

Role of 'patient sensitization on patient charter' for tuberculosis care and support: The beneficiaries' perspective

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Background Improvement of knowledge regarding the rights and responsibilities of patients with tuberculosis (TB) (patient charter) through sensitization meeting may have a positive effect on their life and yield better treatment outcomes.

Participants and methods With the objective to understand beneficiaries' (who availed TB care and support services) perspective, 30 patient interviews from eight districts of Jharkhand were conducted with a semistructured questionnaire. The sample was drawn from 120 cured patients with TB of 770 patients with TB sensitized on patient charter.

Results Of 30 respondents, 23.3% (7, $n=30$) are female; 6.6% (2, $n=30$) belong to extrapulmonary cases; 10% (3, $n=30$) and 6.6% (2) are diagnosed through fine needle aspiration cytology and chest radiography modes, respectively; and all of them got detected at public health facilities. Most of the respondents are empowered completely or partially. Overall, 56.6% (17, $n=30$), 13.3% (4, $n=30$) and 30% (9, $n=30$) of the respondents are satisfied, unsatisfied, and neutral about patient charter role on treatment outcome. Only 13.3% (4, $n=30$) acted as TB ambassadors. Three thematic areas emerged out of this study: empowered patients with TB [100%, (30, $n=30$)], content patients with TB [56.6% (17, $n=30$)], and TB ambassadors [13.3% (4, $n=30$)]. Here empowered patients with TB refers to those who acquired the requisite knowledge about TB, content patients with TB refer to those who are satisfied with the information and services of patient charter meeting, and TB ambassadors

are those who helped the neighborhood in getting rid of TB. Moreover, empowerment is considered when knowledge-related questions were responded properly, and satisfaction is considered when needed information and services were offered leading to better treatment outcome.

Conclusion It is evident from the study that the patient charter has substantially empowered the attendees in getting positive treatment outcome; however, further improvement is needed with the help of other stakeholders involved in TB control. Moreover, the charter should be creating more TB ambassadors which would help in mobilizing the community to identify the hidden cases of TB for control through 'word of mouth'.

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Introduction

Tuberculosis (TB) is a major public health crisis affecting millions of people worldwide. The global TB burden report in 2017 stated that there were 6.1 million reported new cases in 2016, which is equivalent to 61% of the estimated incidence of 10.4 million [1]. TB is the ninth leading cause of death worldwide and is the leading cause of death from a single infectious agent ranking above HIV in the world. As per the report, 10.4 million people fell ill owing to TB in 2016. Of these, 90% were adults, consisting of 65% male, and 10% of the people were living with HIV. The geographical distribution of the disease reveals that 56% of the total cases come from five countries in the world; India, Indonesia, China, the Philippines, and Pakistan, in a descending order as per the incidence of cases [1]. In addition drug resistant TB is continuing as a biggest threat these days. There were 600 000 new cases of rifampicin-resistance TB (RRTB) in 2016, the most effective first-line drug, of which 490 000 had multidrug-resistant TB (MDR-TB). Most distressing is that half (47%) of these cases are from India, China, and Russian Federation, in a descending order as per

the incidence of cases [1]. It is evident from the aforementioned fact that India always ranks top in any category of TB morbidity and mortality and ranks fourth in Global TB burden [2]. The report further suggests that, in 2016, in India, the TB treatment coverage was 63% (39–120) [1].

Given the situation, the WHO, in 2006, drafted the stop TB strategy to control the high incidence and mortality around the globe, which is consistent with the goals of Millennium Development Goals [3]. The major emphasis of stop TB strategy was to have a patient-centered approach for TB care and to ensure quality TB drugs to every corner of the society [3]. The patient-centered approach enables and empowers the patients with TB to actively participate as informed participants in activities and decisions related to TB

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care and management [4]. Patient-centered approach and empowering the patients with TB for TB care and control is endorsed by the International Standards of TB care (ISTC) that ensures the human rights issues of patients with TB and delivers equality-based TB care to each and every patient with TB around the globe [5]. Furthermore, the stop TB partnership also encloses key ideas that emphasize on the importance of the role of national TB control program staffs and the patients with TB, both cured and suffering, as well as the community at large [3].

It has been seen that patients with TB around the world have developed patient charters to help facilitate TB care and control [6]. These charters, around the world, help patients with TB in ensuring their rights as patients with TB and enable them to exercise their responsibilities as patients with TB including that of the society and the health system at large [6]. In this research a similar patient charter in one of the eastern Indian states has been studied from the perspectives of beneficiaries of TB care and its impact on TB care and control.

Objective

The study was aimed at understanding the perspectives of beneficiaries of TB care, who attended the patient charter, on its effect, in terms of care and support, during their journey as patients with TB.

Participants and methods

Study setting

The study was carried out in the state of Jharkhand, one of the eastern Indian states of India. The state notified 35130 TB cases in 2016 from public sector. Of the total cases notified, 32782 (93%) cases constitute the pulmonary cases and 2348 (7%) cases constitute the extrapulmonary cases. The treatment outcome of 16724 patients with TB reported in 2015 by the state was as follows: cured, 86%; completed, 5%; died, 3%; failure, 1%; defaulted, 4%; transferred out, 0%; and switched to Cat-IV, 0% [2].

Study design

The study adopted a qualitative research method, and the data were collected through in-depth interviews. The data collection was carried out after the event of the patient charter meeting at the door step of the patients instead of collecting the same at the patient charter meeting, with the sole purpose of offering convenience to the respondents. The data collection was primarily carried out by the fourth author (L.S.) with the help of other three authors. A pilot test of the

questionnaire was also carried out, and the questionnaire was revised as per the feedback gained through the pilot testing.

Study instrument

For the purpose of collecting data, a questionnaire was used, which consists of 18 questions. The questionnaire consists of 17 multiple-choice questions with four options and one subjective question. The questionnaire contains questions related to demographic profile, diagnosis and treatment history, topics related to regimen, adherence, and compliance and roles and responsibilities related to patients with TB, and their role in creating a TB-free community.

Sampling and data collection

The study was conducted between January and March 2017. The participants included in this study are the cured patients with TB who had attended, at least once, a TB patient charter meeting during the entire course of their treatment. Cured patients with TB were deliberately chosen to understand their perspective about the role of the patient charter meeting on TB care and support, as per the objective of the study. The sample was drawn from 120 cured patients with TB of 770 patients with TB sensitized on patient charter. A final list of 30 patients was chosen through simple random sampling technique from the pool of 120 cured patients with TB. These patients represented eight different districts of the state of Jharkhand.

The data collection was done with the help of a semistructured questionnaire and fourth author (LS) collected the data for the same. As questionnaire was a semistructured one, thus the data were directly jotted down, verbatim, by the researchers in the questionnaires instead of audio tapping. The questions were asked in Hindi language to all the participants as all of them understand Hindi language. Verbal informed consent was taken from each of the participants before conducting the interview. After completion of the interview, the complete interview was read out in front of the participants for confirmation.

Data analysis

Inductive thematic content analysis was applied to analyze the obtained data. Initially, all the responses were read carefully and repeatedly, and some categorization and contextualization were made. After this, the raw categorizations were further contemplated and then thematic areas were brought about. At the end of this process, three thematic areas

were brought about for the analysis of the obtained data.

Ethical consideration

The ethical approval for this study was taken from the Institutional Ethics Committee (IEC) of the Catholic Health Association of India, Secunderabad, India. Three of the research team members conducted the interview. Verbal consent was taken from the agreed participants. Written consent could not be taken from most of the respondents as they were illiterate or they had problems in reading and/or signing the consent document. All the patients were given the freedom of leaving the interview at any point in time during the interview process.

Results

It is evident from Table 1 that of the 30 respondents, 23.3% (7, $n=30$) were female, and all the respondents belonged to rural community. Of the 30 subjects, 6.6% (2, $n=30$) belonged to extrapulmonary category, 27 cases had new smear positive (NSP) results, and 3.3% (1, $n=30$) cases were relapse cases. The percentage of frequency of different diagnostic approaches used in this study are as follows: Cartridge-Based Nucleic Acid Amplification Test (CBNAAT) - 3.3% (1, $n=30$), both S-AFB and chest radiography (CXR) - 6.6% (2, $n=30$), other methods - 6.6% (2, $n=30$), CXR - 6.6% (2, $n=30$), fine needle aspiration cytology - 10% (3, $n=30$) and S-AFB - 66.6% (20, $n=30$). Of the 30 patients, 93.3% (28, $n=30$) complained of cough and

Table 1 Characteristics of the sample

Patient no.	Age	Sex	Habitation	Type of TB	Mode of diagnosis	Place/facility of diagnosis	Chief complaints	Type of regimen (Cat-I/Cat-II)
1	22	F	R	P	S-AFB and CXR	GHF	Prolonged cough	Cat-I
2	23	M	R	P	S-AFB and CXR	GHF	Cough, fever, and weight loss	Cat-I
3	44	M	R	P	S-AFB	GHF	Cough, fever, and weakness	Cat-I
4	45	M	R	P	S-AFB	GHF	Persistent cough and fever	Cat-I
5	55	M	R	P	S-AFB	GHF	Cough >2 weeks	Cat-I
6	50	M	R	P	S-AFB	GHF	Cough >2 weeks and chest pain	Cat-I
7	45	M	R	P	S-AFB	GHF	Sweating at night	Cat-I
8	28	M	R	P	S-AFB	GHF	Chest pain, cough, and fever	Cat-I
9	25	M	R	P	S-AFB	GHF	Cough and hemoptysis	Cat-I
10	30	M	R	P	S-AFB	GHF	Cough and hemoptysis	Cat-I
11	50	M	R	P	S-AFB	GHF	Cough >2 weeks	Cat-I
12	32	M	R	EP	Other	GHF	Weight loss and weakness	Cat-I
13	18	F	R	P	S-AFB	GHF	Cough and weakness	Cat-I
14	40	F	R	P	S-AFB	GHF	Fever, cough, and weight loss	Cat-I
15	48	F	R	P	S-AFB	GHF	Cough >2 weeks	Cat-I
16	29	F	R	P	S-AFB	GHF	Cough >2 weeks	Cat-I
17	26	M	R	P	S-AFB	GHF	Fever, cough, weight loss, and loss of appetite	Cat-I
18	18	M	R	P	S-AFB	GHF	Cough >2 weeks and fever	Cat-I
19	26	M	R	P	S-AFB	GHF	cough, weight loss, and loss of appetite	Cat-I
20	27	M	R	P	S-AFB	GHF	Cough, weight loss and loss of appetite	Cat-I
21	26	M	R	P	S-AFB	GHF	Cough, weight loss, and loss of appetite	Cat-I
22	30	M	R	P	CBNAAT	GHF	Relapse	Cat-II
23	19	F	R	P	S-AFB	GHF	Fever, cough, and loss of appetite	Cat-I
24	25	F	R	EP	Others	GHF	Swelling of lymph node	Cat-I
25	30	M	R	P	S-AFB	GHF	Cough and fever	Cat-I
26	35	M	R	P	CXR	GHF	Cough >2 weeks	Cat-I
27	35	M	R	P	CXR	GHF	Cough >2 weeks	Cat-I
28	10	M	R	P	FNAC	GHF	Cough and fever	Cat-I
29	10	F	R	EP	FNAC	GHF	Swelling of lymph node	Cat-I
30	35	F	R	P	FNAC	GHF	Cough and fever	Cat-I

Cat-1, category-1; cat-II, category-II; CBNAAT, cartridge-based nucleic acid amplification test; CXR, chest radiography; EP, extrapulmonary; F, female; FNAC, fine needle aspiration cytology; GHF, government health facility; M, male; P, pulmonary; R, rural; S-AFB, sputum for acid-fast bacilli.

associated symptoms as their chief complaints, 3.3% (1, $n=30$) complained of sweating at night, and 3.3% (1, $n=30$) complained of weight loss and weakness as the chief complaint. All the 30 patients were diagnosed at the public health facilities, and 96.6% (29, $n=30$) were on Cat-I and 3.3% (1, $n=30$) were on Cat-II regimen provided by the national TB control program of India. The two regimens, Cat-I and Cat-II, are the prescribed regimens under the Revised National Tuberculosis Control Program (RNTCP) of India and are administered under two different phases: intensive phase (IP) and continuous phase (CP). The Cat-I drugs consist of isoniazid, rifampicin, pyrazinamide and ethambutol in IP and isoniazid and rifampicin in CP. Cat-I is recommended for new cases of sputum smear positive, sputum smear negative and extrapulmonary cases for a duration of 2 months in IP and 4 months in CP. Similarly, the Cat-II drugs consist of isoniazid, rifampicin, pyrazinamide, and ethambutol and injectable streptomycin in IP and isoniazid, rifampicin, and ethambutol in CP. The Cat-II is recommended for previously treated cases of smear positive relapse, smear positive failure, and smear positive treatment after default cases for a duration of 3 months in IP and 5 months in CP. These drugs are available in patient-wise boxes (PBW) containing the full course of treatment and are color coded, indicating red for new/Cat-I and blue for previously treated/Cat-II cases [7,8].

'Others' refer to the diagnostic modalities adopted by the treating physicians other than aforementioned modalities.

Furthermore, the inductive thematic analysis of the data yielded three thematic areas; empowered patients with TB, Content patients with TB, and TB Ambassadors. Table 2 defines each of the thematic areas.

Most of the respondents were empowered completely [76.6%, (23, $n=30$)] or partially [23.3%, (7, $n=30$)]. The complete and partial empowerment was decided based on their response to TB-related questions: complete correct response implied to complete empowerment, and the substantial correct response implied to partial empowerment. Overall, 56.6% (17, $n=30$), 13.3% (4, $n=30$), and 30% (9, $n=30$) of the respondents were satisfied, unsatisfied, and neutral about patient charter role on treatment outcome. Only 13.3% (4, $n=30$) acted as TB ambassadors.

Table 2 Thematic categories and their definitions evolved through this study

Thematic category	Definition
Empowered patients with TB	Refers to those who acquired the requisite knowledge about TB and got aware about the disease and relevant health services available for TB. Moreover, empowerment is considered when knowledge-related questions were responded correctly
Content patients with TB	Refers to those who are satisfied with the information and services provided through patient charter. Furthermore, satisfaction is considered when needed information and services were offered leading to better treatment outcome
TB ambassadors	TB ambassadors are those who helped the neighborhood in getting rid of TB by disseminating TB-related knowledge and health services

TB, tuberculosis.

Discussion

The section delineates about the thematic areas identified through the inductive thematic analysis, in detail.

Empowered patients with TB

It was observed that most of the beneficiaries were empowered with the TB information, as elicited by the interviews. Empowerment is important from the perspective of disease control and prevention. The knowledge base and the positive attitude toward health seeking created through the patient charter are significant. Research suggests that knowledge and perception regarding a particular health condition help the general population as well as the patients in taking right help at the right time. It helps them take preventive and precautionary measures for a particular disease [9]. A similar study conducted in Chhattisgarh in which the slum dwellers were empowered through a structured TB awareness strategy found that a considerable level of improvement in the knowledge and a positive attitude to access public health facilities for TB care were the major outcomes [10]. One of the beneficiaries reported the following:

I was not aware that TB can happen because of crowded and closed houses. I was thinking that it spreads in the family, like father to son or mother to son. Now I am aware that it is because we lived in a house without ventilation and the bacteria transmitted from me to my son through air only (A patient charter beneficiary).

This statement of one of the beneficiaries indicates that some people believe that TB is hereditary, and the TB patient charter has clarified that TB does not run in

families owing to its hereditary nature rather the close housing conditions make people experience the disease in families.

Another beneficiary narrated that she was not aware that TB can happen anywhere in the body after getting diagnosed with Tubercular lymphadenitis. She reported the following:

I was thinking that TB can only happen in chest (Lungs) not anywhere in the body. I had this swelling of gland on my neck since long and one of your staffs told me to get it tested. The doctor took something from this swelled gland, tested and reported me that I am suffering from TB. It was shocking to know that this is due to TB; however, after attending the meeting, I got clarified and took medicines regularly. (An extrapulmonary TB patient beneficiary)

It is very clear from the aforementioned statement that people in rural areas were not aware of extrapulmonary TB and the patient charter meeting made people aware that TB can happen anywhere in the body, although pulmonary TB is the most common form of TB.

Content tuberculosis patients

It was further observed that patients with TB attending the patient charter meetings/sessions were found to be satisfied with the information they were provided with. This is also evident from the fact that most of the patients with TB were empowered with the TB-related knowledge, which otherwise implies that the patients with TB were content. This may not be always true that if a person is getting knowledge with some information, s/he is also satisfied with the information; however, in most instances, it is true.

One of the participants of the patient charter stated the following:

I am happy that I got the opportunity to be a part of the meeting once. I was clarified with all the doubts about the disease and the diagnostic and medical facilities available for the disease. The responses of the facilitators were really good and I recommended one of my friend to send his wife to the meeting as she is also suffering from cough (A male patient with TB).

Similarly, one of the female patients with TB stated the following:

I was feeling little depressed owing to my disease and it was primarily due to ignorance about the disease among my in-laws especially my mother-in-law. I got to know about the meeting from my husband who was recommended by one of

his friends who is also a TB patient. I took my mother-in-law with me to attend the meeting and the end result is that I am taken care of properly in my in-laws house with all the necessary care and support (A female patient with TB).

Empowerment along with satisfaction of patients with TB attending the patient charter meetings can help in achieving the important goal of TB care and control nationally. As per the International Standards of TB care and Control, empowerment and satisfaction of people attending the patient charter meeting are the catalyst for effective collaboration with health providers and authorities and are essential to victory in the fight to stop tuberculosis [11].

Tuberculosis ambassadors

Albeit it is expected that all the patients with TB cured through the rigorous treatment process should inform the merits of their treatment to the nearby community; however, this does not happen always owing to some of the reasons in the community. The reasons could be; most of them cannot remember all the information provided to them; despite sensitization, some of the patients still keep secret of their TB status; many do not find time; etc. However some patients do act as TB ambassadors and spread the merits of their treatment to their nearby community.

Through this study, it was also observed that some of the participants who got cured acted as the TB ambassadors in their nearby community. One of the cured patients with TB stated the following:

Sir I am very happy now that I am free from the disease and now working comfortably as I was working earlier. Sir, I am a mason and have to do some strenuous work as well and owing to continuous cough I was not able to work and people were also feeling awkward with me. One day while I was at home one of your workers came and made me understand about the disease and then I felt that I am having similar symptoms as narrated by your worker thus I underwent sputum examination and found positive to TB. The diagnosis and duration of treatment was bad news for me; however, your worker continuously made me understand the significance of uninterrupted treatment and the result is I am OK now. When I returned to work I found that one of my co-worker is also having similar symptoms thus recommended him and he was diagnosed with TB and is currently under treatment and says-‘Tu thik hogaya to me bhi ho jaunga’ (you got cured of the disease so also I) (One of the cured patients with TB).

One of the recent studies on patient charter in Pakistan revealed that most of the cured patients with TB were interested to serve and contribute toward TB care and control in one way or the other; however, they did not have sufficient information about TB care organizations [12]. In such instances, patient charter meetings can be of great help in bridging such knowledge gaps. The role of patient charter meeting has been further substantiated by the fact that patients with TB cannot understand the disease unless they are made part of planning and implementation of relevant policies [13]. Thus, a trustworthy relationship between patients with TB and service provider serves as an important tool for TB care and control, as evident from different studies [14,15]. Furthermore, the patient charter meetings helped in providing the complete information and empowered the patients with TB [6,16] which invariably helped in disseminating relevant information to their nearby community. Moreover, emotional support and help from friends and peer always helps in completing the treatment without any hurdle, with a feeling that they are not alone, and it is evident from various studies that friends, peer, and family members very often support mentally, emotionally, and sometimes financially as well [17,18]. Patients with TB getting help from the community in which they reside and from the peer and the family members can lead to achieving a TB-free community and is only possible if the all these stakeholders get the right information in time.

Conclusion

It is not very uncommon that the patients in rural communities are devoid of right information about the disease and the healthcare services available for them, including the overarching rights and responsibilities. Patient charter meeting not only empowers these beneficiaries about the rights and responsibilities but also help facilitate in getting mental and emotional support from their peers and family members. Thus, the role of patient charters in creating a TB-free society cannot be ignored.

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Conflicts of interest

There are no conflicts of interest.

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