients below age 20 years, 31 patients between 21-30 yrs, 46 patients between 31-40 yrs, 38 patients between 41-50 yrs and 18 patients above 50 years (Table 1). There were 89 (59%) males and 61 females (41%). Most of the patients were Hindus 96/150 (64%) followed by Muslims 54/150 (36%). There were 62 patients (41.33%) from urban areas whereas 88 patients (58.66%) from rural background.

Occupationally 24 patients (16%) were student, 41 patients (27%) were skilled and 54 (36%) were unskilled workers. 31 patients (20%) were housewives. Education status of the patients was 27 (18%) educated up to primary level, 30 patients (20%) who studied up to middle school, 55 patients (37%) completed secondary level and 38 patients (25%) with graduation. The patients were categorized into pulmonary TB (PTB) 86 (57%), relapse cases 50 (33.0%) and drug resistant cases 14 (9.0%) (Table 2).

Table 1: Age profile of Patients

SN.	Age group	Frequency	Percentage
1.	< 18	17	11.33
2.	20 - 30	31	20.66
3.	31-40	46	30.66
4.	41- 50	38	25.33
5.	51- 60	18	12.00
	Total	150	100%

**Table 2: Demographic Profile of Patients** 

1 G 1					
1.	Gender				
	Male	89	59.0%		
	Female	61	41.0%		
2.	Religion				
	Hindus	96.0	64.0%		
	Muslims	54.0	36.0%		
3.	Domicile				
	Urban	62	41.33%		
	Rural	88	58.66%		
4.	Occupation				
	Student	24.0	16.0%		
	Skilled worker	41.0	27.0%		
	Unskilled worker	54.0	36.0%		
	Housewife	31.0	20.0%		
5.	Education				
	Up to class 5 <sup>th</sup>	27.0	18.0%		
	Class 5 <sup>th</sup> -8 <sup>th</sup>	30.0	20.0%		
	Class 8 <sup>th</sup> -12 <sup>th</sup>	55.0	37.0%		
	Graduate	38.0	25.0%		
6.	Category				
	Pulmonary TB	86.0	57.0%		
	Relapse cases	50.0	33.0%		
	Drug resistant cases	14.0	9.0%		

## 4. Knowledge about etiology of TB

Forty five percent patients had knowledge about TB being an infective disease whereas 2% knew about it genetic inheritance. And more than half i.e., 53% did not know about the etiology of the disease (Figure 1A).

## 4.1 Knowledge about mode of transmission and prevention

A very big "Yes" was said by 52% of the patients who had knowledge about the mode of transmission and its prevention, whereas 48% patients gave negative answer about the transmission and prevention of TB disease (Figure 1B).

# 4.2 Knowledge about importance of complete treatment and risks of incomplete /leaving treatment

62% patients were very well aware about the benefits of completing the ATT treatment and risks which were related to incomplete treatment where as 38% patients had no idea of about it (Figure 1C).

Figure 1: Knowledge about Tuberculosis disease in patients

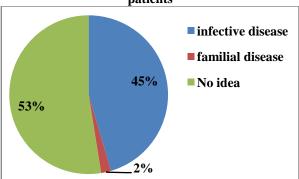


Figure 1A: Knowledge about etiology

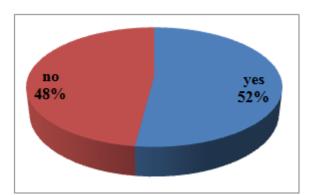


Figure 1B: Knowledge about transmission and prevention

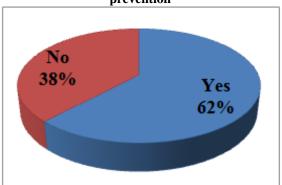


Figure 1C: Knowledge about importance of complete treatment and risk of leaving treatment in between

## 5. Psycho-social impact

### 5.1Major Depressive episodes

60% patients had been found to be suffering from one or more than one symptoms of depression and 40% had no symptoms of depression (Figure 2A). In a comparative study of presence of various symptoms of depression, 56% patients had difficulty in sleeping and loss of appetite; 36%

experienced low esteem; 37% patients had difficulty in decision making and still 38% admitted their studies and occupation being negatively affected due to disease (Figure 2B).

## 5.2 The panic behavior

Patients admitted to have suffered from one or more panic episodes. Panic episodes or symptoms of depression were found in 26% patients where as it was absent in 74% patients (Figure 2C).

Figure 2: Psycho - Social Impact in TB patients

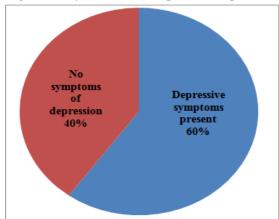


Figure 2A: Patients having depression

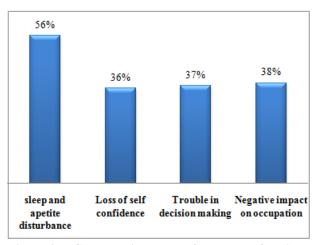


Figure 2B: Comparative study of presence of various symptoms of depression in patients

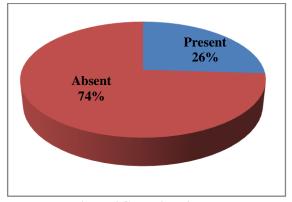
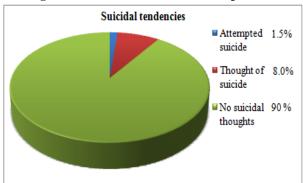


Figure 2C: Panic episodes

### 6. Suicidal tendencies

Suicidal thoughts have been seen in only 8% of patients and the main reason behind these thoughts was the neglect of friends and family where as 1.5% patients had attempted suicide (Figure 3). More than 90% patients were found to be normal.

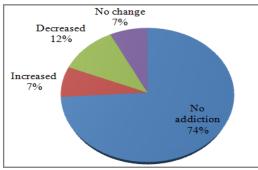
Figure 3: Suicidal tendencies in TB patients



### 7. Substance abuse

Twenty six percent of patients were using psycho active substances. But the change in frequency of use after disease were found to have increased in 7%, decreased in 12% and no change in 7%. Causes of addiction were found as a past habit in most of the patients whereas it was a disease related problem in 41% of patients. In about 7% of patients an increase in the use of psycho-active substances has been seen and in most of these cases the major reason was to bear with the depression and cold behavior of the society. Out of these 26%, the distribution of various psychoactive substances with nicotine was 66.5%, with cannabis it was 5%, with alcohol 26% and with Opiods 2.5% (Figure 4).

Figure 4: Changes in frequency of using psychoactive substances after disease



### 8. Social problems

Many patients have reported considerable decrease in their social life and many have received ill treatment from friends and society. Patients, mostly females (55%) faced some sort of social problems/ stigmas whereas 45% patients had no social problems (Figure 5A). Out of these, 50% patients admitted to have kept their disease secret from

society and had fear of disclosure. Patients having feeling of detachment from society were found to be 33%. Whereas patients that have experienced significant decrease in their social activities after disease were 44%. Only 20% patients admitted to their close friends, family members and relatives about suffering from TB disease (Figure 5B).

Figure 5: Social problems found in TB Patients

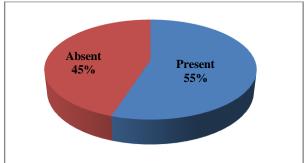


Figure 5A: Social problems

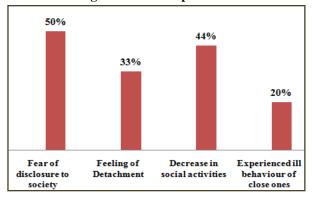
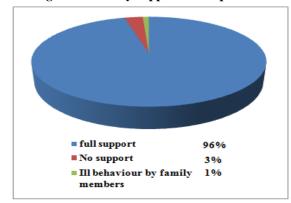


Figure 5B: Magnitude of various social problems experienced by patients

## 9. Family support

Majority of patients (96%) were getting full support and cooperation from their family members whereas only 1% of patients claimed of ill treatment and torture from their family members. 3% patients did not have any support from family. Some patients (60%) themselves maintained distance from their family members from the fear of infecting them as well. (Figure 6)

Figure 6: Family support to TB patients



### 10. Discussion

India is the highest TB burden country with WHO [2,3] giving an estimated incidence of more than 2 million cases of TB for India out of a global incidence of 9.6 million cases. TB is a major health issues in India presently but what makes it worse is the emergence of MDR, XDR and now the extremely drug resistant (XXDR) strain.

The study results clearly show that large number of patient suffering from TB do not have knowledge about the etiology, mode of transmission and methods of prevention of the TB disease [8]. While some studies have shown an independent association of low income and living in unequal income status with depression in women. Some patients stress the anxiety and fear they experience because they feel insecure and vulnerable when their conditions worsen.

About 38% of patients have no idea about the importance of complete treatment as well as the consequences of leaving the treatment in between and hence they get resistant strains of TB due to incomplete treatment [6]. About 60% of people have experienced one or more symptoms of depression such as decreased appetite sleep disorders, lack of confidence and this has severely affected their working potentials at workplace and schools [6,9]. Many patients have reported considerable decrease in their social life and many have received ill treatment from friends and society. Magnitudes of various social problems experienced by the patients were found to be different.

The main reason behind suicidal thoughts was the neglect of friends and family. A major chunk of patients (50%) have kept their disease a secret from the society as they fear that the disclosure of their disease might change the attitude of society towards them. An increase in the use of psycho-active substances has been seen in some patients and in these cases the major reason was to bear with the depression and cold behavior of the society [7, 10]. On the other hand, this study showed that poor living conditions such as poor housing, which is associated with low income, remained significantly associated after adjustment for education. Some studies in industrialized countries have shown an independent association of low income and living in unequal income states with depression in women [11,12].

TB not only accounts for a significant proportion of the global burden of disease but presents a real challenge on how to make a community responsible towards TB control. TB cause deterioration in patient's health related quality of life. Even though progress in scaling up interventions to address the co-epidemics of TB and HIV has continued, new ways to strengthen infection control is needed [13]. Thus, it is imperative that TB control programmes at public health clinics design strategies to improve the quality of health of TB patients. Awareness

programs can be organized to give proper knowledge about the disease to the patients and attendants and the nature of treatment so as to remove fear, misconceptions and minimize relapse cases. Psychological workshops can be planned for psychologically affected patients so as to boost his or her morale and thereby ensuring proper treatment and rehabilitation.

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Conflict of interest: None declared

**Ethical approval:** The study was approved by the institutional ethical and review committee of the KGMU hospital (ref code: 77<sup>th</sup> ECM II B- IMR-Student/P129.1.2016) and all the participants gave written consent.

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