# **Original Research Article**

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# Reducing the burden of Tuberculosis: an emphasis on improving awareness among caregivers

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# ABSTRACT

**Background:** Tuberculosis (TB) is one of the common communicable disease affecting human beings since ancient times. Though effective chemotherapy emerged during 20th century had raised hope towards eliminating TB burden, it still remains as a distant goal. Awareness about TB among close contacts of active disease is of paramount importance in preventing its spread and promoting early diagnosis and treatment. This study aimed to assess the knowledge about tuberculosis among caregivers of tuberculosis patients.

**Methods:** This was a cross sectional study that enrolled 300 subjects who were then caregivers of tuberculosis patients admitted in the Department of Pulmonary Medicine. Subjects were interviewed according to a predesigned panel of questions meant to assess their basic knowledge and perceptions about tuberculosis symptomatology, diagnostic modalities, treatment and prevention.

**Results:** About 90.3% (n=271) of subjects had heard about TB previously and about 37.7% (n=113) considered themselves to be well aware of it. Most of them believed TB to be communicable (90.3%, n=271). Majority believed that TB affects lungs only (n=206, 68.7%), with most commonly perceived symptom being cough (n=285, 95%). Knowledge regarding disposal of sputum was poor (n=110, 36.7%). About 168 (56%) subjects considered usage of face mask by the patient as an effective tool for TB prevention.

**Conclusions:** Caregivers of tuberculosis patients lack proper knowledge about major aspects of the disease. Public awareness and care giver education programs needs to be implemented along with standard TB care to reduce transmission of TB among close contacts.

**Keywords:** Awareness, Caregiver, Community, Diagnosis, Knowledge, Prevention, Revised National Tuberculosis Control Program, Symptoms, Treatment, Tuberculosis

## **INTRODUCTION**

Tuberculosis (TB), the age old disease has affected mankind for thousands of years. Mycobacterium tuberculosis, the causative agent of TB is carried in airborne particles of 1-5 microns in diameter, called droplet nuclei.<sup>1</sup> TB bacilli is known to spread from one person to other through air while coughing, talking or

sneezing. TB has high morbidity and mortality, making it one of the top 10 causes of death and the leading cause from a single infectious agent (above HIV/AIDS).<sup>2</sup>

Administration of proper course of treatment forms the backbone of TB control measures. From 1940s, development and use of effective drugs substantially accelerated the reduction of TB burden. However, communicability of this disease still needs to be well addressed. The infectiousness of a person with TB is directly proportional to the number of tubercle bacilli one expels into the air.<sup>3</sup> It is well-known that a tuberculosis cavity of 2 cm diameter usually contains about 100 million bacilli.<sup>4</sup> Active TB patients can infect 10-15 other people in a year through close contact.<sup>5</sup> Various studies from developing countries had shown TB prevalence of about 3.1% among household and close contacts of a person with active TB.<sup>6</sup> Achieving the targets of "End TB Strategy" needs to prevent the disease spread among close contacts and high risk population.

Studies across the world have revealed high prevalence of misconceptions and limited knowledge about TB and its treatment.<sup>7-9</sup> Knowledge regarding nature of disease, symptoms, treatment and prevention among the public is an important determining factor in disease control. Lack of proper awareness about TB and high prevalence of social stigma results in reluctance to seek medical attention, which in turn delays diagnosis and treatment initiation. Also, it is well known that non-adherence to treatment often results from poor understanding of the disease and its treatment course.<sup>10</sup> Inadequate treatment often results in emergence of drug resistant TB in the community. On the other hand, greater knowledge about TB will help in better acceptance of treatment.<sup>11</sup> Hence, educating the patients to change their misconceptions can enhance disease control in endemic areas.<sup>12</sup>

The current focus of the Revised National Tuberculosis Control Programme (RNTCP) of Government of India is on using Directly Observed Treatment Short Course (DOTS) to achieve 90% notification for all cases, 90% treatment success rate for all new and 85% for retreatment cases.<sup>13</sup> Achieving these goals requires active community participation by creating awareness on the etiology, symptomatology, management, preventive measures, and information of availability of services. Hence, as a basic step towards this, it is relevant to assess the knowledge of caregivers of tuberculosis patients regarding the nature of disease, treatment and preventive measures to ensure the appropriateness of current patient education strategies.

# **METHODS**

This was a cross sectional study conducted in Department of Pulmonary Medicine, Government Medical College, Patiala, Punjab, India. Study included 300 subjects who were then caregivers of tuberculosis patients admitted in the same department. Subjects who met the inclusion criteria were enrolled for the study during January 2017 to June 2017. Study was approved by institutional ethics committee. Informed written consent was obtained from all participants. Demographic data was collected and then they were interviewed according to a predesigned panel of questions in their own mother tongue and responses were marked in an objective manner. The questions were designed to assess the basic knowledge and perceptions of the subjects about tuberculosis including symptomatology, diagnostic modalities, treatment and prevention. Questions were not validated. All interviews were carried out by a single investigator and data obtained were entered in Microsoft Excel spreadsheet and analyzed.

### Inclusion criteria

- Caregivers of TB patients admitted in pulmonary medicine department.
- Age 15 years or above.

## Exclusion criteria

- Those with hearing impairment or cognitive disabilities.
- Those who did not give consent.

#### RESULTS

Among 300 subjects enrolled for the study, majority (n=186, 62%) were females. Most of them were within the age group of 31-45 years (n=88, 29.3%), with an average age of 41.34 years. Higher number of the subjects emerged from rural background (n=208, 69.3%) and had only primary school education (n=116, 38.7) (Table 1). Most of the subjects were housewives (n=93, 31%) (Figure 1).





Though many (n=271, 90.3%) had heard about TB as a disease previously, only 37.7% (n=113) were confident to have good knowledge about it. Large number of participants (n=238, 79.3%) considered TB as a dangerous disease and majority knew that it was common in India (n=249, 83%).

Most of the subjects stated that TB could spread from one person to another through cough (n=168, 56%). However, a large number believed that TB could spread through

contaminated water (n=72, 24%). Most important source of knowledge about TB was doctor (n=133, 44.3%) followed by health worker (n=64, 21.4%) (Table 2).

Higher percentage of the study population believed that TB affects lungs only (n=206, 68.7%), with most commonly perceived symptom being cough (n=285, 95%). Majority believed that all TB patients would develop cough (n=261, 87%) (Table 3).

About 133 (44.3%) subjects considered sputum testing as investigation of choice for diagnosis while 102 (34%) thought it was chest x- ray. Majority did not believe in alternative medicines for tb (n=278, 93.7%) and knew that treatment of tb was free (n=270, 90) in government sector. About 83.7% (N=248) Believed tb was curable with minimal duration of treatment being 6 months (n=188, 62.7%). most of the subjects knew that they should not stop treatment by themselves upon symptomatic improvement (n=255, 85%).

# **Table 1: Demographic profile of patients.**

Parameter	Group	Frequency	Percentage	
Gender	Male	114	38	
	Female	186	62	
Age	15-30	72	24	
	31-45	88	29.3	
	46-60	63	21	
	61-75	47	15.7	
	76 or above	30	10	
Residence	Rural	208	69.3	
	Urban	92	30.7	
Education Status	Illiterate	64	21.3	
	Primary school	116	38.7	
	Secondary school	78	26	
	Graduate	41	13.7	
	Postgraduate	1	0.3	
Table 2. Conversion of a present non-sections about TP				

Table 2: General awareness and personal perspectives about TB.

Parameter	Group	Frequency	Percentage
Proviously beard about TP?	Yes	271	90.3
Previously heard about TB?	No	29	9.7
	None	148	49.3
Dravious avresure to TD	Had TB in the past	39	13
Previous exposure to TB	Friend/relative had TB	107	35.7
	Currently having TB	6	2
A	Yes	113	37.7
Are you well aware about TB?	No	187	62.3
	Yes	238	79.3
I B is a dangerous disease?	No	62	20.7
	Yes	249	83
I B is common in India?	No	51	17
	Doctor	133	44.3
Course of language days about TD	Health worker	64	21.3
Source of knowledge about 1B	TV/radio/newspaper	60	20
	Friends/relatives	43	14.3
	Drinking dirty water	72	24
	Eating fast food	30	10
How TB spreads?	Mosquito bite	21	7
	Close contact with TB patients, through cough	168	56
	Genetic	9	3
Can TB spread from one person to	Yes	271	90.3
another?	No	29	9.7

Parameter	Group	Frequency	Percentage
	Children only	21	7
TD offects	Young adults only	11	3.7
I B affects	Elderly only	33	11
	Anyone	235	78.3
	Males only	19	6.3
TB affects	Females only	11	3.7
	Both	270	90
TD involves	Lungs only	206	68.7
I B IIIvolves	Lungs and other organs	94	31.3
	Cough	285	95
	Breathlessness	206	68.7
	Fever	208	69.3
Symptoms of TB	Weight loss	167	55.7
	Loss of appetite	67	22.3
	Blood in sputum	113	37.7
	Others	65	21.7
All TP patients develop cough?	Yes	261	87
All 1 B patients develop cough?	No	39	23

# Table 3: Knowledge about TB symptomatology and spread.

# Table 4: TB diagnosis, treatment and prevention.

Parameter	Group	Frequency	Percentage
	Blood test	44	14.7
Which to tast is used to confirm TD?	Sputum test	133	44.3
which to test is used to commin 1 B?	Chest X ray	102	34
	Others	21	7
Do you baliaya alternatiya madicinas cura TR?	Yes	22	7.3
Do you believe alternative medicines cure TB?	No	278	92.7
Do you know TB tests and treatment are free in	Yes	270	90
government hospitals?	No	30	10
Have you heard about DOTS?	Yes	35	11.7
Have you heard about DOTS?	No	265	88.3
Do you know where to get TP treatment from?	Yes	238	79.3
Do you know where to get TB treatment from?	No	62	20.7
TR is curable?	Yes	248	82.7
	No	52	17.3
	1 week	13	4.3
What is the minimum duration of treatment for	1 month	37	12.3
TB?	6 months	188	62.7
	1 year	62	20.7
Can you stop treatment by yourself when	Yes	45	15
symptoms subside?	No	255	85
Can TP again after gotting ourad?	Yes	188	62.7
Can TB occur again after getting cureu?	No	112	37.3
TR patients can est non vegetarian food?	Yes	87	29
TB patients can eat non-vegetarian rood?	No	213	71
	Patient using face mask	168	56
How to provent TP?	Caregivers using face mask	90	30
now to prevent TD?	Keeping windows closed	6	2
	Separating all personal belongings	36	12
Are you aware about any vaccine available	Yes	64	21.3
against TB?	No	236	78.7
Do you know how to dispose sputum of TB	Yes	110	36.7
patient?	No	190	63.3

Greater percentage of study population believed that TB patients should not eat non-vegetarian food (n=213, 79.1%) and majority did not know how to dispose sputum (n=190, 63.3%). About 236 subjects (78.7%) were not aware about vaccine availability against TB. About 192(64%) subjects considered usage of face mask by patients as a method for TB prevention while 60 (20%) considered separation of their personal belongings from that of patients as a better way (Table 4).

# DISCUSSION

Adequate basic knowledge about tuberculosis is mandatory among the population of endemic countries, where control of this disease forms a major health obstacle in economic development of the country. Imparting knowledge to caregivers needs a special attention in TB care. Current study population consisted of higher number (68%) of females. Majority of female participants were bound to be caregivers as they were housewives and were staying at home or at hospital along with their patient.

It emphasizes an increased risk of acquiring TB infection among them as they live in closed environment along with contributory factors like poor nutrition, low health seeking behavior and low income. However, according to a study conducted by Horton et al, in many settings women are more likely to have a timely TB diagnosis than men, probably because men seeking care in private facilities rather than government setups.<sup>14</sup>

Higher number of participants (29.3%) belonged to age group of 31-45 years that represents the productive group of population. Loss of pay has an adverse impact on the economy of their family, leading to poor nutrition and hence high chance for acquiring the disease. Gupta et al, found that there is a significant socio-economic statushealth gradient in TB prevalence i.e., tuberculosis risk increases with lowering of socio-economic status.<sup>15</sup> Fox et al, also showed that inadequate nutrition was associated with increased susceptibility to infection.<sup>16</sup>

A large percentage of subjects (21.4%) were illiterate and had comparatively poor knowledge which draws attention towards policies to strengthen education in order to curb the disease burden. Tasnim et al, also had pointed out this fact as one fourth of their study population were illiterate.<sup>17</sup> Majority of the current study group were from rural background (n=208, 69.3%) where false beliefs and superstitions caused tendency to seek alternate medicine. However, current study population had a preference towards modern medicine (n=278, 92.7%).

About 51% of participants had previous experience with TB- either they themselves were old case of tuberculosis or had personal contacts with TB patients in the past. Hence, the study population was expected to possess good knowledge about tuberculosis. However, a large number of subjects (n=187, 62.3%) admitted having poor

awareness in this regard, which highlights the prevailing unaddressed aspect of caregiver education. Projecting this figure at the community level would prove a far low level of awareness among general population. As pointed out by Muniyandi et al, majority of people would not have even heard about TB.<sup>18</sup> Also, our study revealed high misbeliefs about causation of TB (24% thinks TB spread through dirty water) and is probably due to low literacy and prevailing general concept of disease spread as in case of waterborne diseases. Knowledge about TB spread has not been consistently high among various communities, as documented by Kulkarni and Sonawanein the past.<sup>19,20</sup>

Doctors were most important source of information to our participants. Hence doctors should spend time on patient/relative education and clear doubts especially in rural settings. Patients and relatives has high level of trust on doctors, as evidenced by Vukovic which enable them to emerge as best ambassadors of TB care in the community.<sup>21</sup> Healthcare workers also possess important role in this aspect.<sup>22</sup> Hence, it is high time to re-evaluate the effectiveness of mass communication and caregiver education strategies adopted so far in rural settings.

Majority of study population (n=285, 95%) considered cough to be a universal TB symptom and believed that all TB patients would develop cough. A large group (n=206, 68.7%) did not know about extra-pulmonary TB (EPTB). This could prevent caregivers from extending concern to subtle symptoms of EPTP that may develop from their close pulmonary TB contact(s), delaying an early diagnosis and prompt treatment. Previously, Jorstad et al, had figured out that many EPTB patients experience a long delay in the initiation of treatment, especially patients with TB lymphadenitis.<sup>23</sup> Recently, Purohit et al, also observed very poor awareness of EPTB among patients.<sup>24</sup>

Timely initiated treatment has the potential to reduce morbidity and the economic loss for the patient. Hence, health care workers should focus upon explaining the nature of EPTB also, to the patients as well as relatives. Lack of awareness about sputum disposal is an important matter of concern. Methods of sputum collection, disinfection and disposal should be emphasized during patient education sessions to attain а low communicability rate of the disease. A number of caregivers believed that using face mask by themselves rather than by patients would protect them from acquiring TB infection.

Cough hygiene, although a highly perceived fact, is seldom practiced in the real time scenario, especially in households. Similarly, avoiding non-vegetarian food was also would have adverse impact on TB outcome due to poor nutritional status. A thorough counselling during treatment initiation, not only to the patient, but also to the caregivers would suffice for attaining the put forth goals of TB control to a greater extent.

#### CONCLUSION

Tuberculosis, one of the most common communicable disease of mankind imposes a huge burden in this community health. Knowledge of the public regarding the disease, treatment and prevention is a factor that contributes to controlling the TB epidemic. Current study reveals that knowledge regarding tuberculosis spread, treatment and prevention are poor among the caregivers of TB patients admitted in a tertiary care hospital. Hence, public education programs should be implemented as a valuable tool in health care facilities to promote better awareness about tuberculosis.

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