Original Article

Identifying and Addressing Factors Contributing to Pretreatment Loss to Follow-Up of Tuberculosis Patients Referred for Treatment from Medical Colleges in Pondicherry: An Implementation Research

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Abstract

Background: In India, there is no feedback regarding 34% of tuberculosis (TB) patients diagnosed and referred from medical colleges for treatment to peripheral health institutions (PHIs). **Objectives:** The aim of this study is to measure the effectiveness of the new intervention package, developed based on qualitative study in reducing pretreatment loss to follow-up (PTLFU) of all TB patients diagnosed and referred for treatment from medical colleges to PHIs. **Materials and Methods:** An intervention was developed based on the findings of in depth-interviews conducted among different stakeholders such as TB patients who did/did not report, service providers working in four medical colleges in Pondicherry. Intervention consisting of phone calls, home visits, etc., was implemented for a period of 6 months. The baseline and endline proportion of TB patients for whom feedback received was determined from the available records (Revised National TB Control Program State Task Force Quarterly reports). **Results:** Patient's ignorance, lack of faith in healthcare system, side effects and social stigma, unpleasant experience in hospitals, poor accessibility to directly observed treatment, short-course centers, drugs shortage, poor coordination between program and hospital staff were the risk factors for PTLFU. At baseline, the proportions of feedback received about TB patients referred for treatment from medical colleges to PHIs was 46%. After the initiation of interventions, it increased to 61% and 66% in the first and second quarters of 2017, respectively. **Conclusion:** Risk factors for PTLFU were multi-factorial related to both patient and health system. Simple, feasible interventions such as phone calls and home visits to TB patients were effective in reducing PTLFU.

Keywords: Lost to follow-up, qualitative research, quasi-experimental studies, risk factors, tuberculosis

Introduction

Tuberculosis (TB) is the one of leading causes of death worldwide, especially in developing and underdeveloped countries. Globally, ten million people are developing TB and 1.3 million are dying due to TB every year. India has the highest burden of TB in the world, accounting for more than one-fourth (27%) of the global incidence.[1] The objectives of the Revised National TB Control Program (RNTCP), are to achieve and maintain cure rate of at least 90% among new TB patients and to achieve and maintain case detection of at least 90% of the estimated TB cases in the community. One of the important obstacles in achieving the high cure rates is pre-treatment loss to follow-up (PTLFU) of TB patients. A PTLFU is a TB patient who is documented as sputum smear-positive in the laboratory

Access this article online

Quick Response Code:

Website: www.ijcm.org.in

DOI: 10.4103/ijcm.IJCM_118_19

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How to cite this article: Stalin P, Manikandan M, Antony V, Murugan N, Singh Z, Kisku KH, *et al*. Identifying and addressing factors contributing to pretreatment loss to follow-up of tuberculosis patients referred for treatment from medical colleges in Pondicherry: An implementation research. Indian J Community Med 2020;45:27-31.

Received: 25-03-19, **Accepted:** 26-12-19

sputum register, but who does not appear in the TB patient treatment register and is therefore not registered and started on treatment.[2] The risk factors for default among new patients have been reported in several studies from India;[3-8] however, data on PTLFU of TB patients diagnosed and referred for treatment from medical colleges to peripheral health institutions (PHIs) are lacking. In medical colleges, more than 200,000 TB patients are diagnosed every year in India. More than two-third of them are referred for treatment to PHIs. However, medical colleges are receiving feedback of approximately 67% of the patients from PHIs.[9] Remaining unreported patients could be the potential source of infection to others in the community which in turn leads to overall increase in morbidity and mortality. The challenge is to identify these patients, trace them and start them on treatment as soon as possible. Therefore, the objectives of this study were as follows: (1) to identify the factors contributing for PTLFU among TB patients diagnosed and referred for treatment from medical colleges to PHIs using qualitative study (2) to develop sustainable feasible interventions based on the findings of the qualitative study to reduce PTLFU, and (3) to measure the effectiveness of the developed interventions in reducing the proportion of PTLFU.

Materials and Methods

A mixed method study was conducted in four medical colleges located in Pondicherry district of State Puducherry, India. A qualitative study was conducted to understand the reasons for PTLFU of TB patients diagnosed and referred for treatment from medical colleges to PHIs, in-depth interviews were conducted among different stakeholders with the use of interview guide. A sample of TB patients who did not report (no feedback) and report (feedback) to the PHI were selected by systematic random sampling from the list of TB patients registered in the TB treatment register maintained at the four medical colleges during the first two quarters of 2016. A total of 34 in-depth interviews [Table 1] were conducted among the study participants at their homes/directly observed treatment, short-course (DOTS) centers using in-depth interview guides by the field staff who were trained in qualitative research by the experts from National Institute of Research in TB, Chennai. During the interviews, key notes were taken by the field staff. All the interviews were audio-recorded. The transcription of audio data was done in Tamil and was later translated into English. Qualitative data were analyzed in a stepwise manner, i.e., coding, free listing of codes, theme formation, data summarization, and conclusion drawing.

A quasi experimental study was conducted to measure the effectiveness of interventions in reducing the proportion of PTLFU among TB patients. Baseline proportion of TB patients (diagnosed and referred during the 3rd and 4th quarters of 2016) for whom feedback received was determined from the RNTCP State Task Force (STF) Quarterly Reports. Based on the findings from the qualitative study among the stakeholders, intervention package was developed and implemented for 6 months between January 16 and June 15, 2017. The components of the intervention package are as follows: Three field workers were recruited, and one each was posted at the respective colleges. Health education and counseling were provided to the patients by the field workers along with the RNCTP staff. Information, Education and Communication (IEC) Pamphlets were issued. IEC Posters were displayed in places such as outpatient department, wards, and sputum collection center. Correct postal addresses of the patients were obtained for communication. Mobile numbers were collected and verified with missed calls. Phone calls were made to the patients after 3–4 days of referral. Home visits were made if the patients did not attend/respond to the phone calls. Training and regular supervision of field staff, RNTCP laboratory technician, and health visitor were conducted. DOTS directories were prepared for Pondicherry district and two neighboring districts of Tamil Nadu. Efforts were taken to establish regular communication between RNTCP medical officers at medical colleges and Senior Treatment Supervisors at Tuberculosis Units to facilitate the initiation of treatment for referred TB patients at PHIs and giving the feedback to medical colleges. After intervention for 6 months, we compared the baseline proportion of feedback received with the 1st and 2nd RNTCP STF quarterly reports of 2017 to assess the effectiveness of intervention package. Chi-square test was used to calculate *P* value for comparing the proportions of feedback received among baseline, 1st quarter, and 2nd quarter. $P < 0.05$ was considered as statistically significant.

Table 1: Number of in-depth interviews conducted among different key stakeholders

Study participants	Number of in-depth interviews
TB patients - reported	12
TB patients - not reported	11
RNTCP medical officers	1
Laboratory technician	4
TB - health visitor	4
Senior treatment supervisor	2
Total	34

*Only one medical college had RNTCP medical officer. TB: Tuberculosis, RNTCP: Revised national tuberculosis control program

All the project staffs were working under the direct supervision of the study investigators. Individual log books and project register were maintained. Monthly supervisory visits were made by the investigators to the all study sites. Fortnightly, progress reports were submitted by the field staff to the investigators and appropriate actions were taken. Quarterly review meetings were conducted at regular intervals.

The study protocol was approved by the Institutional Ethics Committee. Participant information sheet was provided to the study participants. Written informed consent was obtained. Confidentiality and privacy of the data were maintained. Permission was obtained from State TB officer and RNTCP STF Operational Research Committee chairperson.

Results

Patient-related factors

Unawareness about the disease and its treatment was told as a reason for not reporting by many patients. They also expressed their lack of faith in health-care system, especially the free drugs provided at Government facilities. Some of them were concerned about their privacy and confidentiality of the information due to issues related to social stigma. Side effects of the drugs and lack of family support were also mentioned by many patients.

"Initially, I was taking the drugs without any problem. Later I had stomach ache and vomiting. Therefore, I was not able to take the drugs…" (45 years/M).

Patients who reported to PHIs were aware about the nature of disease and treatment available. They wanted to take the drugs regularly because they felt that it was important to prevent the occurrence of disease among the family members. They also had adequate family support.

"If I take tablets regularly, I will be cured from TB. I don't want my family members to get the disease from me…" (35 years/M).

Health-care providers said that lack of awareness, poor family support, fear of losing wages, old age, alcohol intake, tobacco intake, presence of comorbidities such as diabetes, hypertension made the TB patients vulnerable to lost to follow-up. One TB Health Visitor (TBHV) said that migrant population did not have proper residential address. Many TB patients did not give their correct and complete address.

"They think, 'if we take tablets we can't drink alcohol', so just to continue alcohol, they don't want to take drugs…." (TBHV).

Health system-related factors

Many patients said that they did not report due to their unpleasant experience at medical college hospital such as harsh comments by health staff, long waiting period and no proper briefing and counseling about the disease. Patients were not referred to the correct PHIs where they reside. Therefore, the distance of DOTS centers from patient's houses was long which made them inaccessible. However, some patients preferred the place of treatment to be located far away from their houses due to issues related to stigma. There was also unavailability of drugs at the time of reporting to the referred DOTS center. Patients were asked to come back after some time, but they did not report back.

"They didn't inform me properly about the disease. I was referred to a hospital where they told that I was supposed to go to some other hospital which is quite far from my home…" (67 years/M).

Patients who reported had overall good experience at the medical college hospital like friendly and caring staff, short waiting period, and proper counseling. Before referring, the health staff discussed with them regarding the place of treatment and referred to appropriate DOTS centers which are nearer to them.

"Doctor asked me 'which is the nearest primary health centre' for getting tablet and then asked me to get the TB tablets there…" (52 years/M).

Most of the TB patients suggested that monetary support, healthy foods, and transport facility should be provided to them.

Health-care providers mentioned that lack of coordination between TBHV and Primary Health Centre (PHC) staff as one of the reasons for TB patients not reporting to the PHIs. In the absence of TBHV, other PHC staffs were not willing to provide RNTCP services.

"*There are some issues when TBHV is on leave. Other staffs are busy with their own works. They are not willing to take additional responsibilities of TBHV…" (STS).*

Health-care providers suggested that proper health education and counseling should be given to both patients and their family members and the contact details of the patients should be verified at the time of registration. They also said that referral system should be strengthened through preparing DOTS center directory. TBHV should follow-up the patients through phone calls and home visits. Table 2 shows the key findings of the qualitative study.

Effects of intervention

Out of 618 TB patients referred from medical colleges to PHIs for treatment, feedback was received for 282 (46%) TB patients at baseline. After the initiation of interventions, the proportion of feedback received from four medical colleges increased to 61% and 66|% in the first and second quarters of 2017, respectively [Table 3]. This difference was statistically significant ($P < 0.05$). It clearly showed that our interventions were effective.

According to our project data [Table 4], a total of 520 (99%) of 525 TB patients diagnosed at four medical colleges were

Table 2: Patient and health system-related factors contributed to pretreatment lost to follow-up of tuberculosis patients referred from medical colleges

Patient-related factors	Health system-related factors
Old age	Unpleasant experience at hospitals
Alcohol and tobacco	Poor referral mechanism
Losing daily wages	Poor accessibility to DOTS center
Migrant population	Temporary unavailability of drugs
Comorbidities	Unavailability of TBHV
Unawareness about the disease	Lack of coordination between TBHV and other PHC staff
Lack of family support	
Wrong contact details	
Lack of faith in health care system	
Social stigma	
Privacy and confidentiality issues	
Side effects of drugs	

DOTS: Directly observed treatment, short-course, TBHV: Tuberculosis health visitor, PHC: Primary health center

Table 3: Progress of feedback received from peripheral health institutions about tuberculosis patients referred from medical colleges based on revised national tuberculosis control program state task force quarterly report data (January–July 2017)

Colleges	Before intervention		During intervention				*P*
	July–December 2016		January–March 2017		April–June 2017		
	Referred (*n*)	Feedback, *n* (%)	Referred (*n*)	Feedback, *n* (%)	Referred (*n*)	Feedback, *n* (%)	
A	209	130 (62)	95	63 (66)	89	60 (67)	0.62
B	84	35 (42)	34	17 (50)	51	33 (65)	0.00
C	204	70 (34)	76	57 (75)	99	73 (74)	0.00
D	121	47 (39)	32	8 (25)	44	21 (48)	0.13
Total	618	282 (46)	237	145 (61)	283	187 (66)	0.00

Feedback was based on TB number received from the respective TUs. TB: Tuberculosis, TUs: Tuberculosis units

Table 4: Overall performance of all four medical colleges as per the project data (January–June 2017)

Parameters	Total (%)
TB patients referred for treatment	520
Number of sputum smear positive	322 (62.0)
Number of sputum smear negative	32 (6.2)
Number of extra pulmonary cases	166 (31.8)
Category_I	445 (85.6)
Category_II	75 (14.4)
Complete postal address	520 (100.0)
Mobile number obtained	504 (97.0)
Missed call checked	467 (89.8)
Alternate mobile number	86 (16.6)
Referral slip issued	520 (100)
IEC pamphlet issued	498 (95.8)
First phone call	485 (93.4)
Second phone call	213 (41.0)
Phone call to PHI	30 (5.8)
Home visit	93 (18.0)
Reported within 1 week	452 (87.0)
Reported within 2 weeks	485 (93.3)
Reported after 2 weeks	7 (1.3)
Not reported	28 (5.4)

TB: Tuberculosis, IEC: Information, education, and communication, PHI: Peripheral health institution

referred for treatment to PHIs. Eighty seven percentage of them reported within 1 week to the PHIs. Only 5.4% did not report at all due to various reasons such as private treatment, and death. We were able to obtain complete postal address and mobile numbers for 100% and 97% of referred TB patients, respectively. Performance data on reporting and the initiation of treatment were based on information obtained from patients through phone calls. However, 18% of them were checked by personal home visits and verification of patient treatment cards.

Discussion

In our study, we found that the reasons for PTLFU were multi-factorial which are related to both patient and health system. Patient's ignorance, lack of faith in health system, fear of side effects due to drugs and social stigma were the important patient-related factors for PTLFU. Their unpleasant experience at the health facilities were also contributing to it. Health staff were not adequately counseling and educating the TB patients before referring them to PHIs. According to the health staff, people who were addicted to tobacco and alcohol, migrant population and associated with comorbidities such as diabetes and hypertension were high risk groups for PTLFU. Similar risk factors were also identified in other studies conducted in India.[10,11]

After 6 months of interventions, the RNTCP STF quarterly report data showed that the proportion of feedback was increased significantly from 46% to 66%. This showed that our intervention package was effective. However, the overall proportion of referred TB patients who reported to PHIs during this period of 6 months was 95% as per the project data which was collected by our field staff by directly contacting the TB patients and PHIs through phones and/or home visits. This difference between program and project data showed that the proportion of reported TB patients might be underestimated in the TB program and it was definitely not as low as 46%. The PHIs were not properly sending the feedback to the medical colleges/district TB Officer/State TB Officer about the referred TB patients. Our project staff mostly contacted the TB patients than the PHIs due to unavailability of contact numbers. Now, DOTS directories are prepared after significant efforts by the team and can be used for the same purpose.

The main strength of our study is its design, i.e., implementation research which was conducted with active involvement of program staff in multiple medical centers with large sample size. Data collected regarding the reporting of patients to PHIs through mobile phone by the project staff may be less reliable. However, 20% of them were visited at home and their treatment cards were verified by our staff.

Conclusion

Our study suggests that simple interventions such as phone calls and home visits to TB patients can reduce the PTLFU. All the above interventions were implemented by the project staff in collaboration with RNTCP staff. However, the contribution by project staff was more than the program staff. Therefore, to

sustain the effects of interventions, RNTCP Staff, especially TBHV should be motivated and encouraged to continue the interventions, particularly phone calls and home visits. Their performance should be continuously monitored by the core committee of each medical college and the progress should be discussed during core committee meetings. For this purpose, TBHV are already being paid some incentives but irregularly and insufficiently which has to be improved. Simultaneously, the medical officers and TBHVs at PHIs should be motivated to improve the feedback mechanism. Since our interventions are very simple, cheap, and feasible, it can be scaled up to other medical colleges in India.

Acknowledgment

We express our sincere gratitude to Dr. S. Govindarajan and Dr. R. Veerakumar, State TB Control Officers of Puducherry and Tamil Nadu respectively for granting us permission to conduct the study. We would also like to thank Dr. Karunakaran and Dr. Sudhakar, District TB Officers of Cuddalore and Villupuram Districts of Tamil Nadu for sharing the details regarding the DOTS centers. We thank Dr. S. Yuvarajan, Chest Physician, SMVMCH for his support and co-operation.

Financial support and sponsorship

This implementation research was supported through The Global Fund to Fight AIDS, Tuberculosis and Malaria is an international financing organization and implemented through the Central TB Division, Directorate General of Health Services, Government of India and National Institute of Research in Tuberculosis, Chennai.

Conflicts of interest

There are no conflicts of interest.

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