


BMJ Open Experiences and needs of patients with MDR/XDR-TB: a qualitative study among Saharia tribe in Madhya Pradesh, Central India

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ABSTRACT

Background Drug-resistant tuberculosis (DR-TB) continues to be a major public health threat posing a critical challenge to TB treatment and control worldwide. The present study was conducted among patients with DR-TB of the Saharia tribe residing in Madhya Pradesh state of Central India to document their experiences and needs, and to identify gaps for treatment adherence as this population is known to be poor because of migration and other factors.

Methods We conducted 16 in-depth interviews on purposively selected patients with DR-TB among the Saharia tribe using a predesigned open-ended in-depth interview guide, which included questions on domains like general physical health, diagnosis, treatment adherence, side-effects of drugs and experience related to the health facility. Out of these interviews, various subthemes were extracted. The obtained qualitative data were subjected to thematic analysis.

Results The study helped to understand the experiences and needs of the patients with DR-TB in various stages from diagnosis to treatment. Also, there was the impact of factors like lack of education and awareness, poor living conditions and lack of healthcare facilities on predominance of the disease in the community. Poor access to a healthcare facility, high pill burden and related side-effects, longer duration of treatment, financial burden, misbeliefs and misconceptions were prominent issues posing a challenge to treatment adherence. The narratives pointed out their struggle at every stage be it with diagnosis, treatment initiation or treatment adherence.

Conclusion It is paramount to address the needs and experiences of patients with DR-TB to develop a patient-centric and context-specific approach conducive to the sociocultural set-up of tribal people. This will scale down the attrition rate of tribal patients while adhering to the complete treatment process and reducing the high burden of TB among the Saharia community. In addition, tribal patients should be counselled at regular intervals to increase their confidence in the treatment.

INTRODUCTION

Tuberculosis (TB), caused by *Mycobacterium tuberculosis*, remains one of the top 10 causes of death worldwide. Globally, an estimated

Strengths and limitations of this study

- The present study is a novel one exploring the needs and experiences of patients with multidrug-resistant/extensively drug-resistant tuberculosis (MDR/XDR-TB) belonging to the Saharia tribe in Central India. This becomes particularly relevant since this population group falls in the particularly vulnerable tribal group segment.
- This study captures the attitude and acceptance of the treatment by the participants by giving them space to open up about the experiences they went through in the whole process of treatment.
- The study has incorporated many such experiences verbatim, which would rather be impossible to be captured through a quantitative study.
- The sample was purposive and may not entirely represent the experiences and needs of patients with MDR/XDR-TB in this community.
- Though it is advisable to follow people prospectively, the patients with DR-TB were interviewed for their perceptions and experiences about TB and the available treatment services retrospectively which may result in recall bias.

10 million people fell ill with TB in the year 2018.¹ The burden of the disease varies enormously among countries, from fewer than 5 to more than 500 new cases per 100 000 population per year, with the global average being around 130.¹ The drug-resistant TB (DR-TB) continues to be a public health threat. In 2018, there were about half a million new cases of rifampicin-resistant TB (RR-TB), and India alone contributing about 27% of the world's DR-TB cases.¹ Globally, 3.4% of new TB cases and 18% of previously treated cases had multidrug-resistant TB (MDR-TB) or RR-TB.¹ Treatment success rate of patients with DR-TB was reported to be below 50% in India, which resulted in higher death rates.^{2,3} Loss to treatment follow-up (LTFU) is the key issue in MDR-TB as these cases may remain

infectious, thus spreading the disease and also the possibility of developing further drug resistance among them. There is, however, very limited information available on the factors responsible for LTFU in MDR-TB in India, particularly among the tribal population.⁴⁻⁶

There are over 700 Scheduled Tribes (STs) notified in India, spread over different states and Union Territories of the country. The state of Madhya Pradesh accounts for 21.1% of the ST population of India.⁷ The Saharia tribe—one of the particularly vulnerable tribal group (PVTG)—is mainly located in Gwalior and Chambal divisions of Madhya Pradesh and has the highest reported TB prevalence in the country ranging from 1270 to 3294 per 100 000 population.⁸⁻¹¹ The Saharia tribe is among the most vulnerable population segment that suffers from poverty and unhygienic/overcrowded living conditions. Most community members earn their livelihood as daily wage labourers or labourers in agriculture farms.⁸ Other factors that further increase the risk of TB infection include lack of education, poor access to healthcare facilities, high prevalence of alcohol and tobacco consumption as well as financial constraints. Though the directly observed treatment–short course (DOTS) is being implemented in the area, it also suffers from several constraints including shortages of health workers, irregular drug supplies and poor supervision by the staff. Lack of treatment adherence becomes even more significant in such a situation particularly among the Saharia tribal community with high TB burden.^{4 10 11} So, keeping all these facts and the robust decision of the government of India to eliminate TB by 2025, this study was conducted among patients with DR-TB of Saharia tribe residing in Madhya Pradesh state in Central India to document their experiences and needs, and to identify gaps for treatment adherence.

METHODS

Qualitative approach and research paradigm

The present qualitative research was conducted as a substudy of the main ongoing 'Intensified TB Control Project in Saharia tribe of Madhya Pradesh' which focuses on active case detection through engagement of community volunteers, prompt treatment, and follow-up of cases and health promotion or awareness activities. This project is ongoing in Saharia villages across even districts of the Chambal region, Madhya Pradesh state, where this tribe predominantly resides and encompasses about 0.5 million population.¹²

Study design and theoretical background/population sample

This research used a qualitative study design to identify the experiences and needs of people suffering from extensively drug-resistant (XDR)/MDR-TB in the PVTG. The interview was conducted in the place chosen by the participants without disturbing their routine or privacy. Before each in-depth interview, the participant's approval and comfort were given utmost importance.

Recruitment of participants

The qualitative study was conducted from July 2019 to August 2019 among patients with DR-TB belonging to this tribal group. There is no well-established guideline for estimation of sample size prior to the qualitative study and the study population is also very homogeneous, that is, patients with MDR/XDR-TB of Saharia tribe. We used the principle of saturation and repetition of information to decide the number of participants to be included in the study. In total, 16 participants, who were on anti-TB treatment or being recently treated and were available at the time of field visits, were enrolled through purposive sampling techniques irrespective of treatment duration. Informed consent was taken from each participant before the commencement of the interview.

Data collection technique

All patients were interviewed by a senior researcher with a postgraduate degree in public health and an experience of working in tribal communities. These interviews were carried out during routine field monitoring visits. The researcher is familiar with the local dialect of the Saharia tribe, however, the researcher does not belong to the tribal community. Data from participants were acquired through a preset of specific questions to get an insight into their sociodemographic details and living conditions.

Data collection tool

A predesigned open-ended in-depth interview guide was drafted in consultation with subject experts, clinicians and DOTS providers (available as online supplemental file). The in-depth interview guideline consisting of questions on various domains like general physical health, diagnosis, treatment adherence, side-effects of drugs and experience related to the health facility was used for interviewing the participants. However, the interview tool also had some structured questions related to background characteristics, like age, sex, education status, occupation and history/family history of TB. Audio-recording of the in-depth interviews was recorded simultaneously with prior permission from all the participants.

Data processing

For better comprehension, the interview was conducted in the local language spoken by the participants. The researcher used an audio-recording device for recording the interview and an interview took 30–45 min on average.

Data analysis procedure

All audio-recordings of participants were transcribed in Hindi language and then translated into English for data analysis by the researcher. The interview transcripts were coded, entered manually and analysed to generate themes. The extracted codes were further divided into various categories manually. Four main stages include familiarisation, identifying a thematic framework, coding and interpretation. Interviewer-related bias was addressed by continuously discussing and negotiating the content of keywords, concepts and meaning of verbatim

Table 1 Summary of patients with XDR/MDR-TB interviewed

Sr no	Age	Sex	MDR/XDR	Education	Family type	History of TB in family
P 1	50	M	XDR	No formal education	Extended	No
P 2	48	M	XDR	No formal education	Extended	No
P 3	44	M	XDR	Primary	Nuclear	No
P 4	55	M	XDR	No formal education	Extended	No
P 5	28	M	XDR	Primary	Extended	No
P 6	36	M	MDR	Primary	Extended	No
P 7	45	F	MDR	No formal education	Extended	No
P 8	35	M	MDR	No formal education	Nuclear	Yes
P 9	40	M	MDR	No formal education	Nuclear	Yes
P 10	35	M	MDR	Primary	Nuclear	No
P 11	37	M	MDR	No formal education	Nuclear	Yes
P 12	60	F	MDR	No formal education	Nuclear	No
P 13	18	M	MDR	High school	Extended	Yes
P 14	40	M	MDR	Primary	Extended	No
P 15	45	M	MDR	No formal education	Extended	Yes
P 16	65	M	MDR	No formal education	Extended	No

MDR, multidrug-resistant; P, patient; TB, tuberculosis; XDR, extensively drug-resistant.

quotes. Then, the researchers discussed and clarified the content of each audio-recording of the interview. We used an analysis system, based on the literature review and preliminary assessment of the collected qualitative data in the background of the research question. In the second stage, we generated some major themes, and then, further in-depth analyses of data were done to study the connection between these major themes. The results were presented to the research team to ensure that the experiences of the patients were accurately captured and reflected in the research.

Patient and public involvement

Patients were not involved in the study design, methodology, recruitment and dissemination of findings.

RESULTS

Interviewed participants comprised 5 XDR and 11 MDR cases. The participants, ranging from 18 years to 65 years of age, were interviewed using a predesigned open-ended in-depth interview guide. Out of 16 patients, there were only 2 women as the majority of the patients with DR-TB were men. Most of these patients lacked formal education and only six patients completed primary schooling. Most of them were unable to perform any kind of work or household chores because of their disease (table 1). All participants were married staying with their families. The living condition of the participants was inconceivable, 9 out of 16 participants were living in the *kutcha* house with a single room without any ventilation (table 2). Wood/crop residual was used for cooking on the *chulha* (hearth) inside the living room. The above-mentioned poor living

conditions significantly contributed to the predominance of TB among the tribal population. Patient narratives pointed out the struggles and difficulties of the journey which a patient with DR-TB has to undergo from diagnosis to treatment and are summarised in figure 1. The narratives of patients were broadly divided into six

Table 2 Sociodemographic characteristics of participants

Characteristics	Category	N	Per cent
Type of family	Nuclear	6	37.5
	Extended	10	62.5
Children	No child	0	0
	Less than 2 children	4	25
	More than 2 children	12	75
Type of house	Kutcha	9	56.2
	Semi-pucca	5	31.5
	Pucca	2	12.5
No of rooms in the house	1	14	87.5
	More than 1	2	12.5
Ventilation in living room	No	12	75
	Yes	4	25
TB history in family	No history	11	68.7
	History of contact	5	31.2
Mode/fuel for cooking	Chulha/wood	16	100

TB, tuberculosis.

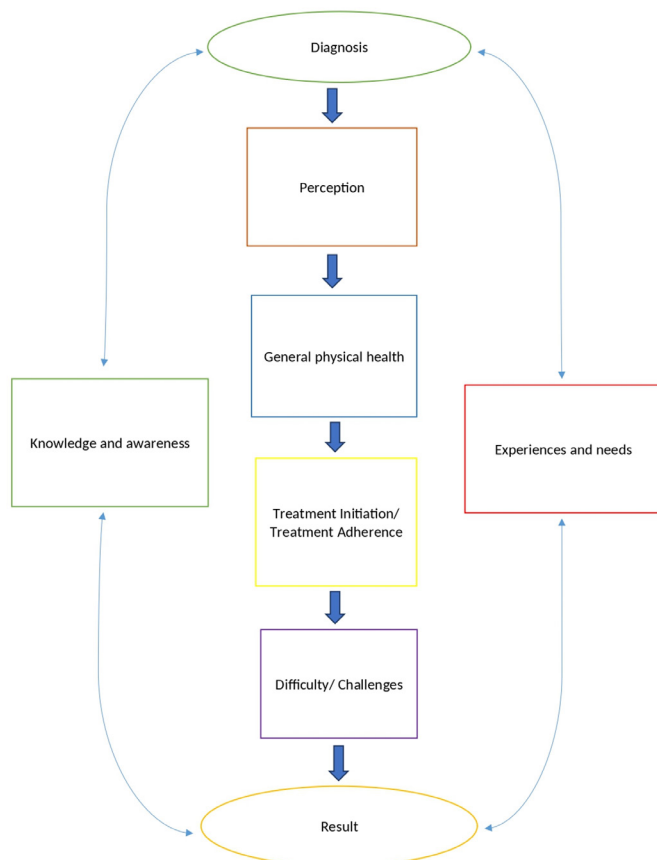


Figure 1 Thematic representation.

themes, where each theme is further divided into two subthemes—pretreatment and during treatment. Six themes and subthemes are presented in [table 3](#), and important individual narratives are presented in [box 1](#).

Pretreatment phase

Perception about disease

Lack of education in the patients and their family leads to several misbeliefs and misconceptions about the disease. A participant (P5) narrated his belief about the disease as “At home, my family members believed that if a person has TB he will die eventually (*sukh sukhar mar jata hai*), people even say this to me...” One thing that everyone understood is that TB is a fatal disease and 14 out of 16 participants had seen death due to this disease either in their close family or in their village which is a traumatising experience and somehow plays a major role in depleting the confidence and fighting spirit of the patient against the disease. One of the major obstacles is the acceptance of the disease or to accept that they are suffering from it. During interviews, it was observed that the moment a patient comes to know that he/she is suffering from a disease, it is a very shocking and traumatising experience for him/her. A participant (P5) shared how difficult it was for him to believe that he is suffering from the disease, “When for the first time, I got the result of the test and came to know that I am suffering from the disease, I felt

as the ground is slipping beneath my feet (*pair keneechai se zameen fisal gayi ho jaise*).”

General physical health and other factors

Due to lack of awareness, many times patients quit treatment and do not complete the course, especially in DR cases. It is seen that the majority of the patients took anti-TB treatment before getting DR-TB. One such condition came out during the interview when a patient himself narrated about not taking medication properly as he (P4) started feeling better, “I took TB medication twice before, and last was six months ago. This is my third time taking medicine. I took medicines for about three months each time and as I started feeling better; I used to stop taking medicines. But now, I will complete the full course of treatment.” The patients also mentioned that they did not understand the reason for their deteriorating health condition and faced many problems.

The study participants belong to resource-deprived areas and are mainly engaged as daily wage labourers, construction workers or doing farming-related work. The supervisors/landlords make them work tirelessly. When these workers are taken out to other places for work, they usually stay in close contact with other labourers working with them, and thus the chances of getting an infection and infecting others increase. Due to illiteracy, lack of awareness about the disease and their belief system, they approach local healers/private practitioners for treatment. One such participant revealed that he was taking treatment from a private doctor for a long time; every time he was getting temporary relief after taking medicines. Further, due to poor access to the healthcare facility and lack of knowledge, people do not know where exactly to go for the right treatment and what is the right treatment. Many times, patients, due to lack of information and misbeliefs, fall into the trap of non-medical practitioners (faith healers, flick burnt (*ojaha*)) who are easy to approach.

Treatment phase

Experiences at the time of treatment

Anti-TB drugs are known for their adverse side-effects. Participants shared their experiences about their suffering and narrated how hard it was for them to overcome them. Side-effects especially nausea, vomiting, breathlessness, anxiety and insomnia were commonly observed; whereas breathlessness, anxiety and nausea were major side-effects observed in the case of patients with DR-TB. However, social stigma was not an obstruction in TB diagnosis or treatment in the study population, as 15 out of 16 participants told that they never faced any stigmatisation and family members took care of them without any discrimination. As one patient (P8) narrated: “I never faced any stigmatization, people never behaved weird/strange with me. I attend all the family functions and social gatherings.” Another patient (P12) reported, “My family takes good care of me and relatives use to visit me for asking about my health every now and then, they never showed

Table 3 Representation of themes

Themes	Subthemes	
	Pretreatment phase	Treatment phase
Challenges	The time from diagnosis to treatment is a big challenge in a patient's life which breaks him in all possible ways, be it emotionally, physically or financially.	
Physical challenges	<ul style="list-style-type: none"> ▶ Physical symptoms discomfit normal activities of daily life. ▶ Like household chores or even taking care of personal chores. 	<ul style="list-style-type: none"> ▶ Adverse effects of drugs are experienced by many patients. These side-effects adversely impact the life of the patient. ▶ Multiple drugs/pill burden is also reported to be difficult to tolerate by the patients.
Health system challenges	<ul style="list-style-type: none"> ▶ Healthcare facilities are difficult to reach because of distance. ▶ The attitude of health facility personnel. ▶ No proper channel or awareness about the facility. 	<ul style="list-style-type: none"> ▶ The facilities at DR-TB centres are not sufficient and the distance that one has to travel to reach the centre is about 120–240 km. ▶ The facilities like place and food in the hospital ward are not proper. ▶ The number of days to be admitted in a hospital for treatment initiation is also longer (15 days).
Economic challenges	<ul style="list-style-type: none"> ▶ Loss of income as no work due to poor physical health. 	<ul style="list-style-type: none"> ▶ Until the time patient gets DBT money for treatment only, one has to pay the large amount out of his/her pocket for travelling, food and daily necessities.
Emotional and psychological challenges	<ul style="list-style-type: none"> ▶ Due to physical ill health, he/she is dependent on others for the daily necessities, so emotional state is devastated. 	<ul style="list-style-type: none"> ▶ Once a patient gets information about his TB disease particularly DR status, the hope of living just vanishes as they consider it to be a fatal disease with no cure.
Social challenges	<ul style="list-style-type: none"> ▶ Lack of involvement in social gatherings due to poor health conditions. 	<ul style="list-style-type: none"> ▶ Stigmatisation is not reported by the participants but they avoid social gatherings due to their poor health condition.

DBT, direct benefit transfer; DR-TB, drug-resistant tuberculosis.

any discrimination because of this disease.” Only one participant (P10) reported some discrimination by family members, as he told: “As such no one directly say something to me, but from their actions, I can feel that they discriminate me, and they also keep distance from me.” Many patients also reported a high pill burden—taking 9–12 tablets at a time as the reason for non-compliance. Fear of injections was also mentioned among one of the reasons restricting them to adhere to the treatment. A patient (P9) reported, “Initially, when treatment started, taking medicines and especially injection daily was horrific, I used to get mad and was unable to do anything and even unable to sit. So, I decided to go for injections on alternate days, thus somehow, I managed to cope with my condition.”

Challenges for treatment adherence

Physical weakness

Many patients reported that they have become very weak due to the disease and are unable to practise their livelihood and support their families. The majority of patients are daily wage labourers and used to work in the field requiring lots of physical strength and energy. A patient (P4) narrated, “There was a time when I used to work hard in the field from morning till evening, even sometimes at night and also used to go to the jungle to collect

wood for cooking. But this disease has made me so helpless, now I can't think of doing my daily routine works.”

Financial burden

One important theme which came out of the interviews is the financial hardships on the patients especially in poor people, as the disease condition shatters their livelihood severely. A patient (P10) reported, “We spent around Rs.3000 per visit to Gwalior (private treatment) and had to visit regularly for six months. But then I stopped treatment as I had no money to go there regularly.”

Treatment at the healthcare facility

Patients reported that they did not get medicine from the health facility/drug provider for continuing their treatment. Lack of access to the healthcare facility, long distances and long duration to reach the healthcare facility made it difficult for the patients to avail proper treatment. Patients are required to go to the DR-TB centre for initiating XDR treatment which is around 120–240 km from the village/district hospital and thus had to make huge out-of-pocket expenditures. Many patients reported this financial burden as well as poor facilities at the DR-TB centre. A patient (P1) reported, “Nobody can stay in the hospital (DR-TB facility). It is not cleaned and in morning hours nobody is there to look after the patients, only at

Box 1 Illustrative quotations of the study participants

Pretreatment phase

Perception about disease

- ▶ At home, my family members believed that if a person has TB he will die eventually (sukh sukh kar mar jata hai), people even say this to me... (P5)
- ▶ From this disease people slowly-slowly die (ghut ghut ke marr jate hai). (P4)
- ▶ There is nobody in my family, except myself and my wife. My brother and sister-in-law died of the same disease, their children are with us. Three people in my family died of the same disease. (P9)
- ▶ My father was the first one to suffer from TB, then my mother got this illness and now I got this disease. It is persisting in my family, my father died because of this disease. (P11)
- ▶ When for the first time I got the result of the test and came to know that I am suffering from the disease, I felt as if the ground was slipping beneath my feet (pair ke neeche se zameen fisal gayi ho jaise). (P5)
- ▶ One year back I went to Gwalior, where I heard for the first time that I am suffering from this disease, and was shocked thinking that how could this happen to me. (P10)

General physical health and other factors

- ▶ I took TB medication twice before, and the last was six months ago. This is my third time of taking medicine. I took these for about three months each time and as I started feeling better; I used to stop taking medicines. But now, I will complete a full course of treatment. (P4)
- ▶ Two years back, my physical condition worsened too much and I was not able to stand or walk for my daily necessity, I needed somebody's help. (P9)
- ▶ Around six years back, I used to work as a labour and had a fever for days. Whenever I complained about fever and weakness to the in-charge (Seth), he used to give me a green cover tablet (hare panni ki dawai). When I got physically weak, he kicked me out of work (mujhe kaam se bahar nikal diya). (P8)
- ▶ About 4–5 years back, when I was working in Jaipur, there was a co-worker (labour) who used to stay with me in the same plot, he suffered from TB and was taking medicine at that time, I feel that I might have got this infection from him. (P5)
- ▶ For about a year I was on private treatment. I used to get fever and cough and the doctor gave me some medicine for these. After getting temporary relief I used to stop taking those medicines, then my health condition used to become the same as before. (P4)
- ▶ I went to Kasba in Rajasthan state, earlier I got an herb (jadibooti) for my illness. After performing the ritual with clove, lemon, and chicken, they gave me one amulet (tabeej). I strongly believe that only after getting the amulet (Tabeej), medicine started working on my body. Earlier I took treatment many times but nothing was effective. (P9)

Treatment phase

Experiences at the time of treatment

- ▶ Still, I feel breathlessness, nausea, and feverish. This is too difficult for me to bear, I feel very anxious. (P12)
- ▶ When I came back from the DR-TB center and took medicine at home, that was the hardest time for me and it lasted for around 10–15 days. As soon as I used to take medicine, I felt very uneasy with nausea and dizziness. At the DR-TB center also I was taking the same medicine but it didn't happen there. But when I came back home, it all started happening. After few days, eventually, it got better, now I don't feel like that anymore. (P5)

Continued

Box 1 Continued

- ▶ I feel severe nausea and anxiety while taking these medicines, 12 tablets are to be taken daily. (P4)
- ▶ It was very difficult to take 10 tablets all together at a time that too on empty stomach, I used to feel anxiety, breathlessness soon after taking medicine. (P11)
- ▶ Initially, when treatment started, taking medicines and especially injections daily was horrific, I used to get mad and was unable to do anything and even unable to sit. So, I decided to go for the alternate day for injection, thus somehow, I managed to cope with my condition. (P9)
- ▶ When I started treatment, I used to take a large number of tablets. I used to feel the heat inside and nausea, urine used to be red, but then also I completed all the dosages. Only injections were left as it was too painful for me to take injections daily. (P1)

Challenges for treatment adherence

- ▶ If I work a little bit or carry 10–20 kg of weight then within few minutes I start feeling breathlessness. I cannot help with anything at home, even not in household chores. (P5)
- ▶ There was a time when I used to work hard in the field from morning till evening, even sometimes at night and also used to go to the jungle to collect wood for cooking. But this disease has made me so helpless, now even I can't think of doing my daily routine works. (P4)

Financial burden

- ▶ I took treatment for around 6 months from Jaipur and Sawai Madhopur (private treatment), there they never disclosed this disease and used to tell that there is some problem in the X-ray (X-Ray me kharabi hai) and will get better within 3–4 months of medication. I spent a lot of money during each visit. (P5)
- ▶ During the last 2 years, I have spent more than Rs.1 lakh for my and my daughter's treatment from many doctors and private hospitals in Gwalior including expenses for food and traveling. (P5)
- ▶ We spent around Rs.3000 per visit to Gwalior (private treatment) and had to visit regularly for six months. But then I stopped treatment as I had no money to go there regularly. (P10)

Treatment at healthcare facilities

- ▶ When I started taking medicine, after one box nobody gave me another one, even I asked the doctor he didn't give me, not even the Anganwadi people. (P11)
- ▶ I have personally visited many times, even I went to the district hospital for medicine but nobody gave us medicine. (wife of P11)
- ▶ Nobody can stay in the hospital (DR-TB facility). It is not cleaned and in morning hours nobody is there to look after the patients, only at day time some staff used to come. Most of the patients come from Morena and go back to their place on the same day. People who are from far places, only stay in the hospital because of their helplessness, as they have no other option (Koi aur suvidha hi nahi hai). (P1)
- ▶ There is no arrangement for food and water, even for testing, we have to go to private labs, where they charge us. Travel cost for reaching the hospital place is another burden. (P1)
- ▶ All tests were done from private; I had to pay for all the tests. It was the peak of summer and there was no water facility or fan/cooler in the hospital. Not many patients as well. (P4)
- ▶ The facility here (district hospital) is better than DR-TB centre, where everyone listens to us and provides everything we want, there we have to ask several times, then only they listen. There we cannot talk to doctors directly, only attendants with us can talk to a doctor. They keep patients at distance. In the DR-TB

Continued

Box 1 Continued

centre, they (health staff) hate patients. But in the district hospital, they never showed such kind of behavior to us. (P5)

Improvement in health

- ▶ After taking medication, there is a lot of improvement, now I don't have bodyache, my appetite is also improved. These days, I eat more and also no cough or breathlessness, as I used to have before. (P1)
- ▶ Now when I go to bed in the night, I wake up directly in the morning, but earlier, I used to cough the whole night because of which I was not able to sleep at night. (P1)

DR-TB, drug-resistant tuberculosis; P, patient.

day time some staff use to come. Most of the patients come from Morena and go back to their place on the same day. People who are from far places, only stay in the hospital because of their helplessness, as they have no other option (Koi aur suvidha hi nahi hai).” Due to the distance and poor facilities in the hospitals (DR-TB centre), the participants mentioned that it would be more convenient if this facility is available at the district hospital itself or in some nearby health facility. Most of the participants were satisfied with the treatment provided in the district hospital. As one patient (P5) reported, “The facility here (district hospital) is better than DR-TB centre, everyone listens to us and provide everything we want, while there we have to ask several times and then only they listen. There we cannot talk to doctors directly, only attendants with us can talk to a doctor. They keep patients at distance. In the DR-TB centre, they (health staff) hate patients. But in the district hospital, they never showed such kind of behavior to us.”

Improvement in health

Once the patient starts taking the right treatment, within few days he starts feeling the difference in his general health, and also improvement in the routine activities like eating, sleeping and also relief in symptoms. Many of the participants discussed their positive reflections of taking medicine and specified, “After taking medication there is a lot of improvement. Now I don't have bodyache and my appetite is also improved. These days, I eat more and also no cough or breathlessness, as I used to have before,” a 50-year-old patient (P1) reported.

DISCUSSION

As per WHO's Global Tuberculosis Report 2019, most WHO regions and many high TB burden countries are not on track to reach the 2020 milestones of the End TB Strategy.¹ The situation is not different in India either. India accounted for the highest MDR-TB burden globally¹ and the constant increase in MDR-TB cases in the country is a matter of great concern as it poses a threat to TB control. This is especially relevant in disadvantaged population groups such as Saharia, a tribal community with an alarmingly high prevalence of TB.^{13 14} DR-TB is also emerging as a serious health problem in this tribe.⁴

The present qualitative study tries to understand issues related to the high TB burden and challenges in adherence to treatment in Saharia tribal community.

The current study was conducted among 16 DR-TB cases of the Saharia tribal community. Although the National TB Elimination Programme (formerly Revised National Tuberculosis Control Programme) has been operational for more than 15 years along with programmatic management of DR-TB from 2013 in this area, the findings of the study suggest that more concerted efforts are required especially at a grass-root level. The study highlights several challenges faced by patients with DR-TB belonging to a marginalised community from Central India. One important issue common to all the participants was their poverty and added financial burden due to the disease treatment of TB. The studies conducted in different settings also highlighted the ‘catastrophic’ costs associated with TB and DR-TB treatment despite the provision of free treatment.^{15 16} Furin *et al*, in a study conducted in South Africa, reported a significant economic burden on patients with RR-TB and households due to the loss of income and the expenses for transportation.¹⁷ 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 delays in transferring benefits. A study conducted in Western India reported that only 7.3% of patients received their first instalment within 2 months of treatment initiation.¹⁸ The delays in access to such grants are also reported by other workers.¹⁵ The economic support during the first few months of treatment is crucial and if linked with counselling, it improves treatment adherence and the chance of cure.¹⁹ The timely payment under DBT/economic support during the first few months of treatment with counselling shall go a long way in improving treatment compliance in patients with DR-TB in this marginalised community.

The majority of patients with DR-TB noted adverse effects to TB treatment. This is an important factor for treatment adherence, as has been mentioned by other authors.^{5 6 17} Many patients also noted the number of tablets, long duration of treatment and painful injections as the reason for non-adherence to the treatment. Similar findings are also reported by other authors in different settings.^{17 20 21} This highlights the importance of continuous counselling of the patients and their family members so that in the course of adverse effects, the patient does not leave the treatment midway.

The patients also reported various problems related to health facilities including the indifferent attitude of the staff and the services provided in DR-TB centres. The poor attention and even maltreatment by health staff; poor maintenance of the facility; lack of basic facilities such as drinking water, fan, etc; and no supply of medicines by health workers were some of the issues noted by them. Many studies also reported such issues in different population groups.^{20 22 23} The patients' and the community's perceptions about the disease, attitudes and beliefs about



the treatment, and work-related issues also determine their response to TB-related services in this tribal community. The beliefs and practices related to TB are reported by other authors.^{23–26} The whole process of diagnosis and treatment of DR-TB is very tiring and traumatising for the individuals, as one has to undergo various phases leading to physical fatigue and mental tiredness. Fighting with the disease condition and overcoming anxiety and fear pose the biggest challenge in patients' life. Most of the patients have seen their kith and kin succumbing to TB, resulting in shattering of their confidence with the constant fear of death. Fear and denial of diagnosis as noted in the present study are also found in other studies.^{23 26 27}

The work-related issues included fear of losing the job, need to earn a living, taking care of family, etc, which are also reported in other studies.^{22–24} The belief in traditional healers for common ailments is also deeply rooted in the community. The easy availability close to their residence and the negligible cost of treatment also explain their preference for traditional healers. This study which was conducted among the most vulnerable sections of society revealed that due to lack of awareness, patients seek treatment from the places/persons where they get misguided, leading to further financial burden. It is not that the patient and his/her family do not take the disease seriously but many times they do not know where to go for the right treatment. Yellappa *et al* mentioned the impact of disease on a patient's family and caretakers' lives, as a family is one of the main sources of support during patients' treatment and recovery.²⁸ This highlights the need for involving the community in TB control activities as the disease impacts all the individuals associated with the patient.

Most of the participants in the study reported that they never experienced any kind of stigma or discrimination from family members or their community. This is in contrast to the findings of other studies carried out among patients with DR-TB in India^{5 21 24} and abroad.^{28–34} This indicates social acceptance of patients with TB in the community. However, patients noted that they choose to refrain from society and avoid social gatherings like weddings, religious functions, community meetings, etc due to their physical weakness. The social acceptance of patients with TB is encouraging and assumes importance as the TB burden is very high in this tribal community. Many studies have reported a strong influence of stigma resulting in non-adherence to treatment as they become demoralised due to weak family support.^{21–23} Due to guilt and fear of getting isolated in the family and the community, patients may also hide their disease.^{22 26 27} It is also encouraging to note that many patients had a positive attitude towards treatment and mentioned that they got relieved of their symptoms and are feeling better with the treatment. Such patients can be effective ambassadors for motivating other patients and family members as they belong to the same community. A study in Ethiopia also reported a positive attitude of patients towards treatment.²⁹

Our study has identified several problems faced by patients with DR-TB living in remote tribal areas by the means of various narratives by the participants where they opened up about the difficult experiences in the course of the disease. These are complex and dynamic with multiple factors affecting treatment adherence. The study mainly highlights social determinants of health like social and economic conditions and also the need for improvement in the healthcare facilities and infrastructure. This emphasises the importance of social factors that could affect individuals' ability to seek healthcare and adhere to a course of treatment.^{30 31} The long distance of the healthcare centre and lack of infrastructure increase patients' struggle to reach the facility in time, especially due to their occupation or other sociocultural obligations.^{32 33} The long-term outcomes in patients with DR-TB especially in patients with XDR-TB are usually poor, thus, putting close contacts and the community at risk of getting the infection.^{35 36} Thus, the threat of spreading the infection with DR strains is one of the major challenges particularly in disadvantaged populations as in the present study. To address these factors, a systematic multipronged approach would be required with a specific focus on 'patient-centred care' for patients with DR-TB as has been found useful in other studies.^{17 31}

Few methodological limitations need to be discussed. First, the sample was purposive and may not entirely represent the experiences and needs of patients with MDR/XDR-TB in this community. Second, the patients were interviewed for their perceptions and experiences about TB and the available TB services retrospectively which may result in recall bias. We however tried to minimise the recall bias through interviewers' training in probing during interviews to facilitate precise replies. Though the findings of the study may not be generalised universally, these are relatable to any remote area and poverty-driven individual and can be generalised with any other similar study setting.

CONCLUSION

The study has important implications for TB policy and practice especially for disadvantaged communities living in remote tribal/rural areas. It provides an insight into the experiences and needs of patients with DR-TB belonging to the Saharia tribe and is useful in devising strategies to improve treatment adherence for this community. In tribal-dominated areas, health facilities need to be cohesive to the social and cultural beliefs of local populations so that they do not hesitate to approach these facilities for their diagnosis and treatment needs. Periodical counselling of patients is a must for proper treatment adherence and to gain their confidence in the treatment and medication process. DR-TB has far-reaching consequences not only on their physical health but also on their socio-economic, psychological and emotional health. To achieve our goal of eliminating TB by 2025, we need to address the challenges faced by the patients and also their support

networks. This emphasises the need for ‘patient-centred care’ where patients’ needs are to be comprehended and prioritised.

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Data availability statement Data are available upon reasonable request. Data supporting our finding are available with the investigators and would be available on reasonable request.

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Intensified TB Control among Saharia PVTG in M.P.

Interview guide

MDR/XDR In-depth Interview

Introduction:

This interview is being conducted to know about the experiences of MDR/XDR- TB patients who are under treatment and also who are denying the treatment. This will help to understand the reasons why treatment adherence is low in MDR/XDR TB cases and what are the problems faced by the individuals who are under treatment. Which will further help in better understanding of the gaps in treatment success.

XDR-TB, an abbreviation for extensively drug-resistant tuberculosis which is a form of TB resistant to at least four of the core anti-TB drugs. XDR-TB involves resistance to the two most powerful anti-TB drugs, isoniazid, and rifampicin, also known as multidrug-resistance (MDR-TB), in addition to resistance to any of the fluoroquinolones (such as levofloxacin or moxifloxacin) and at least one of the three injectable second-line drugs (amikacin, capreomycin or kanamycin).

MDR-TB and XDR-TB both take substantially longer to treat than ordinary (drug-susceptible) TB and require the use of second-line anti-TB drugs, which have more side effects than the first-line drugs used for drug-susceptible TB.

IDENTIFICATION:

District: _____ **Block:** _____ **Village:** _____ **ST. NO.** _____ **HH No.** _____

Name of Patient: _____ **Father/Husband name:** _____

CONSENT:

ICMR-NIRTH, Jabalpur is running Intensified Tuberculosis Control Project among Saharia a PVTG. We are inviting you to take part in this study under this project. The main aim of the study is to identify TB cases with the help of community volunteers and to start their treatment with the help of supervisors and reduce the default rate. For this study, a patient will be asked questions regarding their experience of disease, health condition, and health facilities which will be electronically audio recorded. This study is being carried out for a better understanding of the difficulties and challenges faced by the patient and to identify the gaps for treatment adherence.

I understand that my participation in the study is voluntary and that I have the right to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

I agree to take part in the study. I confirm that my interview will be electronically audio recorded.

Signature of participant**Signature of Interviewer****Name & Signature of witness (1)****Name & Signature of witness (2)**

BACKGROUND INFORMATION OF PARTICIPANT:

1. Age: _____
2. Sex(M/F/O) _____
3. Education: _____
4. Occupation: _____
5. Marital status: _____
6. Type of Family: Nuclear/Extended
7. Total Family Members: _____
8. Type of House: (Kutcha/Semi-pucca/Pucca) _____
9. No. of Room: _____
10. Type of fuel used for cooking: _____
11. Ventilation in living rooms: Yes/No____
12. History of TB patient in family: _____

In-depth-Interview:

(Note: All suitable questions should be asked during the interview and the responses should be recorded in both hard copy and electronically. Record responses/statements without changing the sequence of responses. Do not prompt, but keep on asking 'anything else')

Opening question

1. How are you doing for the day? / how are you feeling now?
2. Can you tell me about your family? Who all are in your family? (*background of the family, occupation of members, the main source of livelihood*)
3. How is everyone at home? (probe: *is someone having any health problem, then specifically about the symptoms of TB*)
4. What did you eat today? (probe: *is his/her dietary habit is different from other family members or changed over the period*)
5. What is your daily routine? What work do you do?

Disease condition

6. How is your health now, (*Ask about his/her perception about health*)

7. When did you get to know something is not alright? (*Ask about the early onset of diseases*)
8. When was your disease (TB) diagnosed and how you came to know? (*Ask for all places he/she visited for diagnosis, month and year of diagnosis*)
9. What was your reaction/ How did you react when you got your diagnosis results (*Ask about his/her reactions after he/she came to know about TB results*)
10. When you started the treatment? (*Ask for all types of treatments he/she had taken including during the period of TB diagnosis traditional/faith healers, quacks, Pvt. or/and Govt health posts*).
11. Do you feel any difficulty / uneasy now? (*General perception about health*)
12. What were the challenges you face in the whole process of diagnosis to treatment start? (*Record all without changing the sequence of responses*)

Health care facility

13. How is your experience with the diagnosis and hospital?
14. Tell something about your experiences at DMC/TU? (*including the behavior of DMC/TU staff*)
15. Tell something about your experience in DRTB center Gwalior? (facility provided, transport)
16. Who is giving medicine to you and who takes care of your medication?
17. If a patient is taking TB treatment from Non-Govt. facilities (Pvt./Quacks/traditional healers, etc.), ask reasons for not visiting Govt health facilities and taking treatment from Govt. health facility.
18. Are you satisfy with the services given to you? (how can it be improved)

Treatment and drugs:

19. Are you taking TB medicine daily? Have you taken any medicine today, (*ask especially about TB medicine*)?
20. Is there any side-effect you are facing? (Probe- *if Yes, record all side effects*)

21. If treatment has not been started yet, What are the reasons for not starting treatment
(ask for all reasons - socio, psychological and economic reasons)

22. If treatment has stopped or discontinued, What are the reasons for not continuing the treatment/or reasons for discontinuation (ask for reasons - socio, psychological, economic, and drug side effects)

Perception about TB

23. What do you think about TB? Ever you heard about TB before you diagnosed?

24. Had you seen any TB patient before (family or friends)?

Financial burden

25. How much have you paid out of pocket for the treatment?

26. How you managed these expanses?

Social/ Psychological impact

27. Because of TB have you ever felt left out/ignored from the society/family functions or gatherings (Ask about any kind of social stigma)

28. Have you ever felt depressed?

Physical health

29. Comparing to your health before the onset of TB symptoms, what differences had you noticed in your health during the onset of symptoms and initiation of TB treatment?
(Ask about the changes he/she noticed during his/her deteriorating health)

30. Comparing to your health status before initiation of the treatment, what difference have you noticed in your health after initiation of the treatment? (Ask about the changes he/she noticed in his/her health after initiation of TB treatment, during his/her deteriorating health)

Lifestyle / behavior

31. Is there any change in your lifestyle because of the disease? (Record all changes)

Closing question

32. What has been the hardest thing for you to deal with till now from the day of diagnosis?
33. Do you want to add something from your side?
34. Do you want to ask something?

THANKS FOR YOUR PARTICIPATION IN THE STUDY.