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Evaluating the Challenges in the Treatment of Multi Drug Resistant Tuberculosis Patients from Patients' Perspective: A Qualitative Study

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Abstract

India not only has the world's highest annual incidence of TB and the highest TB-related mortality, it also has the highest number of multi-drug resistant tuberculosis (MDR-TB) cases in the world. Over the past few years, India has witnessed India a rising trend of MDR TB cases. It has to be mentioned though that there is a lack of robust monitoring system and dearth of prevalence studies to estimate the exact burden of the problem. Treatment success rate of patients with DR-TB was reported to be below 50% in India, which resulted in higher death rates. There are various issues related to patient care which has contributed to low treatment success rate of MDR TB patients. This study has been designed to explore the challenges with respect to the diagnosis of MDR-TB, access to appropriate treatment and care, and adherence to treatment basically from a patient's perspective. The study was conducted among adults (both males and females) diagnosed with MDR TB of > 18 years of age and currently on treatment or having completed treatment within the last 6 months registered in a tuberculosis unit of a rural district. In depth interview guide and focused group discussion were used to collect data from study participants. The patients had raised several concerns during the diagnostic and treatment phase of their treatment. Majority 37 (88%) of the patients reported difficulties in reaching the proper health care facility for getting a correct diagnosis of MDR TB. Many of the patients 23 (54.7%) expressed concern over the irregular supply of drugs for MDR TB treatment. Most of the patients 38(90.4%) complained of having to face stigma at their work place mostly after the diagnosis is revealed. All the patients complained that prolonged and periodic visit to the health centers caused major economic losses for the families being daily wagers. Most of the patients 32 (76.19%) reported facing isolation in the society not only for themselves but for their entire family. A comprehensive approach involving multiple stakeholders is required to address the root causes of patient related challenges in MDR TB treatment.

Keywords: Multi drug resistant, Tuberculosis, Challenges, Treatment.

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Introduction:

Tuberculosis (TB) remains an onerous global public health burden which TB affects an estimated 10 million people globally every year, of which around 3.2 million are women.[1] India not only has the world's highest annual incidence of TB and the highest TB-related mortality, it also has the highest number of multi-drug resistant tuberculosis (MDR-TB) cases in the world.[2]Over the past few years, India has witnessed India a rising trend of MDR TB cases. It has to be mentioned though that there is a lack of robust monitoring system and dearth of prevalence studies to estimate the exact burden of the problem. Reliable estimates of MDR TB frequency are critical at the country level to strategize and enhance the DR-TB management within the national TB control program.[3] India had recorded 64,000 MDR TB infections in 2012 according to the World Health Organization. This makes it the highest MDR TB burden country in the world accounting for 22% of all MDR TB cases worldwide. In the year 2018, an estimated 130,000 cases were reported from India. However, only 44% of suspected MDR cases were diagnosed in that year and around 35.8% received treatment showing gaps in the programmatic aspects of DR TB management. [4]Treatment success rate of patients with DR-TB was reported to be below 50% in India, which resulted in higher death rates.[5] Initially most cases were attributed to improper anti TB medication use and efforts were directed towards DOTS programs that monitor drug compliance and avoid resistance formation. However, it was later discovered that drug-resistant bacteria were still contagious, with similar infection risks for drug-sensitive and treatment-resistant bacilli in individuals who came into contact with untreated patients. Understanding the drug resistance pattern in specific areas is crucial to developing effective treatment plans, as it varies across different regions and time periods. India is considered a hotspot for Mycobacterium tuberculosis infection, and together with Russia and China, accounts for about 62% of the global MDR-TB burden[6]. Despite major improvements in the management and treatment of TB, especially in developing countries, TB remains a serious public health problem

Also, from the programmatic aspect it is found that the adherence to drugs is very poor among MDR TB patients. There are several issues related to it. This stems up from the side effects faced by the patients during their long-term treatment and also issues related to stigma and loss of work among the affected patients. MDR-TB is undeniably a significant universal health threat, and its emergence is an artificial problem.[7]Various stakeholders, the public sector, the health care sector, medical professionals, and the sufferer's family, all bear some responsibility for contributing to this issue in their respective ways. The government's inadequate infrastructure and administrative controls on purchases without a robust quality control system contribute to the problem. The need for well-equipped laboratories further compounds the challenges in diagnosing and managing MDR-TB effectively. Medical professionals, particularly doctors, also play a role in the issue. Their lack of understanding about doses, therapy duration, side effects, typical regimens, treatment failures, and the emergence of medication resistance can be attributed to repeated brand name changes, insufficient patient motivation, and treatment failures.[8] Patients and their families must also be aware of MDR-TB and the importance of adhering to their prescriptions diligently to decrease the risk of developing drug resistance. Raising awareness and

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eliminating the stigma associated with TB is crucial, as stigmatization or discrimination can hinder proper medical management and lead to missed opportunities for diagnosis, treatment interruptions, and unfavourable outcomes.[9]

With this background, the present study was conducted with the following objective:

- To explore the challenges faced by the MDR TB patients with respect to the diagnosis of MDR-TB, access to appropriate treatment and care, and adherence to treatment.

Methods:

Study Area: The present study was conducted among patients reporting for MDR TB treatment in a Tuberculosis Unit in a rural district of North East region of India.

Study participants: Adults (both males and females) diagnosed with MDR TB of > 18 years of age and currently on treatment or having completed treatment within the last 6 months.

Study Period: The study was conducted for a period of one year (2022-2023).

Necessary ethical approval was taken from the IEC of the respective Institute conducting the study.

Screening and enrolment

In the healthcare setting/ community setting, a trained and approved study team member reviewed the information in the participant information sheet with the eligible potential participant and answered any questions she/he may have. If they were interested in the study after information is given, written informed consent was obtained from adults. Illiterate participants had used a thumbprint to document their consent to participate in the study after the consent is read to and reviewed with them in a local language which they understand in the presence of/with the help of a witness of their choosing and all their questions have been answered. The witness signed the consent form as a witness to the consent process. The consent process for all participants was documented.

Study tools:

The tools required to carry out the qualitative study are as follows –

1. In-depth interview (IDI) guide: The interview schedules was developed based on the review of literature with some previously recognized themes. They had open ended questions with a detailed interview guide pertaining to the following aspects:

- Challenges in diagnosis.
- Challenges during the course of treatment.
- Challenges faced at work place and home.
- Challenges at societal level.
- Challenges in the economic front.

2. Focussed group discussion.

A focused group discussion was also conducted among a sub set of the population (4 males and 3 females) to understand the overlapping issues in patient care and treatment and have a better understanding of the issues.

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Data collection
Information on the challenges faced by women with MDR-TB women was collected by conducting in-depth interviews (IDIs) by the study Investigator.

The audio recordings of these interviews as well as the Focussed Group Discussion were transcribed in the native language, followed by translation into English with proofreading of the transcripts. Relevant portions of the text were free listed. Textual annotations were made next to the free-listed items. Textual annotations were summarized on a cover page and used to develop the list of domains/themes.

Results:
A total of 42 patients were interviewed during the study period. Out of these 28 were males and 14 were females.
The socio demographic characteristics of the patients are highlighted in the table below:

Socio demographic variable-Age	**No**	**Percentage**
18-38	5	11.90
38-58	24	57.14
≥ 58	13	30.9
Socio demographic variable-Gender	**No**	**Percentage**
Male	28	66.66
Female	14	33.33
Socio demographic variable-Marital status	**No**	**Percentage**
Married	25	59.52
Unmarried	17	40.47
Educational status		
Illiterate	6	14.28
Literate	36	85.71
Socio demographic variable-SE status: Kuppuswamy classification	**No**	**Percentage**
Upper, Upper Middle, lower Middle	9	21.4
Upper lower, lower	33	78.57

The in-depth interview focused on the difficulties faced by the patients during the process of diagnosis and while on treatment.
The major difficulties/ challenges were grouped into

Challenges during diagnosis
-Challenges in reaching the appropriate health care facility for diagnosis
Majority 37 (88%) of the patients reported difficulties in reaching the proper health care facility for getting a correct diagnosis of MDR TB. The diagnostic facility of MDR TB was only

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available at the tertiary level facility which was the medical college in the district where all patients had to visit for getting the tests done for MDR TB. The travel time was too high and many people had to use public transport to transport to the health care facility. They also reported that almost 2-3 days are required to visit the health care facility and getting the tests done which incurred travel costs and other related expenditure.

- Challenges in completion of formalities for undertaking the diagnosis
Majority 40(95.23%) of the patients raised the concern that there is lack of proper referral and linkage systems which makes it difficult when they reach the diagnostic facility. A lot of formalities are required at every counter with long waiting periods to get the tests done.

- Challenges during the course of treatment
Many of the patients 23 (54.7%) expressed concern over the irregular supply of drugs for MDR TB treatment. It was expressed by the patients that some drugs were not available at the TB treatment centers causing disruptions in the maintenance of therapy. Also, the patients expressed that there is lack of adequate counselling and information given to them during the dispensing of drugs due to which they get confused how to take the drugs.

-Challenges faced at work place and home
Most of the patients 38(90.4%) complained of having to face stigma at their work place mostly after the diagnosis is revealed. The women were not allowed to enter the kitchen and mix properly with their children. They were restricted to go out of their homes. The stigma at home was more reported by the females than the male.

-Challenges faced in the society
Most of the patients 32 (76.19%) reported facing isolation in the society not only for themselves but for their entire family. They were restricted or not encouraged to attend any kind of social events even after 3-4 months of treatment. The societal stigma was faced more by women than man. Both males and females reported a loss of self-esteem after being diagnosed with the infection due to the attitude of the caregivers, family and friends.

-Challenges faced in economic front
Most of the families were from lower socio-economic background. Around 15 were daily wagers,12 were agricultural workers working in the fields while 15 patients owned a small business. All the patients complained that prolonged and periodic visit to the health centers caused major economic losses for the families being daily wagers. Out of pocket expenditures on travel and other necessities while under treatment was being reported by all the respondents.

Focussed Group discussion:
The major themes that emerged from the In depth interviews and FGD's are listed below:
- Lack of referral linkage
- Distance to the diagnostic facility

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- Lack of counselling and support
- Economic losses during the treatment phase
- Stigma and discrimination faced by the patient and family.

Discussion:

In the present study we have tried to bring about a detailed analysis of the challenges faced by the patients during the diagnosis and treatment of MDR-TB from their own perspective. The patients have raised several concerns during the diagnostic and treatment phase of their treatment. The major challenges faced during the diagnosis were related to reaching the appropriate health care facility for diagnosis of MDR TB. It has to be borne in mind that diagnostic facilities for MDR TB are only available at accredited laboratories under NTEP with adequate infrastructure and set up. These facilities in India are very few and far between due to which the suspected patients have to travel a long distance to give the samples for diagnosis. A study conducted in Vietnam also reported lack of facilties for diagnosis of MDR TB at the peripheral health facilities. Also the district staff were not well informed of the PMDT procedures.[10]

It has to be noted here that most people use the public transport during this travel which carries a huge chance of transmission of TB considering the crowded environment in the public transport. Even after reaching the health care facility patients have to remain in long queues for getting the tests done which also involves a lot of paper work and other formalities. The lack of appropriate referral linkages and co-ordination among the health care staff of tertiary and peripheral health care facility complicates the problem. The tertiary health care staff cannot devote much time to the counselling or history taking part because of high case load in these facilities. The study conducted in Vietnam also reported lack of proper linkage between the referring and the testing sites. This resulted in low enrollment of patients. The study also reported irregular supply of drugs as a problem in initiating TB treatment and increase in drop outs.[10]

Also, after the initiation of treatment, the patient has to face a different set of problems. He/She has to come to collect the drugs periodically to the health care centres. Sometimes the drugs are not available under the program which requires the patients to procure the drugs by themselves causing financial stress. Also some patients have poor tolerance to the drugs which complicates the issue of adherence to the long term treatment regime. Studies conducted in Vietnam, China and central India have also reported the same issues hindering the adherence to drugs by MDR-TB patients.[10,11,12]

Most of the patients complained of having to face stigma and discrimination at home, society and mostly at work. Stigma was more for women at their homes where they were excluded from household chores and family functions. Males faced more stigma at their work place as they seemed to feel as sense of isolation due to the change of attitude by the peers. Both males and females reported of having low self-esteem during this phase.

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Almost all patients suffered at the economic front due to the out-of-pocket expenditure and multiple visits required to the health centers. The patients reported to have suffered from anxiety and worries related to their illness being difficult to cure, fear of spreading the disease to their families and isolated.

A study conducted in China also reported that one of the major problems from the illness was financial hardship. Several other studies have established that total costs spent on treating MDR TB patients is catastrophic for the patients specially from low- and middle-income families. [13]The hardships were more for married individuals in our study which is similar to the study conducted in China. A study conducted in South Africa by Furin et al, also highlighted a significant economic burden on patients and households with rifampicin resistant TB due to loss of income and high expenses during transportation.[14]In India, although all notified patients with TB are entitled to cash transfer of 500 Indian rupees per month during the complete course of treatment under the direct benefit transfer (DBT) scheme, there are always administrative delays in transferring benefits.

Providing care providers with proper counselling and organizing peer activities to share their experiences will ensure emotional support and better adherence to treatment. Another challenge is the risk of transmission by the patients. It has been universally reported that MDR TB patients encountered great hardship and emotional, physical and financial drain out. Free and uninterrupted supply of drugs, provision of patient centric support and performance linked incentives together can mark a major step towards disease control and treatment success. A comprehensive approach involving multiple stakeholders is required to address the root causes of patient related challenges in MDR TB treatment.

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