

FACTORS OF SOCIAL EXCLUSION: A STUDY OF TB PATIENTS IN JAMMU URBAN

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ABSTRACT

Tuberculosis remains a major global health problem. It causes ill-health among millions of people each year and ranks as the second leading cause of death from an infectious disease worldwide, after the human immunodeficiency virus (HIV). Under the facilitation by the Central Government Tuberculosis patients (TB) are registered under Directly Observed Treatment Short-course (DOTS) program in Jammu urban. Initially TB is also one of the major diseases that cause enormous economic crisis in low income countries. But with the initiatives taken by the Government, scenario has been changed. The present field survey indicates that along with number of initiatives taken by the Government, there are other factors like socio-economic which affect the patients and clearly indicates exclusion.

KEYWORDS: Tuberculosis, DOTS, RNTC, Exclusion.

INTRODUCTION

The diagnosis of TB affects individual's not only physical health, but also social, economic, and psychological arenas. Since the disease affects the economically productive age group, households are adversely affected. The social impact may include loss of work, divorce, ostracism by family members and the communities. The economic impact includes increased anxiety and depression and lower life satisfaction, with higher unemployment and low income backdrop. The National Tuberculosis Program of India (NTP) was started in 1962 and was initially intended for domiciliary treatment, utilizing self-controlled standard medication regimens. To beat these weaknesses, an overhauled technique to control TB was pilot-tried in 1993. Encouraged by the aftereffects of Pilot tests, the Revised National Tuberculosis Control Program (RNTCP) in 1997 was started. This Revised National Tuberculosis Control Program (RNTCP) -Adopted the DOTS-system, Short-course chemotherapy.

As per the official report compiled by the State Health Department J&K, 10268 persons were diagnosed with TB in 2006 while 12392 persons were tested positive for the disease in 2007. Similarly, 12516 people were diagnosed with TB in 2008 and 9873 (2015). Effective TB control through DOTS strategy helps in lessening poverty by providing diagnosis and free treatment, reducing the economic burden that inflicts TB patients.

The study into socio-economic impact of TB on patients and their family is really hard. The primary impact of disease manifests mainly among patients economic agency. An assessment of the socio-economic affect signifying exclusion has been studies through this survey.

OBJECTIVES

- To assess the social and economic impact of TB on patients registered with Treatment Units.
- Assessing the patient's perception of TB signifying Exclusion.

Survey Area

The survey has been done on TB patients registered under RNTCP who visits Government Chest Disease (CD) Hospital for DOTS as it covers 4 Treatment Units (TU's) of Jammu urban and patients find it more convenient as it is located in the heart of Jammu city with round the clock connectivity.

Field Survey

An interview schedule was used to collect information on demographic and socio-economic characteristics of patients. Information on economic and social impact was collected. In addition, open-ended questionnaire was used to obtain information pertaining to the patient's perception of only the impact of TB on self/family. Social impact was measured in terms of information

about TB socially. Economic impact was measured in terms of reduction of savings, indebtedness, and mortgaged assets, as perceived by the patients.

List of TB patients was compiled from register provided by workers working for different TU's of Jammu urban. Patients were interviewed who visits Govt.CD hospital for collecting medicine of DOTS. Consent has been taken from DTO officer and purpose of the study was

explained to the patients and they were told about the confidentiality of data collected and also of their right to withdraw from the study at any time.

Profile of the Patients

Majority of the patients (36.3%) belonged to the 41-50 years age group and the survey included 65 (60%) males and 45 (40%) females. Most of the patients 45 (40%) were graduates.

Table 1: Socio Demographic Characteristics.

VARIABLE	NO.OF PATEINTS	PERCENTAGE
GENDER		
Male	65	59
Female	45	40.9
AGE		
20-30	15	13.6
31-40	25	22.7
41-50	40	36.3
51-60	30	27
EDUCATION		
Non-Literate	15	13.6
Primary	10	9
Secondary	30	27
Graduation	45	22.7
Post-Graduation	----	22.7
OCCUPATION		
Government Employee	20	18
Private	10	9
Entrepreneur	30	27
Skilled Worker	25	22.7
Daily wagers	25	22.7
Student	----	
INCOME		
Irregular Income	55	50
Regular Income	20	18
Undefined Income	25	22.7

*Source: Field Survey

Medical Status

Among the 110 patients, 39 (35.4%) were sputum positive and 71 (64.5%) were extra-pulmonary TB patients getting treatment under RNTCP.

Table 2: Medical Status of Patients.

GENDER	TYPE	PERCENTAGE
Male	Sputum positive	45 (63.3)
Female		26 (36.6)
Male	Extra-pulmonary TB	30 (76.9)
Female		9 (23)

*Source: Field Survey

Factors Affecting

It has been assessed during the survey that the patients felt socio-economic impact on their life because of TB. Around 64.5% patients were more affected by social impact on their lives and 35.4% felt economic impact.

Economic Factor

The survey clearly indicates that 35.4% perceived economic difficulties after the diagnosis of TB. Their savings have reduced, some of them got indebted and even some of the patients have to mortgage their property. It is significant to mention here that the patients belonging to joint family felt more economic burden on their life. The female patients were more affected economically.

"I was sick for the last few years and the only breadwinner of the family, unable to earn due to weakness. Had to mortgage property as collateral to take loan to run the household." narrated by a daily wager.

A middle aged man working as watchman narrates "I was not able to go on job for 2 months without wages. Unable to manage the household as well as my nutrition.

We had to run the household from the little that had saved for my sisters' marriage."

"I lost my weight and nutrition also, so unable to fulfill my household chores properly. Always depend on someone for my meals also. But the other members do not understand my health issues and tagged me as escapist from my household duties", narrates a 32 year old female living in joint family.

Social Factor

The patient's perceived social impact after diagnosed with TB in the form of fear of rejection, discrimination, had not revealed their disease status to their family and some even to their spouses. Even the patients have to discontinue their jobs. Patients were worried/had mental anguish. The female patients were worried that the disease will be transmitted to her children also.

Social alienation was felt by the patients "On knowing that I have TB, my husband and my in-laws were shocked and took me to my parent's place and left me there. In spite of reassurance by health visitors from hospital, they are refusing to accept me because of TB." said by 24 year old female.

A 40 year old JA said, "I told my employers that I had TB and wanted some leave. My colleagues suggested me that I should discontinue the job and come back only after the doctor gives me the medical certificate of well-being."

Mother of TB patient narrates, "There is great tension in the family. We have not told anyone, as she has to get married in a few years and fear that no proposals may come." As social factor was significantly perceived by more female patients as compared to males.

The present study in an urban setting had covered all TUs of the city and had included both pulmonary and extra-pulmonary TB patients. Following the universal geographic coverage of DOTS program in India, this information is vital for health managers in their efforts to improve the quality of program.

Dialogue

This study has highlighted the fact that majority of patients perceive social factor associated with TB remains deep-rooted and efforts are needed to address this in a comprehensive manner. Individual counseling of TB patients and their family to reduce perceived/actual social impact could be considered under the program throughout the duration of treatment. Social factors were significantly felt more by female patients; they fear rejection and discrimination by other family members, relatives, and friends. With the present scenario of women being triple burden the impact of disease increases. The need for encouragement to organize special support groups for women, who were rejected by family/community.

This study has included only those TB patients registered in the government TU centre and the impact of TB could be different for TB patients getting treated in the private health sector.

Wrapping up

RNTCP is a well-structured program that has covered a large population in a short span of time. After the implementation of DOTS under RNTC, the present survey has shown that with the availability of DOTS, percentage of patients who mortgaged assets or took loans has reduced. Social impact of TB is still perceived by the patients (64.5%). Elimination or reduction of social stress with specific, focused, and intense social support services, awareness generation, and counseling to patients and families need to be built into the program.