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A STUDY ON LEVEL OF KNOWLEDGE, PRACTICE OF PREVENTION AND STIGMA AMONG HOUSEHOLD CONTACTS OF PULMONARY TUBERCULOSIS PATIENTS ON DOTS CHEMOTHERAPY IN INDIA: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Studies on patients with tuberculosis (TB) have shown that their response to symptoms is culturally inclined. Early detection coupled with incorporation of patient health perceptions can refine tuberculosis control plans to enhance patient identification, diagnosis, and treatment outcomes. **Purpose:** To find out the level of knowledge, practice of prevention of tuberculosis and associated stigma among contacts from the same household of pulmonary tuberculosis patients on DOTS chemotherapy. **Methods:** This study is a cross-sectional one. IEC was obtained approved before starting this study. The research was conducted with 220 family contacts (aged 12 and above) using a survey. **Results:** Study subject's awareness on the contagiousness of the disease (45.4%) and the seriousness of the infection (47.8%) was found to be very low. It is worrying to find that only 20% of study subjects were aware of the cause of disease (21.8% - germs). Constitutional weakness (14.5% - low immunity) was almost not considered as a risk factor. Half of the contacts (53.2%) felt they wouldn't tell others about the illness as they would be looked down upon (56.4%). **Conclusion**: The lacuna in the National Tuberculosis Elimination Programme (NTEP) is that it didn't transmit the understanding about the disease to all the affected and their immediate family. The tuberculosis disease report, along with psychological and medical support and chemotherapy, will ensure consistency and achieve the sustainable development goal of "eliminating tuberculosis by 2030."

Keywords: LTBI, TBI, household contacts, TB contacts, TB stigma, prevention

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INTRODUCTION

India has the largest incidence of tuberculosis cases compared to other countries. In 2021, eight countries accounted for more than two thirds of global tuberculosis (TB) cases: India (28%), Indonesia (9.2%), China (7.4%), the Philippines (7.0%), Pakistan (5.8%), Nigeria (4.4%), Bangladesh (3.6%) and Democratic Republic of the Congo (2.9%) . According to World Health Organization (WHO) estimates, mortality from TB in India was 342,000 deaths (12%) in 2022. As per the report net decrease in TB-related deaths from 2015 to 2022 was 19%, while the WHO End TB Strategy milestone is 75% reduction by 2025.

Although effective treatment of tuberculosis has been available since many years now, in developing countries control of tuberculosis has been a rocky road, because tuberculosis control is affected by structural problems as well as the influence of culture and gender. A national assessment of RNTCP (Revised National Tuberculosis Control Programe) clearly shows the multiple steps that patients are made to go through before initiating TB treatment leads to loss of patients from care (Subbaraman *et al*., 2016). There is little research on the mechanisms by which stigma affects tuberculosis (TB) risk or patients' health (Nuttall *et al*., 2022). Research on tuberculosis patients suggests that patients' cultural interpretations of symptoms can have a significant impact on early diagnosis and that awareness of patients' health-related beliefs can be used to improve patients' management, diagnosis, and treatment of tuberculosis. Another study in India estimated that more than 200,000 patients are lost to first-line treatment (PTLFU) each year in the country's tuberculosis program (Thomas *et al*., 2018) Learning about tuberculosis and its spread by was done by personally approaching family members.

The novelty of this research lies in its desire to delve into the dissemination of scientific knowledge and the severity of the disease. The aim of this study is to analyze the level of knowledge, practice of tuberculosis prevention, and the associated stigma among household contacts of sputum-positive pulmonary tuberculosis patients undergoing direct observed treatment shortcourse (DOTS) chemotherapy.

METHOD

Study Design, Sample, and Population

This cross-sectional study was started after Institutional Ethical Committee approval. Prior to the main study, pilot testing was carried out. Based on a review of literature on latent tuberculosis infection, the lowest prevalence for latent tuberculosis infection or TB infection (LTBI/ TBI) among household contacts of sputum positive pulmonary TB patients on Direct Observed Treatment Shortcourse (DOTS) chemotherapy was 46% (Paradkar *et al*., 2020). With the limit of accuracy as 7% and with the Zα value of 1.96, the total sample size arrived for the study is 215. The final corrected sample size was 220 (Praveen, 2020). Strict guidelines as per declaration of Helsinki were followed throughout the study.

Data Source

This study was done among 220 household contacts aged 12 – 68 (both male and female) of the 68 index sputum positive and TB patients on DOTS chemotherapy who were residing in that household for at least six months prior to study who were willing to participate and gave informed consent were included for the study. Based on the investigator's initial approach with the District Tuberculosis Officer (DTO) of Thiruvallur district granting permission to conduct the study, the principal investigator proposed to conduct the study using simple random sampling in three Tuberculosis Units (TUs) by lottery method among ten TUs, namely Naravarikuppam, Kollumedu and Budhur TU. Consent was taken from contacts ahead of visiting their homes. Interview schedule includes a structured and validated questionnaire which was administered by the principal investigator. Data collection tool included questions to know the knowledge of contacts on TB disease, their practice of prevention on spread of the disease from the index case and the stigma which is prevalent among them on the disease and on the index patient due to the disease including their perceived societal stigma. The questionnaire was designed in English and was translated to Tamil for easy flow of the interview schedule and then back translated to verify the corrections.

Data Analysis

Data entry and analysis were done using Statistical Package for Social Sciences (SPSS) Version 16.0. Descriptive statistics were represented in number and percentage of the background variables; 95% CI calculated for prevalence. Chi-square test was used to associate prevalence of latent TB with age, sex, relationships, degree of exposure and risk factors. The risk estimation (OR) was analyzed and a p value of <0.05 was considered significant.

Ethical Clearance

This study was approved by the Intitutional Research Ethics Committee (For PG Students of Medical College) Sri Ramachandra University (Ref: CSP-MED/14/APR/14/93).

RESULT

Level of Knowledge, Practice of Prevention and Stigma

Among all the 220 study participants who are the household contacts, the percentage of response for each domain was calculated. For a better understanding, the responses 'yes and possibly' were grouped into one variable 'YES' and 'uncertain and no' into the variable 'NO'. Overall percentage with 95% CI and percentage for the gender with p value for each domain calculated separately as shown in table below.

Level of Knowledge

Not all of the study subjects (96.8%) knew he/she (index case) had TB. Most of the study subjects rightly identified the symptoms of TB as cough for more than two weeks (80.5%), fever and loss of weight (73.2% each) and blood in cough (70.9%) while 25.4% and 20% of overall study subjects wrongly identified watery eyes and ear pain respectively as TB symptoms. The majority of the participants rightly identified the spread of disease through cough (78.6%), spitting (76.4%), cough with sputum (74.1%) and air (65.5%). while 54.4% of men and 62.3% of women reported open doors to reduce the transmission of the disease. This difference was found to be statistically significant, p<0.01. The majority of household contacts recognised smoking (41.4%), closely followed by alcohol (31%) germs (26.8%) as their perceived cause for TB infection (Table 1). While 93.2% out of 220 study participants reported that the index sputum was disposed away from the house and 91.3% of household contacts leave their doors and windows open most of the time only 59.5% of them insisted the index case to cover and cough. (Table 1, Figure 1) Significant gender difference was not noticed in the prevention practices. The stigma that others would think less of the family was found to be highly prevalent (56.4%) followed closely by not telling others of the disease the index case was suffering from (53.2%). 51.3% of study subjects felt that the disease would cause problems to their children and 51% notified problems in getting the index case married (Figure 2).

Perceived Causes for Tuberculosis

Less than half of household contacts recognised smoking (41.4%), closely followed by alcohol (31%) germs (26.8%) as their perceived cause for TB infection while 13.3% males and 7.7% females reported constitutional weakness as a causative factor for TB and the difference in gender was statistically significant with p value of 0.02.

Table 1. Level of Knowledge on TB among Household Contacts

	Male (%) n = 90	Female (%) n = 130	p value
Knowledge on seriousness and effect on others			
Serious problem?	42(46.7)	63(48.5)	0.66
Know he/ she has TB?	87(96.7)	126(96.9)	0.91
Worry getting TB from patient?	34(37.8)	66(50.8)	0.3
Important to prevent the spread of TB?	87(96.7)	126(96.9)	0.18
Knowledge on Symptoms of TB			
Fever	67(74.4)	94(72.3)	0.43
Cough ≥2 weeks	71(78.9)	106(81.5)	0.94
Coughing up blood	60(66.7)	96(73.8)	0.47
Loss of weight	67(74.4)	94(72.3)	0.7
Watery eyes	21(23.3)	35(26.9)	0.47
Ear pain	17(28.9)	27(20.7)	0.9
Memory loss	11(12.4)	29(22.3)	0.24

Continuation of Table 1. Level of Knowledge on TB among Household Contacts

	Male (%) n = 90	Female (%) n = 130	p value
Knowledge on mode of spread of TB			
Air	56(62.2)	88(67.7)	0.4
Coughing	71(77.9)	102(78.4)	0.8
Spitting	68(75.6)	100(76.9)	0.9
Copious sputum	65(72.2)	98(75.4)	0.9
Physical contact	34(37.8)	47(36.2)	0.3
Sharing bed	32(35.6)	35(27)	0.53
Sharing food	35(39)	47(36.2)	0.23
Knowledge on ways to protect oneself from TB			
Open doors	49(54.4)	81(62.3)	0.01
Wearing mask	62(68.8)	94(72.3)	0.7
Perceived cause for TB			
Ingestion			
Food		1(0.8)	0.72
Water	3(3.3)	1(0.8)	0.04
Alcohol	25(27.8)	43(33.1)	0.2
Smoking	39(43.3)	52(40)	0.14
Abused drug	3(3.3)	2(1.5)	0.04
Health, Illness or Injury			
Prior illness	2(2.2)	3(2.3)	0.2
Constitutional Weakness (Low Immunity)	12(13.3)	10(7.7)	0.02
Environmental			
Sanitation	1(1.1)	4(3.1)	0.7
Personal hygiene	5(5.6)	2(1.5)	0.002
Germs or infection	30(33.3)	29(22.3)	0.02
Airborne exposure	17(18.8)	19(14.6)	0.04
Others		1(0.8)	0.45
No idea	21(23.3)	41(31.5)	0.2

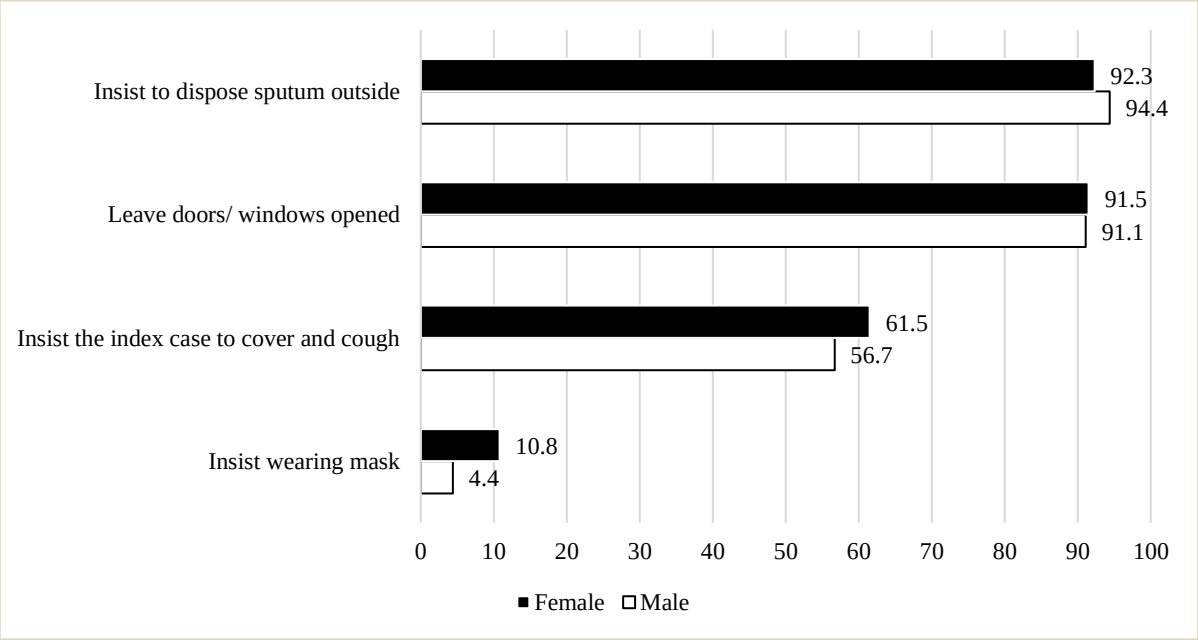

Figure 1. Practice of Prevention of TB among Male and Female Household Contacts (%)

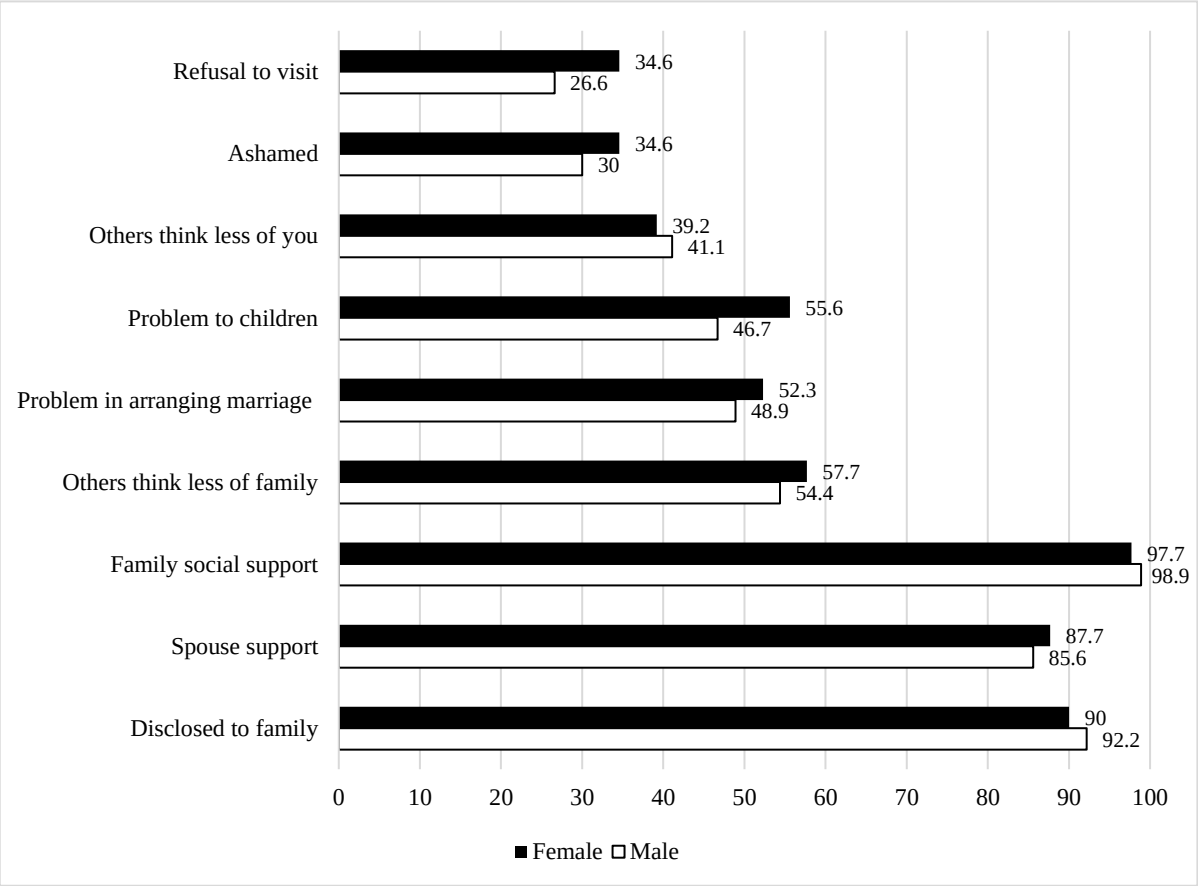

Figure 2. Stigma on TB among Male and Female Household Contacts (%)

DISCUSSION

Although several studies have investigated contacts of tuberculosis patients, very few discuss about the cultural transmission of knowledge based on gender, protection and stigma. Research on the cultural transmission of tuberculosis based on these three goals shows their understanding of the disease, and their perception and behavior of transmission in people living with in the household. Less than half of the contacts were concerned that they might be infected and that the disease could be serious. This reflects a lack of understanding of latent TB infection (TBI), which in the next 10 years might result in TB disease in a majority of the exposed (Fox *et al*., 2015). This finding highlights the importance of national tuberculosis programs providing clear and accurate information to residents at initial screening to understand the risk of recurrent infection years after exposure (Sharath *et al*., 2024).

A fairly good number of contacts correctly knew the symptoms, a finding which could be explained by knowing the symptoms which the index case had been suffering from and partly through the health education given by the DOT provider at the time of treatment initiation. Strictly speaking, 100% of contacts should know the symptoms, which enables them to be aware of their own health status, each of them being at high risk of developing the infection in future.

Though a fair number of participants gave right responses when asked about ways of disease spread, over one third of them incorrectly believed that physical contact and sharing food could transmit TB. While these beliefs point out to their perception of risk fear of contagiousness, they may also lead to stigmatisation, which increases their sense of alienating TB patients (including their families) from society. Crisp health education which clearly conveys the information of air borne nature of TB transmission could be incorporated into screening programs to combat this misperception.

Interestingly more women than men were found to be believing that open doors and windows reduce the transmission of disease

though no significant gender difference was noted on the positive response for curtailing the spread by wearing a mask. This implies only a moderate level of awareness being prevalent among the contacts on personal preventive measures against TB and bridging this gap necessitates health education be imparted not only among patients but the entire family as a whole.

The current TB program apart from being patient centric should also shift its focus toward the contacts and hence the family as a unit. By providing the patients and their care givers with a booklet which has all the information regarding the disease and its prevention, a large amount of knowledge can be transferred which may not be otherwise possible by a STS (Senior Tuberculosis Supervisor) or a HV (Health Visitor) as they are already loaded with documentation, house visits and DOT drug distribution during treatment initiation.

Complementing our previous assessment, the finding pertaining to perceived causes of the disease was also consistent with other studies. Smoking, alcohol, germs, air borne and environmental causes were mostly reported. A few causes such as constitutional weakness, drug abuse and poor personal hygiene were significantly found to be perceived more by men than women. These wrong perceptions and beliefs may further add to the already existing strong sense of alienation from the TB patients and their families. Close to one third had no idea, which reflects the failure of the program in reaching out to the household contacts.

Most of the participants knew very well that the patient's sputum needs to be disposed outside the house. Most of them even mentioned burying it underground and burning. Even though only a little more than half of the participants believed opening doors and windows reduced the spread, most of the study subjects still kept them opened unknowingly, which can be explained by the belief that the cultural practices of keeping doors wide open will welcome good spirits in.

Only half of the study subjects knew about cough etiquette and insisted the index case follow the same while coughing. This shows that patients have to be educated about cough etiquette and the same has to be reinforced in subsequent follow ups and double checked that correct technique is being practiced by patients as well as family members. Another worrisome finding is, despite the fact that most household contacts believed usage of a mask reduced transmission , a very small proportion of them insisted their index cases to wear one and, even worse, only 10% (all females) of those who insisted, threw away the soiled masks in a day or two.

Gender differences were not found among the indicators of stigma. Male and female equally felt that they will support their index case as a family and that the disease was disclosed to them and other family members. This finding is contrary to previous studies (Thomas *et al*., 2020; Zimmer *et al*., 2021) which estimated stigma to be more prevalent among men. Work ostracizing in one indicator which female contacts reported more frequently than the male counterparts, which is contrary to certain studies where men reported higher stigma related to work place ostracizing (Jhaveri *et al*., 2024; George *et al*., 2023; Srivastava *et al*., 2018; Singh *et al*., 2018). Studies have suggested that fear of airborne spread of TB disease, fear of losing social status, fear of being socially isolated, becoming a matter of gossip, verbal abuse, fear of failed marriage prospects, and neglect from family are the reasons for TB stigma (Laji & Asghar, 2024; Daftary *et al*., 2017; Mukerji *et al*.,2018)

Limitations of the study is that a qualitative method like in-depth discussion would be a more accurate way to find out the stigma among household contacts. Strength of the study is that it was done under TB units under the program (NTEP) and thus it provides actual information that is generalisable to the population.

CONCLUSION

Although the level of knowledge on the disease, its symptoms, mode of spread and the ways to prevent the spread among the household contacts is better than studies conducted in the past, it still needs to considerably improve. There are misconceptions of the disease that are still very much prevalent. Contrary to older times, the stigma is no more highly prevalent toward female patients though certain cultural practices of seeing a girl child as a liability and the disease adding more burden to it cannot be

overlooked. The term social mobilisation means 'allowing people to think and understand their situation and to organise and initiate action for their recovery with their own initiative'. Policy makers need to consider the higher risk among household contacts and bring recommendations into the national program so that everyone is protected as a family when an index case is diagnosed from a house or household.

Radical shifting of the view of the current flow of events from top to bottom to community based care which takes into account recommendations and perspectives of TB patients could bring down the stigma around the diseases, which would make the entire treatment, including active screening, more inclusive. Lack of adequate counselling has emerged as the main reason for loss of care of tuberculosis patients (Thomas,, Suresh, 2020).

SUGGESTION

A booklet having all the information regarding the disease, its prevention, the program and its benefits should be provided at the start of the treatment so that every household contact as well as patients themselves benefit from it and it can be referred to, whenever there arises a doubt regarding the disease. The importance of psychosocial counselling is stressed in this article as stigma is deep rooted and it has to be addressed from the roots (one's own subconscious mind). This way, social mobilization can be better achieved and the SDG (Sustainable Development Goals) of 'End TB by 2030' will be attainable.

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CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

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AUTHOR CONTRIBUTION

Vijaiyalakshimi Praveen was involved in all stages right from conceptualization. Arulmozhi Rajaram, Padma Praba Balamurugan and Rajkamal R. were involved in investigation, data analysis, writing the original draft including its review.

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