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Perspectives of women suffering from tuberculosis regarding challenges and barriers to treatment adherence in Central India: A qualitative study

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Abstract

Background: Tuberculosis (TB) is one of the major causes of ill health, one of the top 10 causes of death worldwide and the leading cause of death from a single infectious agent. India alone contributes to 27% to the total TB cases globally and thus is in high burden of Tuberculosis. Gender inequalities in health seeking behavior has severe public health impacts in terms of delay in diagnosis as well as delay in treatment of PTB. This study was undertaken to understand the perspective of females to identify and determine the difficulties faced by them in adhering to TB treatment in Jabalpur, Madhya Pradesh.

Methodology: Qualitative study design was used to understand the perspectives of participants. We carried out 20 interviews with women aged 18-60 years who were lost to follow up (LTFU) for treatment of TB. Analysis was based on content and thematic analysis method. Codes were developed using themes and patterns in the research.

Result: Despite of wide implementation of the National Tuberculosis Elimination Program (NTEP) there are still some barriers which need to be addressed. Out of pocket expenditure, misconceptions related to TB, transportation costs, delayed diagnosis, stigma and socio-cultural barriers, and family responsibilities remain the main barriers among the women of 18-60 years for the TB treatment.

Conclusions: The study highlights the need of raised awareness, sensitization, education of women, approachable health facilities, free transport facilities, reduced burden of out-of-pocket expenditure, and increased community participation.

Keywords: Tuberculosis, challenges, barriers, lost to follow up, Stigma, OOPE

Introduction

Tuberculosis (TB) is one of the oldest infectious diseases known and second leading infectious cause of death worldwide (after Covid-19) [1]. In 2020, an estimated ten million people fell ill with tuberculosis (TB) worldwide including 5.6 million men, 3.3 million women and 1.1 million children [2]. The South-East Asia (SEA) Region is home to 26% of the world's population with 44% burden of TB incidence [3]. Despite of all the progress made till date globally, TB remains major health challenge in poor and developing countries [4]. According to WHO, India was the highest TB burden country in 2019 with estimated incidence of 26.9 lakh cases. In 2018, a total of 21.5 lakh new cases of TB were notified, and Madhya Pradesh contributed about seven percent of all those cases [5].

Government of India is currently running National Tuberculosis Elimination Programme (NTEP) to address the issue. To improve the coverage of programme, a National Strategic Plan 'NSP 2017-2025' was developed. According to this plan, TB elimination has four strategic pillars namely "Detect-Treat-Prevent-Build" [6]. An online notification portal named 'NIKSHAY' was also launched to notify all TB cases online.

However, failure to complete TB treatment may result in poor patient outcomes. Many patient-related risk factors like unemployment, substance use disorder (SUD) and HIV have also been found to be responsible for loss to follow-up during treatment [7]. Several barriers such as stigma, financial burden, income, education, gender discrimination and comorbidities like HIV have been associated with the delay and poor adherence to TB treatment [8, 9]. Gender differences, inequalities, social and cultural barriers also affect treatment in males as well as females but females are affected more than males [10]. Stigma is mainly due to isolation from society and fear of transmission leading to discrimination, which eventually causes failed marriages and neglection by family [11]. While this stigma leads to difficulty in getting married for girls, if married, the women are subjected to domestic violence [12]. In order to address this issue, MoHFW and CTD has devised a National Framework for A Gender-Responsive Approach to TB in India [13].

Though many studies have been conducted in this domain, very limited literature is available regarding the assessment of patient's perspective on barriers faced by them in treatment adherence in the specific context of TB care delivery in India. The present study tries to explore patient's perspective of tuberculosis treatment challenges and barriers.

Materials and Methods

Study Design and sample size

Twenty interviews were conducted out of which fourteen were conducted in person (In Depth Interviews) and six interviews were conducted telephonically. Interviews were conducted in March 2021. Challenges and barriers faced by individuals are subjective, and therefore a Qualitative study design was used for the study to identify these challenges and barriers faced by women.

Study Population

This study was conducted in Jabalpur district in the state of Madhya Pradesh. Females with notified TB infection in the age group of 18-60 years were included in the study.

Inclusion Criteria

Women in the age group of 18-60 years diagnosed with TB who started treatment but were Lost to Follow Up (LTFU), as per the TB notification data. It includes both Pulmonary and Extra Pulmonary Tuberculosis in the year 2019 in both public as well as private sector, are included in the study.

Exclusion Criteria

Women who are less than 18 years and above 60 years of age were excluded from the study. Pregnant women were also excluded from the study.

Initially secondary data was collected from notified TB cases and total notified cases in the year 2019 were calculated. Using the inclusion and exclusion criteria total number of females who were lost to follow up were taken from that data as the study participants. Purposive sampling method was used to collect data from specific target population. Fourteen women were interviewed in person while six women were interviewed telephonically as they were hesitant to meet in person due to high risk of COVID-19 infection. All the interviews were conducted with prior permission of Chief Medical & Health Officer (CMHO), District TB Officer (DTO) and study participants. Before proceeding for every interview verbal and informed consent was taken from every participant.

In-Depth Interviews (IDI)

We conducted 20 In Depth Interviews (IDI's) out of which fourteen interviews were conducted in person while six were telephonic interviews. All the IDI's were conducted using a guide, which was developed and pilot tested in advance. The pilot testing was done to make sure that the questions were understood correctly by the participants.

Study participants were approached with the help of local health staff of the respective village and urban areas. All the participants were interviewed at their homes in open area and interviews were conducted in their local language. All the participants were allowed to narrate their experiences, views, and problems.

Data Compilation and Analysis

The data collection process was iterative. We transcribed and translated all the interviews into English. On the basis of the data collection, contextual themes have been developed and results are presented. Data analysis has been done manually and is based on the content and thematic analysis method.

In order to preserve anonymity, the letter "P" was assigned to all participants, followed by a number, after agreeing to participate in the research (for example: P1, P2 to P20).

Research Tool

We developed a semi-structured in-depth interview guide for the study. The thematic areas of the IDI guide used are as follows:

1. Awareness on TB
2. Delayed Diagnosis
3. Out of Pocket Expenditure
4. Side Effects of the Anti-Tubercular Drugs
5. Stigma Related to TB
6. Misconceptions related to the TB treatment
7. Effect of COVID on Follow ups of patients

Results

Identification of thematic areas was done based on the data collected by interviews. The key findings which came out from the interviews for each thematic area are described below:

1. Awareness on TB

There were mixed responses of the participants about their knowledge on Tuberculosis. Though most of the participants knew about TB previously, there were few women who said that they have never heard about it.

One of the participants said

"No, I never heard about any such disease until I myself got it." (P1).

Most of the participants got knowledge about TB through advertisements in Televisions, radios, etc. But some of them learnt about it when a known person contracted the disease.

One participant responded that-

"If my brother didn't have contracted this disease, I would have never heard about it." (P6)

Another participant responded that

"Now see this disease catch you by air." (P8)

Many participants had a vague idea that this disease is contagious and its bacteria is in the air. Hence, the people who knew about this disease, tried to keep themselves separate from other family members. Extra Pulmonary site of TB was not known to most of the participants except for one. The participant who knew about extra pulmonary TB said:

"There is one child in our neighborhood who suffered from TB in bones which ruined his school studies for one year." (P2)

Patients expressed their worries and concern about the treatment of the disease and tried to help them with their previous experiences.

2. Delayed Diagnosis

Most of the participants gave the history of delayed diagnosis as their first priority for treatment was some local quack instead of a qualified practitioner. Ignoring the symptoms also leads to delayed diagnosis.

One of the participants said

"I kept on thinking that it is simple fever and I don't need to go to doctor, then I stopped going to my job and got treatment from local doctor in my village." (P6)

Poor health seeking behavior was shown by participants until their life or job was affected due to the disease. The housewives as well as working women perceived it as a result of their workload and ignored the symptoms for weeks or even months.

One of the participants said

"Initially I went to a doctor who comes to our village he said it was Typhoid (motijhara) & it is getting complicated and gave me medicines for that, when I didn't get relieved then I got my urine and blood tests done and after that went to government hospital where I was diagnosed for this disease." (P1)

Another participant revealed

"One, two or three weeks passed by taking tonic from private store but still cough was continuing with fever. Later, severe chest pain started along with cough then I went to doctor for checkup." (P5)

Participants revealed that distance and family responsibilities were the main challenge for them. They are more comfortable with the local quacks due to shared trust and relationship.

One of the participants said

"Who will do the household chores and take care of kids if I get sick and who will go that far for checkup in government hospital." (P11)

Females in the society are so reluctant about their own health that they won't go to a proper health facility for checkup until they get severely sick.

3. Out of Pocket Expenditure

Most of the interviewees had history of taking initial treatment from local practitioners or from medical store. Few took whole treatment from private facilities which led to high financial burden throughout the treatment as mentioned by the participants.

For this one of the participants said

"Every month I used to spend 2000 Rs. in medicines and there is no account of money spent in tests. Every time, we used to spend more than 500 Rs in tests, 450 in X-Ray and then expenses in blood tests are also there and there is no account of how much we spent in going to hospital." (P15)

Few patients who were diagnosed from private facilities were advised from doctors to go to government facilities to complete the treatment as cost of treatment is high for TB. Many patients leave the treatment in between due to high treatment cost. Many such patients have taken debts or mortgaged their agricultural farms for treatment.

This is substantiated by what a participant had to say

"We got our whole treatment by mortgaging our agricultural land. Now we are left with no money for the final tests and check-up, so when our land will be free then only, I will go for tests and checkup." (P13)

Another participant said

"It was extremely difficult for the first month, leading to shortage of money and food. Till now, we have spent thousands in treatment." (P18)

Several families are burdened with financial crisis, and they face major challenges in managing family with kids. Some people even lost their jobs due the disease hence wage loss is another major factor for the financial burdens.

4. Side Effects of the Anti-Tubercular Drugs

Drugs used to treat TB may have certain side effects. While some participants consulted treating doctor and tried to continue their treatment, others discontinued their treatment due to side effects. One of the participants responded that-

"I used to have vomiting after taking medicines so I told the person dispensing medicine who asked me to visit doctor but that day the doctor was unavailable so I didn't go again and discontinued the medicines on my own." (P9)

This participant on further probing told that she suffered from severe vomiting and was not able to eat. And few months back the participant visited another doctor for some other treatment where she was suggested to get tested for TB but she refused and never got herself tested.

5. Stigma Related to TB

TB is a highly stigmatized illness. Few patients were uncertain about giving the consent for interview while others were in denial regarding the disease. However, few of the participants had positive support from their family, society, and treatment facilities.

One of the participants replied

"Classmates used to keep distance from me, nobody helped me, my friends also didn't help me and stopped talking to me and I discontinued my studies and since then I have dropped my studies completely." (P9)

Married women were not allowed to work in kitchen, and were kept separated from family & friends.

One of the participants responded

"One of my aunties who lives in the front lane of my locality told me to keep distance and asked me not to visit their home and then she stopped talking to me." (P16)

Though most of them had supportive experience with the staff, there were few instances where they avoided going to nearby government facility due to misbehavior of the staff.

6. Misconceptions related to the TB treatment

Most of the females who did not complete their treatment had a misconception that their disease is cured if the symptoms have subsided and hence, they discontinued the treatment without seeking advice from anyone.

Regarding this, one of the participants said

"I had lump in breast for which was taking treatment then I discontinued to take the treatment as I got relief." (P7)

It usually occurs due to poor knowledge about the disease and on further probing it was revealed that they were not aware about the importance of time period for treatment prescribed irrespective of symptoms.

7. Effect of COVID on Follow ups of patients

COVID-19 also had a very bad impact on the patient's response to the disease. Patients who were on regular treatment they didn't go to health facilities due to COVID and lockdown. They took medicine and they were taking medicines but due to lockdown they didn't go for follow up, hence they were declared as LTFU, as their final investigation is awaited and they were not able to go for follow up.

Discussion

India alone contributes to 27% to the total TB cases globally and thus has a very high burden of disease. In order to fight this challenge, government of India has taken many steps like RNTCP, NTEP, and National Strategic Plan 2017-25 [6]. Despite of all the efforts by the government, challenges like stigma, OOPE, and gender discrimination lead to non-adherence to TB treatment among females [16, 17]. This study was undertaken to understand the perspective of females to identify and determine the difficulties faced by them in adhering to TB treatment. The study revealed that despite there being a strong and effective programme by Government of India, there are many barriers faced by women in adhering to the TB treatment.

In many cases, the first contact made by the patients was with the local unqualified quacks, who provide ineffective treatment to them and eventually leads to unnecessary loss of financial resources. Most of them were treated by these local practitioners whom they trust more than the qualified doctors which leads to another challenge of delayed diagnosis, in addition to the financial burden they face. The study also revealed that seeking treatment at relatively expensive private hospitals or clinics, is another reason for these financial hardships. The study revealed that it eventually leads to patients ending up in debt, mortgaging their agricultural lands. OOPE which patients of TB bear on them for diagnosis and treatment exhausts their resources, making them vulnerable to poverty. When this expenditure is more than 20% of the total family income (catastrophic), it affects treatment adherence and leads to poor treatment outcomes [16]. This also includes expense which patient or their household bear for pre-diagnostic care of patient [17].

Another big barrier for patients is the Out-of-Pocket Expenditure (OOPE) which can be direct or indirect. It has been seen that the average amount of expense which patient or their household bear for pre-diagnostic care of TB patient is catastrophic [17]. This high expenditure in health care significantly reduces the resilience of family against expenses for basic needs like food, housing, children's education, etc [18]. TB specific indicators of total catastrophic costs includes both medical and non-medical expenses which eventually reduces family resilience against expenses on basic needs like food, housing, and education [16]. Patients from low socio-economic status bear more burden of catastrophic costs [18]. Families are stressed, which leads to loss of savings and their assets and debt is incurred [16]. Basic needs for kids and family members were affected in few families and it took months for them to overcome that crisis. In order to address this problem, provisions for support for transportation, symptomatic relief drugs, special diet compensation of wage loss can be implemented.

Another major challenge for LTFU revealed in the study was stigma related to the disease. Stigmatization is closely related to chronic diseases such as HIV/AIDS, TB, epilepsy and mental illnesses, which severely affects patients & their families, and also hampers the effectiveness of health programs [19]. It also causes social suffering to women [15]. This stigma contributes to delayed diagnosis, treatment and non-adherence to treatment among patients [11]. Anticipated spouse support is more definite for men and are conditional for women, which shows women are more vulnerable for stigmatization [15]. This problem also influences the effectiveness of TB control in the whole society and requires a more inclusive approach [14, 20].

Misconceptions related to TB, were revealed as another big challenge during this study. Many of the participants discontinued their treatment as soon as their symptoms were subsided. They didn't have the knowledge that it is mandatory to continue the treatment for the prescribed time duration. This led to discontinuation of medicines and hence these patients were left to follow-up (LTFU). There is no IEC material which is given to patient during the initiation of treatment which they can easily understand by pictures or any other means to adhere to the treatment. They are advised by the treatment provider but they have their own misconceptions regarding the disease. Patient's individual behavior like knowledge about the disease, mental state during treatment, attitude towards treatment, and communication with the health personnel, also affects TB treatment adherence [21].

Adverse effects of anti-tubercular drugs, appears to be another problem for these patients. One of the major health concerns globally is emergence of Multi Drug Resistance TB (MDR-TB). Almost 18% MDR-TB cases were LTFU in 2013, in India [22]. Many times, patients discontinue the treatment due to side effects of the drugs. They never consult for the side effects and do not continue their prescribed treatment. This also led to MDR and extra pulmonary cases. These adverse effects can be treated by counselling or by symptomatic treatment. These adverse drug effects along with certain other challenges related to medication like injectable drugs, burden of pills, workload, prior bad experiences to TB treatment can be considered the most common reasons for LTFU [23].

Gender based discrimination directly affects the health seeking behavior among women. Many women intentionally delay to seek health care as they have high burden of household work along with poor health literacy, poor

decision-making powers in the family, less mobility and access to available resources. There are growing evidences that women are either diagnosed late or not at all diagnosed, there are various socio-cultural barriers which hampers access of women to health facilities. There is high level of stigma associated with the females whether they are married or unmarried for TB [24].

Interviews of different participants showed that it is necessary to spread awareness regarding different aspects like symptoms, prevention, importance of treatment adherence, and service availability, may also help to reduce the burden. Increase community sensitization and strengthening through volunteering like participation of TB champions (patients who have defeated TB and leading a healthy life now and are acting as TB volunteers) to address the problem, can be another approach. Education regarding hygiene, waste disposal and sanitation should be given equal importance among women as well as family members & counselling sessions can be organized to improve the knowledge regarding the availability of services. Gender specific approach is a must to address these challenges. Availability of female staff may help in increasing the comfort for female patients. Though government has introduced a gender-based approach but extensive training is required for better implementation at the grassroot level. Involvement of ASHAs, ANMs, and Anganwadi workers for repeated follow up of patients and home-based screening, if possible, can play a major role in the process. Technological advances in form of telemedicine, electronic assessment methods like 99 DOTS can be of greater help to address the issue. This may also be helpful in avoiding the indirect OOPE and reducing the financial burden. Representation as well as participation of local leaders may play a crucial role in implementation of policies and strengthening the health seeking behavior of females in the society.

Conclusion

The study document a qualitative assessment of women suffering from TB treatment in Central India and identify targets for interventions that may improve TB treatment outcomes. The key thematic areas identified and studied in the study need to be addressed while planning interventions for this population which include need to raise awareness, sensitization, education of women, approachable health facilities, free transport facilities, reduced burden of out-of-pocket expenditure, and increased community participation.

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