Research Article

Barriers to treatment adherence of tuberculosis patients: A qualitative study in West Bengal, India

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ABSTRACT

Background: Defaulter (loss to follow-up) tuberculosis (TB) patients present a challenge to TB program by increasing drug resistance and transmission. Knowing factors contributing to non-adherence to TB treatment might help the program implementers to develop appropriate strategies to tackle the problem. **Objectives:** The objectives of this study were to explore factors contributing to non-adherence among defaulter TB patients and to delve into the perceived barriers to adherence according to directly observed treatment, short-course (DOTS) providers and staffs of TB unit (TU) at Burdwan Municipality. **Materials and Methods:** A total of 14 in-depth interviews of defaulter TB patients, 4 focus group discussions with 30 DOTS provider, and 4 key informant interviews with staffs of TU were conducted from May to November 2017 at Burdwan Municipality, West Bengal. The analysis of free list and pile sort data obtained was undertaken using Anthropac 4.98.1/X Software. **Results:** Key reasons contributing to default appeared to be addiction, improvement and non-improvement of symptoms, side effect and pill burden with long regime of the drugs, loss of daily wages, lack of awareness, stigma, poverty, non-referral by private practitioner, familial problem, negative counseling by friends, and perceptions of government medicines are bad. **Conclusion:** Triangulation of the response from patients, DOTS providers, TB health visitors, and senior treatment supervisor divulged certain contributing factors for non-adherence to TB treatment in the municipality such as addiction and side effect of the drug. Policymakers may consider inclusion of causality analysis and psychological counseling in the program for assessing true burden of drug-related adverse effects and for fighting the effect of addiction, respectively.

KEY WORDS: Pile Sorting; Smith's S Value; Addiction; Defaulters; Qualitative Study

INTRODUCTION

Tuberculosis (TB), the second most leading cause of death from infectious diseases next only to human immunodeficiency virus,[1] is a major public health problem in India. With an estimated incidence of 217 cases/1 lakh population,[2] India is the highest TB burden country in the world. For tackling this burden, Government of India provides free treatment for TB following directly observed treatment, short-course (DOTS) strategy.[2] Studies show that DOTS increases the rate of compliance, reduces the recurrence of the disease, and prevents the development of multidrug-resistant TB.[3-5]

According to revised National TB Control Program (RNTCP), TB default (renamed as treatment after loss to follow-up, i.e., lost to follow-up [LFU]) range, one of the program parameters, should be <10%.[6] However, in case of India, this ranges between 3% and 17%.[2] Poor adherence contributes to worsening of TB situation by increasing drug resistance. Patients' poor adherence to treatment, with an estimate of as low as 40% in developing countries, remains the principal cause of treatment failure globally.[7] Poor adherence to treatment might have taken place due to various demographic, socioeconomic, and behavioral causes. Exploring these factors are the need of hour for successfully tackling TB. Quantitative information of patients treated is already available to the

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healthcare delivery system. Qualitative approach which may compliment quantitative approach helps us to explore intangible factors better.[8] Currently, in India, RNTCP is undergoing many changes, and thus its ideal time to make this a better program by identifying the problem of non-adherence.

Although a few studies have used qualitative methods to explore various contributing factors toward non-adherence to treatment, information in West Bengal, particularly in Purba Bardhhaman district both from beneficiary or service provider's point of view is lacking. In this context, this qualitative study was conducted to explore factors contributing for non-adherence among defaulter (LFU) TB patients registered under RNTCP in Burdwan Municipality of Purba Bardhhaman district and to delve into the perceived barriers to adherence of TB patients according to DOTS providers and staffs of TB unit (TU) in the municipality.

MATERIALS AND METHODS

Study Area

This study was conducted during May–November 2017 at Burdwan Municipality of Purba Bardhaman district, West Bengal, India. Burdwan Municipality had 35 wards comprising two TU, two designated microscopy centers, and 30 DOTS centers. Both TUs had one senior treatment supervisor (STS) and three TB health visitors (TBHV) for supervising 30 DOTS providers.

Study Participants

Study subjects included both beneficiaries and service providers. Beneficiary participants were TB patients registered under RNTCP residing in Burdwan Municipality and recorded as defaulter (LFU) during a reference period of 1 year (January–December 2016). Patients who were already expired, unavailable at address given to TU, unwilling, unable to communicate, or absent/seriously ill on data collection day were excluded from the study. Thus, out of 20 defaulters in the reference period, finally, 14 patients were recruited (3 migrated, 2 expired, and 1 not found in address). Besides this, all 30 DOTS providers of the municipality and four staffs of TU were study subjects.

Data Collection

Background characteristics of TB patients and DOTS providers were collected with a semi-structured schedule. In-depth interview (IDI) of 14 defaulter (LFU) patients who fulfilled eligibility criteria and key informant interview (KII) involving one STS and three TBHV staffs were conducted to explore reasons for non-adherence.

A total of 14 IDI were undertaken to elicit perceptions of the defaulter patients. It was conducted face-to-face with one interviewer and one participant only, lasting not more than 20 min. Participants were posed with questions in a neutral manner, their responses were heard attentively and if necessary follow-up questions were asked. There was no leading question and participants were not shown approval or disapproval of what they said.

Four focus group discussions (FGDs) with DOTS providers were undertaken comprising 6–8 DOTS providers in each session with the help of a predetermined FGD guide composed of some guiding questions. There was a moderator for conducting the discussion, a recorder to note down the proceedings. FGDs were conducted at a place and time convenient to the participants. Participants were asked to sit in semi-circular manner so that each one of them is in the view of the others. A predetermined logical sequence of open-ended questioning was done to stimulate discussion among the participants to understand perceptions, beliefs, and reasons regarding non-adherence. Complete proceedings of the FGD including level of participation and sociogram were noted, and these sessions were electronically recorded. Participants were assured regarding anonymity of their responses. The original recordings were kept safely in a locked facility until they were transcribed word for word, then they were destroyed. Each session lasted for not more than 30 min.

Data Analysis

Data collection and analysis were done simultaneously. After each interview and FGD, data including all field notes and recorded audio were transcribed and translated from local language (Bengali) into English; close to verbatim on the day of data collection. All researchers then coded interview transcripts separately and any discrepancies in the coding were sorted out following exhaustive discussion. These coded notes were thematically analyzed and emerging themes were identified with illustrative quotations. Statements in italics indicate direct quotations from the participants.

Finally, a free listing using Smith's Salience value and pile sorting exercise was conducted by key informants (STS, TBHV). In the pile sorting exercise, the supervisors were asked to group those selected reasons which they feel goes together and suggest solutions for preventing them. The data were analyzed by Anthropac 4.98.1/X Software.[9] To get the collective picture, two-dimensional scaling and hierarchical cluster analysis of pile sort data were undertaken. Debriefing of the findings of free list, pile sorting and FGD to the participants were done to increase the credibility of the results.

Ethical Considerations

The study had got ethical clearance from the Institutional Ethics Committee of Burdwan Medical College and Hospital,

Purba Bardhaman, West Bengal. Informed consent was obtained from each and every respondent. They were assured regarding confidentiality of the information.

RESULTS

Background Characteristics

The study participants comprised 14 defaulters (LFU) TB patients, between 21 and 63 years of age. The mean (±standard deviation [SD]) age of the patients was 45.7 (±12.4) years. The study included 12 male patients and all were alcoholic. 13 participants were married, 12 were Hindu, and 8 subjects reside in a nuclear family. Educational level of the study subjects revealed that 4 were illiterate, 2 below primary level, 5 had completed primary but below secondary, and 1 each for just literate, secondary completed and graduate and above. Among study participants, 5 were unemployed and remaining 9 were unskilled worker. 12 participants belonged to upper lower and rest two to lower middle class. The mean (±SD) duration of consumption of drugs before defaulting was found to be 54.2 (±29.8) days, i.e., <2 months.

Among 30 DOT providers studied, mean (±SD) age was found to be 51.9 (±4.8) years. 27 DOT providers were Hindu and 18 belonged to general caste. Educational level of them revealed that 12 were below secondary, 10 had completed secondary but below higher secondary, 5 with higher secondary completed, and 3 were graduate and above. 22 of 30 DOT providers had experience of ≥10 years' service duration with a mean (±SD) of 11.9 (±5.8) years.

Causes of Non-adherence and Barriers to Adherence

IDI of the defaulter (LFU) patients as well as FGDs of DOTS providers had identified several causes of non-adherence. Themes that emerged during interviews were summarized in Table 1. Some of the important causes elicited in the study were described below:

Addiction

Alcohol addiction was voiced as a major barrier to treatment adherence by most of the service providers. Moreover, most of the patients were adamant and did not listen to DOTS provider. In spite of having very low earnings, most of the patients spent more on addiction, especially alcohol. One provider described that:

> *"One major problem is alcoholism. Initially, patients took medicines and abstained from alcohol for a good few days but as soon as the condition improved, they again turned toward alcohol and stopped taking medicines"* (Field Training Supervisor [FTS] 2, 56 years).

Symptomatic Improvement

For layman, symptomatic relief is usually associated with cure of the communicable disease.[10] This was reflected in the study and one patient mentioned:

> *"I discontinued treatment after 2 months because I felt better and I thought I was cured"* (Patient 6, 55 years, M).

Adverse Effects of Drugs and Loss of Daily Wages

IDI and FGD both had reported side effects of the anti-TB drugs and adverse reaction was other major reasons for non-adherence to treatment. A FGD participant said:

> *"Patients gave reasons like nausea, vomiting, fatigue, haziness of vision which they had suffered from after taking medicines especially during intensive phase"* (FTS 23, 48 years).

A patient told:

> *"I became fatigued after taking medicines and couldn't work properly which lead to loss of daily wages. That's why I stopped taking medicines"* (Patient 14, 34 years, M).

Large Number of Pills and Long Duration of Regimen

According to patients, major point of contention was the large number of drugs to be consumed for such a long duration. One of the patient's relatives died of TB. He was not convinced and said that:

> *"These medicines do not work regardless of the way you take them"* (Patient 4, 44 years, M).

Social Stigma

Social stigma and discrimination had also been reported as a cause during IDI of patients. Patients did not want DOTS provider to visit their home and also did not want to attend their center due to a potential disclosure of their disease. A patient told that:

> *"I was a rice mill worker when diagnosed of having the disease. But when the mill owner came to know about the disease, I lost my job. Then I decided not to take medicines as I had to earn livelihood"* (Patient 1, 47 years, M).

Free listed items (with Smith's S value) for non-adherence to treatment by key informants were presented in Table 2. The two-dimensional scaling and hierarchical clustering of the pile sort data showed two-independent and five subgroups of reasons for non-adherence [Figure 1]. Independent reasons were addiction and perception of

Table 1: Pile sorting of causes of non-adherence into themes with reasons and suggested solution by key informants (STS, TBHV)

Pile number	Theme	Causes of non-adherence	Reasons for grouping	Suggested solutions
1	Financial problem	1. Less investment on food 2. Poverty 3. Missing of daily wages	Directly attributed to financial status of the patient	1. Provision of food items with or without help from NGOs 2. Universal basic income
2	Medication-related factors	1. High number of tablets to be consumed 2. Long duration of therapy 3. Improvement of symptoms 4. Non-improvement of symptoms 5. Adverse effects	Directly related with drugs and duration of the regimen	1. Introduction of regimen with shorter duration 2. Dosages if possible, adjusted or reduced per tablets 3. Provision of drugs to take care of S/E along with ATD
3	Program-related factors	1. Unable to collect medicines 2. Lack of awareness among patients	Directly related with RNTCP implementation	1. Reinforcing house tracking and counseling of patients by DOTS provider 2. Widespread IEC activities
4	Social factors	1. Familial problem 2. Negative counseling by friends and relatives 3. Stigma and discrimination	Directly related to individual	1. Increasing emphasis on counseling to counter prevalent social dogma by the health-care workers
5	Addiction	1. Alcohol	Directly related to behavior and social problem	1. BCC, IEC, deaddiction center 2. Psychological counseling should be made available under RNTCP 3. Ensure stringent law against alcohol smuggling
6	Individual perception	1. Perceptions of government medicines are bad	Quality of free items is perceived as improper	1. Increasing awareness among local leaders, requesting them to spread the same among the population 2. More emphasis on advertising the RNTCP treatment as high quality, zero cost option
7	Other allied factors	1. Lack of proper response from community leaders 2. Non-referral by private practitioner	Not direct lacunae of the program but influencing the adherence	1. Enforce strict legislation compelling private practitioner to refer 2. Strong and empathetic political commitment needed

NGO: Non-government organization, S/E: Side effect, BCC: Behavior change communication, IEC: Information education communication. RNTCP: Revised National Tuberculosis Control Program, DOTS: Directly observed treatment, short-course, ATD: Antituberculosis drugs

government medicines bad. Improvement of symptoms, non-improvement of symptoms, adverse effects, high number of tablets to be consumed, and long duration of therapy were clubbed together as key informants (STS, TBHV) felt that these three were primarily related to medication. For subgroup of less investment on food, poverty and missing of daily wages, key informants felt these were financial problem. For another subgroup of related reasons such as inability to collect medicines and lack of awareness among patients, the role of programmatic factors was strongly suspected. Lack of proper response from community leaders and non-referral by private practitioners were clubbed together by them as other allied factors. According to the key informants, reasons such as familial problem, negative counseling by friends and relatives and stigma were associated and clubbed as social factors. For almost, all the reasons suggestion for solution was also sought from the key informants [Table 1].

DISCUSSION

The present study had focused on IDI of defaulter patients, FGD of DOTS providers, and KII of supervisors to explore factors contributing to treatment non-adherence. The study revealed this problem is multifactorial [Figure 2]. Addiction, improvement of symptoms, side effect and pill burden with long regime of the drugs, loss of daily wages, lack of awareness, stigma, and discrimination were major contributing factors for non-adherence to TB treatment in this municipality.

This study revealed that current long-term regimen and higher number of tablets per dose were important factors for non-adherence to antitubercular therapy which is corroborating with previous studies.[11,12] Adverse effects such as nausea, vomiting, and fatigue were also found to be associated with non-adherence in this study, in concurrence with other studies.[13-15] Therefore, patients should be well informed about

the side effects and counseled regarding pill burden to maintain compliance. PaMZ (Pretomanid [Pa 824], Moxifloxacin, and Pyrazinamide) and BPaMZ drug combination used in stand trial might provide solution to the problem of long duration of present RNTCP regime.[16] Addiction especially alcohol abuse by patients presented another considerable barrier for treatment adherence in this study. This was also reported by multiple studies.[17-21] Alcoholism interferes with efficacy of drugs as well as hampers the regularity of regimen. This also poses a hindrance to the care, support, and counseling by DOTS providers. Therefore, psychological counseling for deaddiction might be made available under RNTCP. Laws and legislation must be also made stringent against alcohol consumption. The current study explored that with gradual improvement of clinical features some of the patients became non-adherent. Allen S reported comparable findings in South Africa in 2006.[10] However, no improvements in symptoms despite taking medicines also lead to interruption of treatment. This finding was supported by Khan *et al.*[22] and Jaiswal *et al.*[21] Mere symptomatic relief is not the end of disease. This should be emphasized by DOTS provider during treatment. In this study, financial factors were found to be another important reason associated with non-adherence, corroborating with Xu *et al.* study.[23] The main financial burdens, as evidenced in the present study, were the poverty and poor socioeconomic condition of the patients. Some of the patients cited missing of daily wages as the reason behind interruption of regimen. Again, lack of food security was also reported by the respondents as another reason of non-adherence to treatment in the present study. This is in line with other qualitative studies.[22,24] Saxena and Bhardawaj[25] also suggested that considerable amounts could be invested in incentives and enablers (such as food packages and transport vouchers) to minimize the risk of default. Stigma and social discrimination also had found to influence the compliance among patients in the current study. This study also revealed family and community support played key role for influencing treatment adherence. A supportive family can comfort and motivate patients to complete their treatment. Similar findings were reported in Pakistan,[22] Ethiopia,[26] and Canada.[27] Therefore, community-based TB treatment programs and stronger involvement of local social networks are the need of the hour. Although an Ethiopian study[28] had found that long distance from health facilities, the use of traditional healing systems and diagnostic delay

Table 2: Relative ranking of causes of non-adherence to treatment of TB patients

Causes	Smith's S value
Addiction	0.95
Improvement of symptom	0.93
Adverse effects	0.90
Number of tablets to be consumed	0.76
Long duration of regimen	0.70
Loss/missing of daily wages	0.45
Lack of awareness	0.42
Social stigma	0.38
Poverty	0.38
Lack of proper response from community leaders	0.34
Non-referral by private practitioner	0.25
Familial problem	0.20
Less investment on food	0.19
No improvement despite medications	0.16
Negative counseling by friends	0.13
Perceptions of government medicines are bad	0.12
Inability to collect medicines	0.08

TB: Tuberculosis

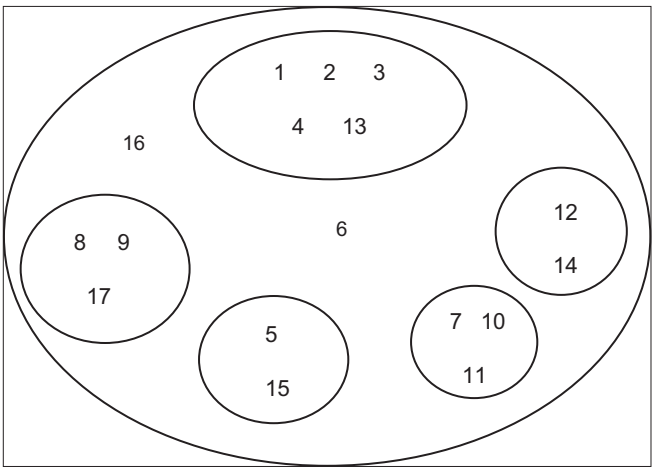

Figure 1: Cognitive map showing relationship between perceived barriers to adherence to treatment by directly observed treatment, short-course provider. (1) Improvement of symptoms; (2) S/E; (3) high number of tablets; (4) long duration of regimen; (5) inability to collect medicine; (6) addiction; (7) less investment on food; (8) familial problem; (9) negative counseling by friends; (10) poverty; (11) missing of daily wages; (12) lack of proper response from community leaders; (13) no improvement of symptoms; (14) non-referral by private practitioner; (15) lack of awareness; (16) perception of government medicines bad; (17) social stigma

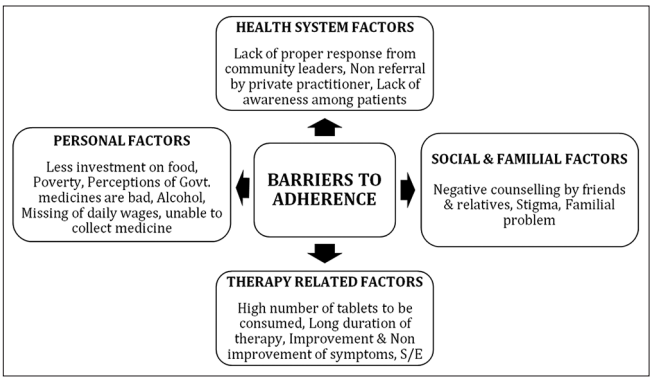

Figure 2: Factors related to defaulting (lost to follow-up) tuberculosis treatment

by healthcare providers as main reasons for not initiating a timely TB treatment; these were contrary to the finding of the current study. In our study, the care providers were found to be committed to the DOTS care delivery and despite their huge workload they managed to provide information to the patients during the treatment supporter selection process.

Main strength of this study lies in the design itself. Qualitative study is most suitable to identify the perceptions or reason behind any behavior. Moreover, the current study had applied different data collection techniques such as IDI, FGD, and KII depending on the type of participant. This had helped in data triangulation. Furthermore, the use of statistical software (Anthropac) in this study made analysis more scientific. Besides this, all DOTS providers, supervisors, and defaulter patients during 1-year reference period in the Burdwan Municipality were included as study subjects. The study was conducted in one municipality area and this might be one limitation of the study. If some of the upper tier program officers could be included as subjects, then it might be possible to get any other reasons.

To conclude, shorter regimen, awareness among patients, family support, committed DOTS providers, and support for livelihood of the patients were some of the important factors to prevent defaulter.

CONCLUSION

The present study highlights several reasons for non-adherence as well as perceived barriers to adherence to TB treatment among service providers. Health professionals, policymakers, and program implementers should be aware of such factors and initiate sustained health education campaigns directed toward patients, healthcare providers, patients' close contacts, traditional health practitioners, religious leaders, and the community for increasing awareness about "sure cure for TB" on recommended completion of treatment. Policymakers may consider inclusion of causality analysis and psychological counseling in the program. Further, research may be considered in this regard.

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