BMJ Open

Experiences and needs of MDR/XDR TB patients among Saharia tribe in Madhya Pradesh, Central India

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-044698
Article Type:	Original research
Date Submitted by the Author:	14-Sep-2020
Complete List of Authors:	Nigam, Samridhi; ICMR-National Institute of Research in Tribal Health, Microbiology Sharma, Ravendra; National Institute of Medical Statistics Yadav, Rajiv; ICMR-National Institute of Research in Tribal Health, Microbiology Rao, Vikas; ICMR-National Institute of Research in Tribal Health, Community Medicine Mishra, Prashant; ICMR-National Institute of Research in Tribal Health, Microbiology Lingala, Mercy; ICMR-National Institute of Research in Tribal Health, Microbiology Bhat, Jyothi; ICMR-National Institute of Research in Tribal Health, Microbiology
Keywords:	Tuberculosis < INFECTIOUS DISEASES, PUBLIC HEALTH, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Experiences and needs of MDR/XDR TB patients among Saharia tribe in Madhya Pradesh, Central India

Samridhi Nigam[1], Ravendra K Sharma[2], Rajiv Yadav[1], VG Rao[1], Prashant Mishra[1], Mercy Aparna. Lingala[1] and Jyothi Bhat[1*],

1. ICMR-National Institute of Research in Tribal Health, Jabalpur

2. ICMR- National Institute of Medical Statistics, New Delhi

Corresponding author:

Dr. Jyothi Bhat, M.D.

ICMR-National Institute of Research in Tribal Health

Nagpur Road

P.O. Garha

Jabalpur 482003

Phone: +91 761 2370800

Email: drjyothibhat@rediffmail.com

Abstract

Background

Drug-resistant Tuberculosis (DRTB) continues to be a major public health threat worldwide. This study was conducted among drug resistant tuberculosis patients of Saharia tribe residing in Madhya Pradesh state in central India to document their experiences, needs and to identify gaps for treatment adherence.

Methods

We concluded sixteen in-depth interviews on purposively selected drug resistant TB patients among Saharia tribe using a pre-designed 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 health facility. Data was analyzed manually using thematic approach. Out of these interviews various sub-themes were also extracted.

Results

The study helped to understand experiences and needs of the DRTB patients in various stages from diagnosis to treatment and how various factors like lack of education and awareness, poor living condition, lack of healthcare facilities are responsible for pre-dominance of the disease in the community. In these, we found many issues mainly poor access to health-care facility, high pill-burden, long duration of treatment, financial burden, misbeliefs and misconceptions about the disease. Patients narratives pointed out their struggle at every stage being it with diagnosis, treatment initiation or treatment adherence. The side-effects of the drugs make their treatment journey further difficult.

Conclusion

This study gave an insight about the experiences and needs of the DRTB patients, which are required to be addressed, to improve the present condition and sufferings. Overall, the diagnosis and treatment facilities need to be improved with 'patient-centric' approach to bring down the high burden of TB among the Saharia community.

Keyword

Tuberculosis, Drug resistant TB, MDR, XDR, Tribe, Saharia, India

Article Summary:

Strengths:

- The study is the first of its kind exploring the needs and experiences of the MDR/XDR TB patients belonging to Saharia tribe. Patient's narratives pointed out their struggle at every stage being it with diagnosis, treatment initiation or treatment adherence. The side-effects of the drugs make their treatment journey further difficult.
- The study has important implications for TB policy and practice especially for disadvantaged communities living in remote tribal/rural areas. It provides an insight about the experiences and needs of the DRTB patients belonging to the Saharia tribe and is useful in devising strategies to address the challenges faced by the patients and also their support networks.
- High prevalence of pulmonary tuberculosis and emerging drug-resistant tuberculosis is a serious health problem in Saharia, an indigenous population in central India. Treatment success and loss to treatment follow up is the key issue in MDR-TB especially in marginalised populations. The understanding of the experiences and needs of DRTB patients and the community is essential to achieve TB elimination goal.

Limitations

- The study was conducted in a marginalised population having very high TB prevalence. The majority of the participants are illiterate. Though it is advisable to follow people prospectively, they were interviewed for their perceptions and experiences about TB and the available TB services retrospectively. This may result in recall bias.
- We interviewed DRTB patients who were under treatment at the time of the study or who completed treatment in recent past. Thus, the patients in different treatment phases may provide different perspectives and needs.

Introduction:

Tuberculosis (TB), caused by Mycobacterium tuberculosis, remains one of the top 10 causes of death worldwide. Globally, an estimated 10.0 million people fell ill with TB in the year 2018. The burden of disease varies enormously among countries, from fewer than five to more than 500 new cases per 100000 population per year, with the global average being around 130.[1] The drug-resistant TB (DRTB) continues to be a public health threat. In 2018, there were about half a million new cases of rifampicin-resistant TB and India alone contributing about 27% of world's DRTB cases. Globally, 3.4% of new TB cases and 18% of previously treated cases had multidrug- resistant TB or rifampicin-resistant TB (MDR/RR-TB).[1] Treatment success rate of DRTB patients were 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 spreading the disease and also possibility of developing further drug resistance among them. There is however, very limited information available in the country on the factors responsible for LTFU in MDR-TB.

There are over 700 Scheduled Tribes (ST) notified in India, spread over different states and Union Territories of the country. The state of Madhya Pradesh accounts for 21.1% of scheduled tribe population of India.[4] 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 tuberculosis prevalence in the country ranging from 1270 to 3294 per 100000 population.[5-9] The Saharia tribe is among the tribal group which majorly suffer from poverty and poor living condition like overcrowding, where they reside in close knitted groups of community members. with limited resources of income mostly engaged as daily wage labour or labour in farms.[5] These people sustain in the conditions like lack of education, poor access to health care facility, financial constrain, indulgence into risk-factors like tobacco smoking and alcohol consumption.[7] These associated factors make them more prone to infection of TB and DRTB. The lack to treatment adherence and the causes responsible for it becomes more relevant in such a community having very high prevalence of tuberculosis. So, keeping all these facts and the robust decision of Government of India to eliminate TB by 2025, this study was conducted to understand the experiences and needs of drug resistant tuberculosis patients among Saharia tribe of Madhya Pradesh and to suggest the possible solution for improving their retention-in-care / treatment adherence.

Methods:

The present study was conducted as a sub-study of the main ongoing study 'Intensified TB control project in Saharia tribe of Madhya Pradesh'. This qualitative study was conducted during July 2019 to January 2020 among the drug resistant patients belonging to Saharia tribe in Chambal region of Madhya Pradesh where they predominantly reside. The patients who were under treatment for drug resistant tuberculosis in the recent past, or who were under medication at the time of survey were enrolled. Sixteen participants were selected through purposive sampling techniques irrespective of their phase of treatment. Data from participants were acquired to get an insight into their socio-demographic details and living conditions. A pre-designed open-ended in-depth interview guide consisting questions on various domains like general physical health, diagnosis, treatment adherence, side-effects of drugs and experience related to health facility was prepared and used for interviewing the participants (Table 1). These included five extensively-drug resistant (XDR) and eleven multi-drug-resistant (MDR) cases. Audio-recording of the in-depth interviews were simultaneously done with prior permission from the participants. All audio recordings of participants were transcribed directly into English. Transcripts were coded, entered manually, and analysed to generate themes. The extracted codes from the collected data were divided into various categories manually. A thematic network analysis was also designed from the transcripts.

Ethics:

The main ongoing study has been approved by Institutional Ethics Committee (IEC) of ICMR-NIRTH, Jabalpur. The study objectives were explained to all participants and a written consent for their participation and audio-recording was obtained.

Patient and Public Involvement

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

Results:

The participants ranging from 18 years to 65 years were interviewed using a pre-designed open- ended in-depth interview guide. Out of total 16 cases, there were only two females as majority of the DRTB cases were males. Most of them were uneducated and six completed primary schooling. Most of the patients were unable to perform any kind of work or household chores because of their disease. All participants were married and were staying with their respective families. Living condition of the participants were inconceivable, as 9 out of 16 participants were living in kutcha house with a single room without any ventilation (Table 2). The wood/crop residual was used for cooking on chulha inside the same room. All these depriving situations highlight some of the reasons why the disease is pre-dominated in this tribal group. Patient narratives pointed out the struggles and difficulties of the journey which a drug resistant patient has to undergo from diagnosis to treatment (Figure 1)**.**

Pre- Treatment Phase

Perception about disease

Due to lack of education, the patients and their family owned several misbeliefs and misconceptions about the disease and narrated their belief for the disease saying that -

- *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, 28 year Male*

- *From this disease people slowly-slowly die (ghut ghut ke marr jate hai) – P4, 55 year Male*

One thing that everyone understood is that it is a fatal disease and 14 out of 16 participants had seen death due to this disease either in close family or their villagers which is a traumatizing experience and somehow play a major role in depleting the confidence and fighting spirit of the patient against the disease-

- *There is nobody in my family, except myself and my wife. My brother and sister-in-law died of same disease, their children are with us. Three people in my family died of same disease. P9, 40 years Male*

- *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, 37 years Male*

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 come to know that he/she is suffering from disease, it is very traumatizing experience for him. The participants shared how difficult it was for them to believe that they are suffering from the disease which they are scared of –

- *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 neechai se zameen fisal gayi ho jaise) – P5, 28 years Male*

- *One year back I went to Gwalior, there 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, 35 years Male*

General physical health and other factors

Due to lack of awareness, many a times patients quit treatment and do not complete the course, especially in drug resistant cases. It is seen that majority of the patients took anti- TB treatment before getting DRTB. One such condition came out during the interview when patient himself told about not taking medication properly as he started feeling better –

- *I took TB medication twice before, and 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 full course of treatment. P4, 55 years Male*

The patients also mentioned that they did not understand the reason for their deteriorating health condition and faced many problems.

- *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, 40 years Male*

The study participants belong to resource deprived area and are mainly engaged as daily wage labours, construction workers or farming related works. The supervisors / landlords make them work tirelessly, one such participant told that -

- *Around six year back, I used to work as a labour and had 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, 35 years Male*

When these workers are taken out to other places for work, they usually stay in close contact with other labours working with them and thus the chances of getting infection increases. During the interview, one participant revealed that -

- *About 4-5 years back, when I was working in Jaipur, there was a co-worker (labour) who used to stay with me in same plot, he suffered from TB and was taking medicine at that time , I have a doubt may be from him I got this infection.– P5, 28 years Male*

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 private doctor since long; every time he was getting relief for time being after taking medicines -

- *For about a year I was on private treatment. I used to get fever and cough and doctor gave me some medicine for these, After getting temporary relief I used to stop taking those medicines, then my health condition use to become same as before. P4,55 years Male*

Further, due to poor access to health-care facility and lack of knowledge, people do not know where exactly to go to get right treatment and what is the right treatment. Many a times, patients due to the misbelieve fall in the trap of non-medical practitioners (faith healers, flick burnt (*ojaha*)) who are closer to their easy reach -

- *I went to Kasba in Rajasthan state, earlier I got a herb (jadibooti) there for my illness. After performing ritual with clove, lemon and chicken, they gave me one amulet (tabeej). I strongly believe that only after getting amulet (Tabeej), medicine started working on my body. Earlier I took treatment many times, but nothing was effective. – P9,40 Male*

Treatment Phase

Anti-TB drugs are known for their adverse side-effects. Participants shared their experiences about their suffering and told how hard it was for them to overcome those side effects. Side-effects especially nausea, vomiting, breathlessness, anxiety and insomnia were commonly observed whereas breathlessness, anxiety and nausea were major side-effects observed in the DRTB patients as 14 out of 16 reported these.

- *Still, I feel breathlessness, nausea and feverish. This is too difficult for me to bear, I feel very anxious – P12, 60 years Female*

- *When I came back from DRTB 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 DRTB center also I was taking 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, 28 years Male*

Many patients also reported high pill burden - taking 9 to 12 tablets at a time – as the reason for non-compliance. Injections were also mentioned among one of the reasons restricting them to adhere to the treatment.

- *I feel severe nausea and anxiety while taking these medicines, there are 12 tablets which are to be taken daily. P4, 55 years Male*

- *It was very difficult to take 10 tablets all together at a time that too on empty stomach, I use to feel anxiety, breathlessness soon after taking medicine. – P11, 37 years Male*

- *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 alternate day for injection, thus somehow, I managed to cope with my condition. – P9, 40 years Male*

- *When I started treatment, I used to take large number of tablets. I used to feel 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, 50 Years Male*

Difficulties/ Challenges for Treatment adherence

Physical weakness

Many Patients told that they have become very weak due to the disease and are unable to perform any kind of work for earning and support their family. Most of these patients are daily wage labours and use to work in field which require lots of physical strength and energy.

- *If I work little bit, or carry 10-20 kg of weight then within few minutes I start feeling breathlessness. I cannot help in anything at home, even not in household chores. - P5, 28 years Male*

- *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 jungle to collect wood for cooking. But this disease has made me so helpless, now even I can't think of doing my own daily routine works. – P4, 55 years Male*

Financial Burden

One important theme which came out of the interviews is the financial burden on the patients especially in poor people, the disease condition shatter their livelihood severely.

- *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 lot of money during each visit. – P5, 55 year Male

- *During the last 2 years, I have spent more than Rs.1 lakh for me and for my daughter's treatment from many doctors and private hospitals in Gwalior including expenses for food and travelling. P5, 28 years Male*

- *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, 35 years Male*

Treatment at health care facility

Patients also reported that they did not get medicine from the health facility / drug provider for continuing their treatment -

- *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, 37 years Male*

- *The Patient's wife also said, "I have personally visited many times, even I went to district hospital for medicine but nobody gave us medicine" – Wife of P11, 37 years Male*

Lack of access to health care facility, long distance, and the time to reach health care facility made it difficult for the patients to get proper treatment. Patients are required to go to DRTB center for initiating XDR treatment which is around 120 to 240 KM from the district hospital and thus have to pay from their pocket. Many patients reported this financial burden as well as poor facilities at DRTB center -

- *Nobody can stay in the hospital (DRTB facility). It is not cleaned and in morning hours nobody is there to look after the patients, only at 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, they only stay in the hospital because of their*

helplessness, as they have no other option (Koi aur suvidha hi nahi hai). - P1, 50 Years Male

- *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, 50 year Male*

- *All tests were done from private; I had to pay for all the tests. It was peak of summer and there was no water facility or fan/cooler in the hospital. Not many patients as well. - P4, 55 years Male*

Due to the distance and poor facility in the hospital (DRTB 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 also satisfied with the treatment provided in the district hospital

- *The facility here (district hospital) is better than DRTB centre at Gwalior),, here everyone listens to us and provide 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 doctor. They keep patients at distance. In DRTB centre they (health staff) hate patients. But in district hospital, they never showed such kind of behavior to us. – P5, 28 year Male*

Improvement in health

Once the patient starts taking the right treatment, within few days he himself 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 about their positive reflections of taking medicine and specified that -

- *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 like I used to have before. - P1, 50 years Male*

- *Now when I go to bed in the night, I wake-up directly in the morning, but earlier, I used to cough whole night because of which I was not able to sleep in nights. - P1, 50 Years Male*

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] While discussing about the scenario in India it is no different, as India is the highest TB burden country with highest MDR-TB burden in the world notifying 130,000 MDR/RR-TB patients in 2018.[1] 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 alarmingly high prevalence of tuberculosis.[8] The drug-resistant tuberculosis is also emerging as a serious health problem in this tribe.[10] This assumes more significance in view of the commitment by Government of India to eliminate TB by 2025 which is not possible without addressing the basic grass root issues including the experiences and needs of the patients. The present qualitative study tries to understand these issues in high TB burden Saharia tribal community.

The current study was conducted among 16 drug resistant TB cases of the Saharia tribal community. Though the National TB Elimination Programme (NTEP; formerly Revised National Tuberculosis Control Programme - RNTCP) has been implemented for more than 15 years and the programmatic management of drug Resistant TB (PMDT) from 2013 in this area, the findings of the study indicate that more efforts are required especially at grass-root level. The study highlights several challenges faced by DRTB patients belonging to a marginalised community from central India. One important issue common to all the participants was their poverty and the added financial burden due to tuberculosis. The studies conducted in different settings also highlighted the "catastrophic" costs associated with TB and DRTB treatment in spite of the provision of free treatment.[11,12] Furin et al. in a study conducted in south Africa reported significant economic burden on Rifampicin-Resistant Tuberculosis patients and households due to the loss of income and the expenses for transportation.[13] In India, although all notified TB patients are entitled for cash transfer of Indian Rupees (INR) 500 per month during the complete course of treatment under the direct benefit transfer (DBT) scheme, there are delays in benefit transfer. A study conducted in

western India reported that only 7.3% patients received first instalment within two months of treatment initiation.[14] The delays in access to such grants are also reported by other workers.[11] 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.[15] The timely payment under DBT / economic support during the first few months of treatment with counselling shall definitely help in improving treatment compliance in drug resistant TB patients in this community.

Majority of DRTB patients noted adverse side effects to TB treatment. This is an important factor for treatment adherence, as has been mentioned by other authors.[13,16,17] 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.[13,18,19] This highlights the importance of continuous counseling of the patients and their family members, so that in the course of side-effects they do not leave the treatment.

The patients also reported various problems related to health facilities including the attitude of the staff and the services provided in DRTB centres. The poor attention and even the maltreatment by heath staff, poor maintenance of the facility, lack of basic facilities such as drinking water, fan etc, and no supply of medicines by health worker were some of the issues noted by them. Many studies also reported such issues in different population groups.[18,20,21]

The patients and the community 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 tuberculosis are reported by other authors.[21-24] The whole process of diagnosis and treatment of DRTB is very tiring and traumatizing for the individuals, one has to undergo through various phases comprising of physical fatigue and mental tiredness. Fighting with the disease condition and also overcoming the anxiety and fear is the biggest challenge in patients' life. Most of the patients have seen their near & dear ones dying of TB, resulting in shattering their confidence with constant fear of death. Fear and denial of diagnosis was noted in the present study as also found in other studies.[21,24,25]

The work-related issues included fear of losing job, need to earn a living, taking care of family etc. which are also reported in other studies.[20-22] The belief in traditional healers for common ailments is also deep rooted in the community. The easy availability nearer to their

residence and the negligible cost of treatment also explains their preference for traditional healers. This study which was conducted among the most vulnerable section of the 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's 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 V et al (2016) mentioned about the impact of disease in patient's family and caretakers lives, as the family is one of the main source of support during patients treatment and recovery.[26] This highlights the need for involving the community in TB control activities as the disease impact all the individuals associated with the patient.

We could hardly find any kind of stigmatization in the present study, as 15 out of 16 participants told that they never faced any stigmatization. This indicates social acceptance of the individual in the community. However, patients noted that they themselves choose to refrain from the society and avoid social gatherings like marriages, religious functions, community meetings etc. due their physical weakness. The social acceptance of TB patients is encouraging and assumes importance as the TB burden is very high in this tribal community. Many studies have reported the strong influence of stigma resulting in non-adherence to treatment as they become demoralized due to weak family support.[19-21] Due to guilt and fear of getting isolated in the family and the community, patients may also hide their disease.[20,24,25] It is also encouraging to note that many patients had positive attitude towards treatment and told 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 these belong to the same community. A study in Ethiopia also reported positive attitude of patients towards treatment.[27]

Our study has identified several problems faced by DRTB patients living in remote tribal areas by the means of various narratives by the participants where they opened up about the different difficult experiences in the course of 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 health care facilities and infra-structure. This emphasizes the importance of social factors that could affect individuals ability to seek health care and adhere to a course of treatment.[28,29] The long distance of health-care center and lack of infra-structure increases patient's struggle to reach the facility in time, especially when they have occupation or other

socio-cultural obligations.[30,31] The long term outcomes in DRTB patients especially in XDR patients are usually poor putting close-contacts and community at risk of getting the infection.[32,33] Thus, threat of spreading the infection with drug resistant strains is one of the major challenges particularly in disadvantaged populations as in the present study. To address these factors, a systematic multi-pronged approach would be required with a specific focus on 'patient centered care' for DRTB patients as has been found useful in other studies.[13,29] Though the findings of the study may not be generalized universally, these are relatable to any remote area and poverty driven individual and can be generalized with any other similar study settings.

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 about the experiences and needs of the DRTB patients belonging to the Saharia tribe and is useful in devising strategies to improve treatment adherence in the tribal community. In tribal dominated areas, health facilities need to be cohesive to their social and cultural beliefs and conducive to them so that they should not hesitate to approach these facilities for their diagnosis and treatment needs. Periodic counseling of patients is must for proper treatment adherence and to gain their confidence in the treatment and medication. The TB disease particularly drug resistant TB has far reaching consequences not only on their physical health but also on their socio-economic, psychological and emotional health. In order 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 emphasizes the need for 'patient centered care' where patients are to be given at most importance which they deserve.

Contributorship statement

SN, RKS, JB designed the study, SN, PM, ML did data collection, SN, RKS, RY carried out the analysis, SN, VGR, RKS and JB wrote the manuscript. All the authors read and edited the manuscript.

Acknowledgement

Authors would like to extend their gratitude towards the Director, ICMR-NIRTH, Jabalpur for the support in the study and also to all the participants who have given their time for the interview and believed in us for giving proper response. Last but not the least, thanks are due to all the district coordinators and field staff for their constant support.

Funding

It is a sub-study under the ongoing study on Intensified TB Control Project among Saharia tribe, a PVTG in Madhya Pradesh. The main study is funded by the Government of Madhya Pradesh.

Competing interests

None declared

Availability of data and materials

Data supporting our finding are available with the investigators.

Table -1: Representation of themes

	Pre- treatment phase	Treatment phase
Challenges	The time from diagnosis to treatment is a big challenge in patient's life which breaks him in all possible ways be emotionally, physically, or financially.	
Physical Challenges	Physical symptoms discomfit normal activities of daily life Like household works or even taking care of personal chores	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	Health care facilities are difficult to reach because of distance. No proper channel or awareness about the facility to the patients about where to go and to whom to approach.	The facilities at DRTB centres are not sufficient and the distance that one has to travel to reach the centre is about 120 to 240 kms The facilities like stay and food in the hospital ward are not proper. Number of days to be admitted in hospital for treatment initiation is also more (15 days)
Economic Challenges	Loss of income as no work due to poor physical health	Till the time patient gets DBT money, one has to pay the large amount out of his/her pocket for travelling, food and daily necessities.
Emotional and psychological Challenges	Due to physical ill health, he/she is dependent on others for the daily necessities, emotional state is devastated.	Once a patient gets information about his tuberculosis disease particularly DR status, the hope of living just vanish as they consider it to be a fatal disease with no cure.
Social Challenges	Lack of involvement in social gatherings due to poor health condition	Stigmatisation is not reported by the participants but they themselves avoid social gatherings due to their poor health condition.

Table 2: Social-demographic characteristics of participants

Age	**Range in years**	**Frequency**
	< 35	3
	35 to 44	7
	45 to 54	3
	55 and more	3
Sex	Male	14
	Female	2
Education	No formal education	10
	Primary+	6
Occupation	Non- working	14
	Labours	2
Marital Status	Unmarried	0
	Married	16
Type of Family	Nuclear	6
	Extended	10
Children	No Child	0
	Less than 2 children	4
	More than 2 Children	12
Type of House	Kutcha	9
	Semi – Pucca	5
	Pucca	2
No. of rooms in the house	One	14
	More than 1	2
Ventilation in living room	No	12
	Yes	4
TB history in Family	No History	11
	History of contact	5
Mode/fuel for Cooking	Chulha/Wood	16

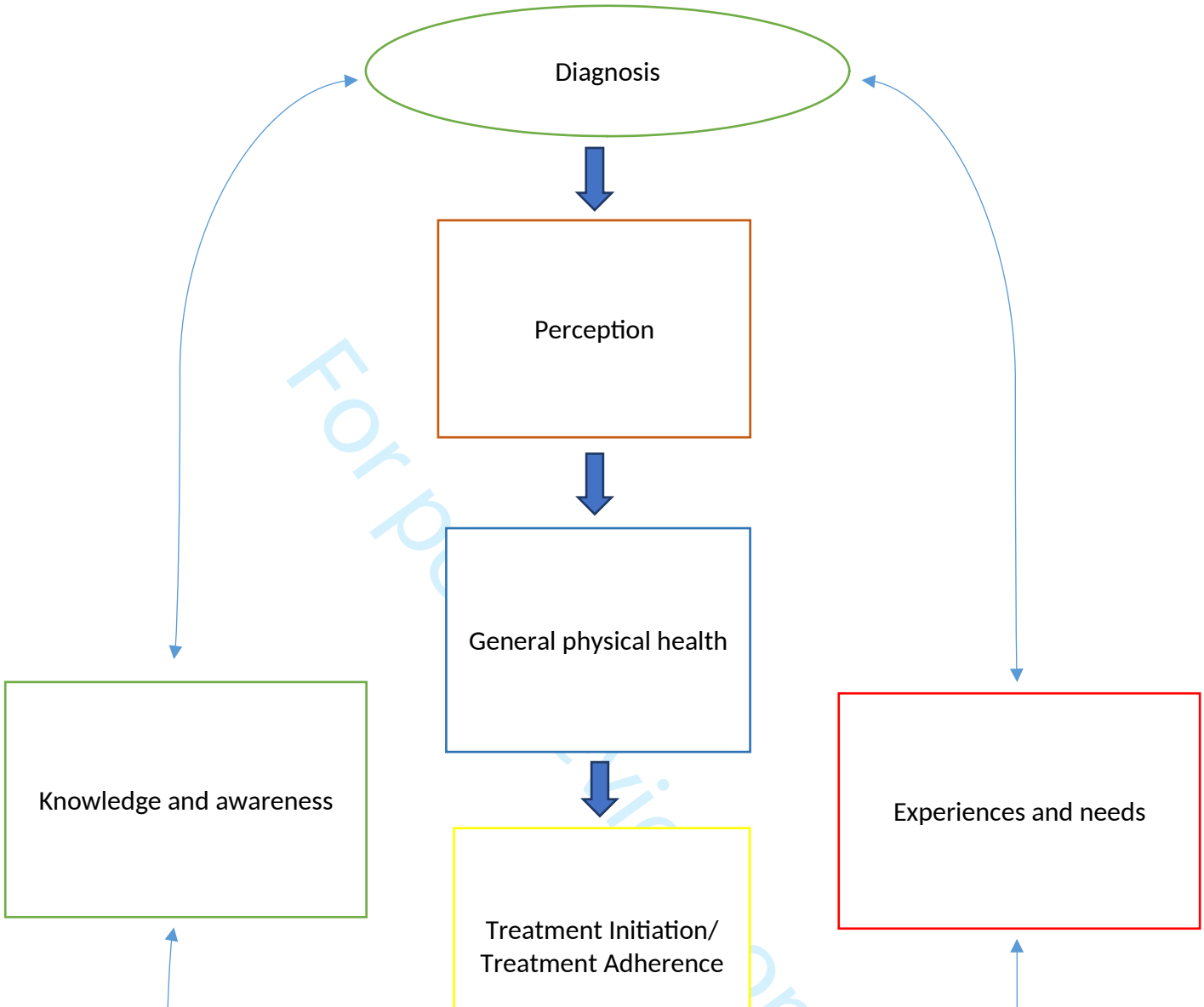
References:

1. World Health Organisation. Global Tuberculosis Report 2019. World Health Organisation, 2019. https://www.who.int/tb/publications/global_report/en/
2. World Health Organisation. The end TB strategy. World Health Organization, 2015. https://www.who.int/tb/strategy/End_TB_Strategy.pdf
3. World Health Organization. Drug-resistant TB: surveillance and response: supplement to global tuberculosis report 2014. World Health Organization, 2014. https://apps.who.int/iris/handle/10665/137095
4. Government of India. Annual Report 2017-18. Ministry of tribal affairs, Government of India 2018. https://tribal.nic.in/writereaddata/AnnualReport/AR2017-18.pdf
5. Rao VG, Gopi PG, Bhat J, *et al*. Pulmonary tuberculosis: a public health problem amongst the *Saharia*, a primitive tribe of Madhya Pradesh, central India. *Int J Infect Dis* 2010;14:e713–6.
6. Rao VG, Gopi PG, Yadav R, *et al*. Tuberculous infection in *Saharia*, a primitive tribal community of Central India. *Trans R Soc Trop Med Hyg* 2008;102:898–904.
7. Rao VG, Gopi PG, Bhat J, *et al*. Selected risk factors associated with pulmonary tuberculosis among Saharia tribe of Madhya Pradesh, central India. *Eur J Public Health* 2012; 22(2):271-3.
8. Rao VG, Bhat J, Yadav, R, *et al*. Pulmonary tuberculosis – a health problem amongst Saharia tribe in Madhya Pradesh. *Indian J Med Res* 2015; 141(5): 630-35.
9. Chakma T, Rao PV, Pall S, *et al*. Survey of pulmonary tuberculosis in a primitive tribe of Madhya Pradesh. *Indian J Tubec* 1996; 43: 85-9.
10. Prakash R, Kumar D, Gupta VK, *et al*. Status of multidrug resistant tuberculosis (MDR-TB) among the Sahariya tribe of North Central India. *J Infect Public Health* 2016; 9: 289—297.
11. Ramma L, Cox H, Wilkinson L, *et al*. Patients' costs associated with seeking and accessing treatment for drug-resistant tuberculosis in South Africa. *Int J Tuberc Lung Dis* 2015;19(12):1513–19.
12. Foster N, Vassall A, Cleary S, *et al*. The economic burden of TB diagnosis and treatment in South Africa. *Soc Sci Med* 2015;130C:42–50.
13. Furin J, Loveday M, Hlangu S, *et al*. "A very humiliating illness": a qualitative study of patient-centered Care for Rifampicin – Resistant Tuberculosis in South Africa". *BMC Public Health* 2020;20:76 (https://doi.org/10.1186/s12889-019-8035-z).

14. Patel BH, Jeyashree K, Chinnakali P, *et al*. Cash transfer scheme for people with tuberculosis treated by the National TB Programme in Western India: a mixed methods study. *BMJ Open* 2019; 9(12): e033158. Published online 2019 Dec 29. doi: 10.1136/bmjopen-2019-033158.
15. Baral S, Aryal Y, Bhattrai R, *et al*. The importance of providing counselling and financial support to patients receiving treatment for multidrug-resistant tuberculosis: mixed method qualitative and pilot interventional study. *BMC Public Health* 2014;14:46.
16. Deshmukh RD, Dhande DJ, Sachdeva KS, *et al*. Patient and Provider Reported Reasons for Lost to Follow Up in MDRTB Treatment: A Qualitative Study from a Drug Resistant TB Centre in India. *PLoS One* 2015;24:10(8);e0135802. doi: 10.1371/journal.pone.0135802. eCollection 2015.
17. Parmar MM, Sachdeva KS, Dewan PK, *et al*. Unacceptable treatment outcomes and associated factors among India's initial cohorts of multidrug-resistant tuberculosis (MDR-TB) patients under the revised national TB control programme (2007-2011): Evidence leading to policy enhancement. *PLoS One* 2018;11:13(4):e0193903. doi: 10.1371/journal.pone.0193903. eCollection 2018.
18. Jaiswal A, Singh V, Ogden JA, *et al*. Adherence to tuberculosis treatment: Lessons from the urban setting of Delhi, India. *Trop Med Int Health* 2003;8: 625–33.
19. Shringarpure KS, Isaakidis P, Sagili KD, *et al*. "When Treatment Is More Challenging than the Disease": A Qualitative Study of MDR-TB Patient Retention. *PLoS One* 2016; 9;11(3):e0150849. doi: 10.1371/journal.pone.0150849. eCollection 2016.
20. Harper M, Ahmadu FA, Ogden JA, *et al*. Identifying the determinants of tuberculosis control in resource-poor countries: Insights from a qualitative study in The Gambia. *Trans R Soc Trop Med Hyg* 2003;97: 506–10.
21. Khan A, Walley J, Newell J, *et al*. Tuberculosis in Pakistan: Socio-cultural constraints and opportunities in treatment. *Soc Sci Med* 2000;50: 247–54.
22. Greene JA. An ethnography of non-adherence: Culture, poverty, and tuberculosis in urban Bolivia. *Cult Med Psychiatry* 2004;28: 401–25.
23. Liefooghe R, Michiels N, Habib S, *et al*. Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan. *Soc Sci Med* 1995;41: 1685–92.

24. Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through ‘‘TB clubs’’ in rural north Ethiopia. *Soc Sci Med* 2003;56: 2009–18.
25. Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: Lessons learned from Vietnam. *Qual Health Res* 2002;12: 473–91.
26. Yellappa V, Lefèvre P, Battaglioli T, *et al*. Coping with tuberculosis and directly observed treatment: a qualitative study among patients from South India. *BMC Health Serv Res* 2016;19;16:283. doi: 10.1186/s12913-016-1545-9.
27. Tulloch O, Theobald S, Morishita F, *et al*. Patient and community experiences of tuberculosis diagnosis and care within a community-based intervention in Ethiopia: a qualitative study. *BMC Public Health* 2015;25;15:187. doi: 10.1186/s12889-015-1523-x.
28. Nathanson E, Lambregts-van Weezenbeek C, Rich ML, *et al*. Multidrug-resistant tuberculosis management in resource-limited settings. *Emerg Infect Dis* 2006;12(9):1389-97. doi: 10.3201/eid1209.051618.
29. Horter S, Stringer B, Reynolds L, *et al*. "Home is where the patient is": a qualitative analysis of a patient-centred model of care for multi-drug resistant tuberculosis. *BMC Health Serv Res* 2014;21;14:81. doi: 10.1186/1472-6963-14-81.
30. Hargreaves JR, Boccia D, Evans CA, *et al*. The social determinants of tuberculosis: from evidence to action. *Am J Public Health* 2011;101(4):654–62.
31. Lewis CP, Newell JN. Improving tuberculosis care in low income countries - a qualitative study of patients’ understanding of “patient support” in Nepal. *BMC Public Health* 2009;9:190.
32. O'Donnell MR, Jarand J, Loveday M, *et al*. High incidence of hospital admissions with multidrug-resistant and extensively drug-resistant tuberculosis among South African health care workers. *Ann Intern Med* 2010;19;153(8):516-22. doi: 10.7326/0003-4819-153-8-201010190-00008.
33. Pietersen E, Ignatius E, Streicher EM, *et al*. Long-term out- comes of patients with extensively drug-resistant tuberculosis in South Africa: a cohort study. *Lancet* 2014 5;383(9924):1230-9. doi: 10.1016/S0140-6736(13)62675-6. Epub 2014 Jan 17.

Figure 1:Thematic Representation:



BMJ Open

Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-044698.R1
Article Type:	Original research
Date Submitted by the Author:	09-Mar-2021
Complete List of Authors:	Nigam, Samridhi; ICMR-National Institute of Research in Tribal Health, Microbiology Sharma, Ravendra; National Institute of Medical Statistics Yadav, Rajiv; ICMR-National Institute of Research in Tribal Health, Microbiology Rao, Vikas; ICMR-National Institute of Research in Tribal Health, Community Medicine Mishra, Prashant; ICMR-National Institute of Research in Tribal Health, Microbiology Lingala, Mercy; ICMR-National Institute of Research in Tribal Health, Microbiology Bhat, Jyothi; ICMR-National Institute of Research in Tribal Health, Microbiology
Primary Subject Heading:	Infectious diseases
Secondary Subject Heading:	Qualitative research
Keywords:	Tuberculosis < INFECTIOUS DISEASES, PUBLIC HEALTH, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Samridhi Nigam[1], Ravendra K Sharma[2], Rajiv Yadav[1], VG Rao[1], Prashant Mishra[1], Mercy Aparna. Lingala[1] and Jyothi Bhat[1*],

1. ICMR-National Institute of Research in Tribal Health, Jabalpur

2. ICMR- National Institute of Medical Statistics, New Delhi

Corresponding author:

Dr. Jyothi Bhat, M.D.

ICMR-National Institute of Research in Tribal Health

Nagpur Road

P.O. Garha

Jabalpur 482003

Phone: +91 761 2370800

Email: drjyothibhat@rediffmail.com

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 drug-resistant tuberculosis patients of Saharia tribe residing in Madhya Pradesh state of Central India to document their experiences, needs and to identify gaps for treatment adherence as it is known to be poor in this population because of migration and other factors.

Methods

We conducted sixteen in-depth interviews on purposively selected drug-resistant TB patients among the Saharia tribe using a pre-designed 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 sub-themes were extracted. The obtained qualitative data were subjected to thematic analysis.

Results

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

Conclusion

It is paramount to address the needs and experiences of DR-TB patients and develop a 'patient-centric' and context-specific approach conducive to the socio-cultural setup of tribal people. This will scale down the attrition rate of tribal patients while adhering to the complete treatment process and reduce high burden of TB among the Saharia community. In addition, tribal patients should be counseled at regular intervals to increase their confidence in the treatment and medication.

Keyword

Tuberculosis, Drug resistant TB, MDR, XDR, Tribe, Saharia, India

Article Summary:

Strengths:

- The present study is a novel one exploring the needs and experiences of MDR/XDR TB patients belonging to the Saharia tribe in central India.
- The study has important implications for TB policy and practice especially for disadvantaged communities living in remote tribal/rural areas.
- The study findings on the experiences and needs of DR-TB patients belonging to the high TB burden Saharia tribal community are useful in devising strategies to address the challenges faced by the patients and also their support networks.

Limitations

- The sample was purposive and may not entirely represent the experiences and needs of MDR/XDR TB patients in this community.
- Though it is advisable to follow people prospectively, they were interviewed for their perceptions and experiences about TB and the available TB services retrospectively which may result in recall bias.

Introduction:

Tuberculosis (TB), caused by Mycobacterium tuberculosis, remains one of the top 10 causes of death worldwide. Globally, an estimated 10 million people fell ill with TB in the year 2018.[1] The burden of the disease varies enormously among countries, from fewer than five to more than 500 new cases per 100000 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, and India alone contributing about 27% of the world's DR-TB cases. Globally, 3.4% of new TB cases and 18% of previously treated cases had multidrug-resistant TB or rifampicin-resistant TB (MDR/RR-TB).[1] Treatment success rate of DR-TB patients 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 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.

There are over 700 Scheduled Tribes (ST) notified in India, spread over different states and Union Territories of the country. The state of Madhya Pradesh accounts for 21.1% of the scheduled tribe population of India.[4] 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 tuberculosis prevalence in the country ranging from 1270 to 3294 per 100000 population.[5-9] The Saharia tribe is among the most vulnerable population segments that suffer from poverty and unhygienic/ overcrowded living conditions. Most community members earn their livelihood as daily wage laborers or labour in agriculture farms.[5] 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 Revised National Tuberculosis Control Programme, now National Tuberculosis Elimination Programme (NTEP) adopting internationally recommended 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 amongst the Saharia tribal community with high TB burden[7,8,9]. So, keeping all these facts and the robust

decision of the Government of India to eliminate TB by 2025, this study was conducted among DR-TB patients of Saharia tribe residing in Madhya Pradesh state in central India to document their experiences, needs and to identify gaps for treatment adherence.

Methods:

The present qualitative research was conducted as a sub-study of the main ongoing study 'Intensified TB control project (ITCP) in Saharia tribe of Madhya Pradesh' which focuses on active case detection through the engagement of community volunteers, prompt treatment and follow up of cases and awareness activities. The ITCP is ongoing in Saharia villages in seven districts of Chambal region of Madhya Pradesh state where this tribe predominantly resides and encompasses about 0.5 million population. The qualitative study was conducted from July 2019 to August 2019 among drug-resistant tuberculosis (DR-TB) patients belonging to the Saharia tribe in these districts. The patients who were under treatment for DR-TB in the recent past, or who were under medication at the time of the survey were enrolled. As there is no well-established guideline for estimation of sample size as a priori for qualitative study and the study population is also very homogeneous i.e., MDR/XDR TB patients of Saharia tribe, we used the principle of saturation and repetition of information to decide the numbers of patients to be included in the study. In total sixteen participants who were on anti-TB treatment or in the recent past and available at home at the time of field visits and gave written consent were selected through purposive sampling techniques irrespective of treatment duration. All patients were interviewed by a senior researcher having postgraduate degree in Public Health and experience of working in tribal communities. These interview were carried out during her routine field monitoring visits. The researcher is familiar with local dialact of Saharia tribe, however researcher doesn't belong to the tribal community. Data from participants were acquired through pre-set of specific questions to get an insight into their socio-demographic details and living conditions. A pre-designed open-ended in-depth interview guide was drafted in consultation with subject experts, clinician and DOTS providers. The Guideline consisted 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 past/family history of TB.

Audio-recording of the in-depth interviews was recorded simultaneously with prior permission from all the participants. All audio recordings of participants were transcribed in Hindi language and then translated into English for data analysis. Transcripts were coded, entered manually, and analysed to generate themes. The extracted codes were further divided into various categories manually. We used an analysis system based on the literature review and preliminary analysis 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.

Ethics:

The present research is a part of an ongoing study that has been approved by the Institutional Ethics Committee (IEC) at ICMR NIRTH (NIRTH/IEC/2273/2016). The study objectives were explained to all participants and written consent for their participation and audio-recording were obtained.

Patient and Public Involvement

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

Results:

Interviewed participants comprised five extensively-drug resistant (XDR) and eleven multi-drug-resistant (MDR) cases. The participants ranging from 18 years to 65 years of age were interviewed using a pre-designed open-ended in-depth interview guide. Out of 16 patients, there were only two females as the majority of the DR-TB patients were males. 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 same 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 drug-resistant patient has to undergo from diagnosis to treatment and are summarized in Figure 1**.** The narratives of patients were broadly divided into six themes wherein, each theme is further underneath into two sub-themes – pre-treatment and during treatment. Six themes and sub-themes are presented in table 3, and important individual narratives are presented in table 4.

Pre- Treatment Phase

Perception about disease

Lack of education in the patients and their family lead to several misbeliefs and misconceptions about the disease. A participant (P5) narrated his belief for the disease as *"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…".* 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 traumatizing 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 disease; it is a very shocking and traumatizing experience for him. A participant (P5) shared how difficult it was for him to believe that he is suffering with 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 ke neechai 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 drug-resistant cases. It is seen that 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 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 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 labours, construction workers, or farming-related works. 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 labours working with them, and thus the chances of getting infection and infecting others increases. 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; every time he was getting temporarily relief after taking medicines. Further, due to poor access to the health-care 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 misbelieves 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 case of DR-TB patients. 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 stigmatization. Many patients also reported a high pill burden - taking 9 to 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 practice their livelohood and support their family. Majority of patients are daily wage labours

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 even 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, 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 health care facility

Patients reported that they did not get medicine from the health facility/drug provider for continuing their treatment. Lack of access to the health care facility, long-distances, and long durations to reach health care facility made it difficult for the patients avail proper treatment. Patients are required to go to the DR-TB center for initiating XDR treatment which is around 120 to 240 kms from the 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 center. 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 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 facility 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 district hospital. As one patient (P5) reported that "*The facility here (district hospital) is better than DR-TB centre at Gwalior, 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". – P5

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 that "*After taking medication there is a lot of improvement. Now I don't have body ache 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 years 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 globally [1] 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 tuberculosis.[10,11] The drug-resistant tuberculosis is also emerging as a serious health problem in this tribe.[7] The present qualitative study tries to understand issues related to high TB burden and challenges in adherence to treatment in Saharia tribal community.

The current study was conducted among 16 drug-resistant TB cases of the Saharia tribal community. Although the National TB Elimination Programme (NTEP; formerly Revised National Tuberculosis Control Programme - RNTCP) has been operational for more than 15 years along with programmatic management of drug-resistant TB (PMDT) from 2013 in this area, the findings of the study suggest that more concerted efforts are required especially at grass-root level. The study highlights several challenges faced by DR-TB patients 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 tuberculosis. The studies conducted in different settings also highlighted the "catastrophic" costs associated with TB and DR-TB treatment despite the provision of free treatment.[12,13]

Furin et al. in a study conducted in South Africa reported a significant economic burden on Rifampicin-Resistant Tuberculosis patients and households due to the loss of income and the expenses for transportation.[14] In India, although all notified TB patients are entitled to cash transfer of Indian Rupees (INR) 500 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 installment within two months of treatment initiation.[15] The delays in access to such grants are also reported by other workers.[12] The economic support during the first few months of treatment is crucial and if linked with counseling, it improves treatment adherence and the chance of cure.[16] The timely payment under DBT / economic support during the first few months of treatment with counseling shall go a long way in improving treatment compliance in drug-resistant TB patients in this marginalised community.

The majority of DR-TB patients noted adverse effects to TB treatment. This is an important factor for treatment adherence, as has been mentioned by other authors.[14,17,18] 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.[14,19,20] This highlights the importance of continuous counseling of the patients and their family members so that in the course of adverse effects the patient does not leave the treatment mid-way.

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.[19,21,22] 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 tuberculosis are reported by other authors.[22-25] The whole process of diagnosis and treatment of DR-TB is very tiring and traumatizing for the individuals, one has to undergo various phases comprising of physical fatigue and mental tiredness. Fighting with the disease condition and overcoming anxiety and fear poses the biggest challenge in patients' life. Most of the patients have seen their kith-and-kins succumbing to TB, resulting in shattering of their

confidence with constant fear of the death. Fear and denial of diagnosis as noted in the present study are also found in other studies.[22,25,26]

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.[21-23] The belief in traditional healers for common ailments is also deep-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's 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 V et al (2016) mentioned the impact of disease in a patient's family and caretakers' lives, as family is one of the main sources of support during patients' treatment and recovery.[27] This highlights the need for involving the community in TB control activities as the disease impacts all the individuals associated with the patient.

We could hardly find any kind of stigmatization in the present study, as most of the participants (15 out of 16) never faced any stigmatization. This indicates social acceptance of TB patients in the community. However, patients noted that they choose to refrain from society and avoid social gatherings like marriages, religious functions, community meetings, etc. due to their physical weakness. The social acceptance of TB patients is encouraging and assumes importance as the TB burden is very high in this tribal community. Many studies have reported strong influence of stigma resulting in non-adherence to treatment as they become demoralized due to weak family support.[20-22] Due to guilt and fear of getting isolated in the family and the community, patients may also hide their disease.[21,25,26] 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 these belong to the same community. A study in Ethiopia also reported a positive attitude of patients towards treatment.[28]

Our study has identified several problems faced by DR-TB patients 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 health care facilities and infrastructure. This emphasizes the importance of social factors that could affect individuals' ability to seek health care and adhere to a course of treatment.[29,30] The long distance of the health-care center and lack of infra-structure increases patient's struggle to reach the facility in time, especially due to their occupation or other socio-cultural obligations. [31,32] The long-term outcomes in DR-TB patients especially in XDR patients are usually poor thus putting close-contacts and the community at risk of getting the infection.[33,34] Thus, the threat of spreading the infection with drug-resistant strains is one of the major challenges particularly in disadvantaged populations as in the present study. To address these factors, a systematic multi-pronged approach would be required with a specific focus on 'patient-centered care' for DR-TB patients as has been found useful in other studies.[14,30]

Few methodological limitations need to be discussed. Firstly, the sample was purposive and may not entirely represent the experiences and needs of MDR/XDR TB patients in this community. Secondly, 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 minimize the recall bias through interviewers training in probing during interviews to facilitate precise replies. Though the findings of the study may not be generalized universally, these are relatable to any remote area and poverty-driven individual and can be generalized 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 the DR-TB patients belonging to the Saharia tribe and is useful in devising strategies to improve treatment adherence in the tribal community. In tribal-dominated areas, health facilities need to be cohesive to the social and cultural beliefs of local populations. So that they should not hesitate to approach these facilities for their diagnosis and treatment needs. Periodic counseling of patients is a must for proper treatment adherence and to gain their confidence in the treatment and medication. The TB disease particularly drug-resistant 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 emphasizes the need for 'patient-centered care' wherein patients needs are to be comprehended and prioritized.

Contributorship statement

SN, RKS, JB designed the study, SN, PM, ML did data collection, SN, RKS, RY carried out the analysis, SN, VGR, RKS, and JB wrote the manuscript. All the authors read and edited the manuscript.

Acknowledgment

The authors would like to extend their gratitude towards the Director, ICMR-NIRTH, Jabalpur for the support in the study and also to all the participants who have given their time for the interview and believed in us for giving proper response. Last but not the least, thanks are due to all the district coordinators and field staff for their constant support.

Funding

It is a sub-study under the ongoing study on Intensified TB Control Project among the Saharia tribe, a PVTG in Madhya Pradesh. The main study is funded by the Government of Madhya Pradesh.

Competing interests

None declared

Availability of data and materials

Data supporting our findings are available with the investigators.

Table 1: Summary of XDR/MDR patients interviewed

Sr. No.	Age	Sex	MDR/XDR	Education	Family Type	History of TB Patient 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

Table 2: Social-demographic characteristics of participants

Characteristics	Category	N	Percent
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
ype of House	Kutcha	9	56.2
	Semi – Pucca	5	31.5
	Pucca	2	12.5
No. of rooms in the house	One	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

Table 3: Representation of themes

Themes	Sub-themes	
	Pre- treatment 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 emotionally, physically, or financially.	
Physical Challenges	• Physical symptoms discomfit normal activities of daily life. • Like household works or even taking care of personal chores.	• 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	• Healthcare facilities are difficult to reach because of distance. • The attitude of health facility personnel. • No proper channel or awareness about the facility.	• The facilities at DR-TB centres are not sufficient and the distance that one has to travel to reach the centre is about 120 to 240 kms • The facilities like stay and food in the hospital ward are not proper. • The number of days to be admitted in a hospital for treatment initiation is also more (15 days).
Economic Challenges	• Loss of income as no work due to poor physical health.	• Till the time patient gets DBT money for treatment only, one has to pay the large amount out of his/her pocket for traveling, food, and daily necessities.
Emotional and psychological Challenges	• Due to physical ill health, he/she is dependent on others for the daily necessities, emotional state is devastated.	• Once a patient gets information about his tuberculosis disease particularly DR status, the hope of living just vanish as they consider it to be a fatal disease with no cure.
Social Challenges	• Lack of involvement in social gatherings due to poor health conditions.	• Stigmatisation is not reported by the participants but they avoid social gatherings due to their poor health condition.

Table 4: Illustrative quotations of the study participants

Pre – Treatment 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 neechai se zameen fisal gayi ho jaise) – P5* - *One year back I went to Gwalior, there 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 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 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 same plot, he suffered from TB and was taking medicine at that time, I have a doubt may be from him I got this infection.– P5* - *For about a year I was on private treatment. I used to get fever and cough and doctor gave me some medicine for these, After getting temporary relief I used to stop taking those medicines, then my health condition use to become the same as before.- P4* - *I went to Kasba in Rajasthan state, earlier I got a herb (jadibooti) there 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 - *I feel severe nausea and anxiety while taking these medicines, there are 12 tablets that 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 use 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 in 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 own 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 me 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 health care 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* - *The Patient's wife also said, "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 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). - 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 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 at Gwalior),, here everyone listens to us and provide 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 doctor. They keep patients at distance. In DR-TB centre they (health staff) hate patients. But in 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 like 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 whole night because of which I was not able to sleep in nights. - P1*

Figure 1:Thematic Representation:

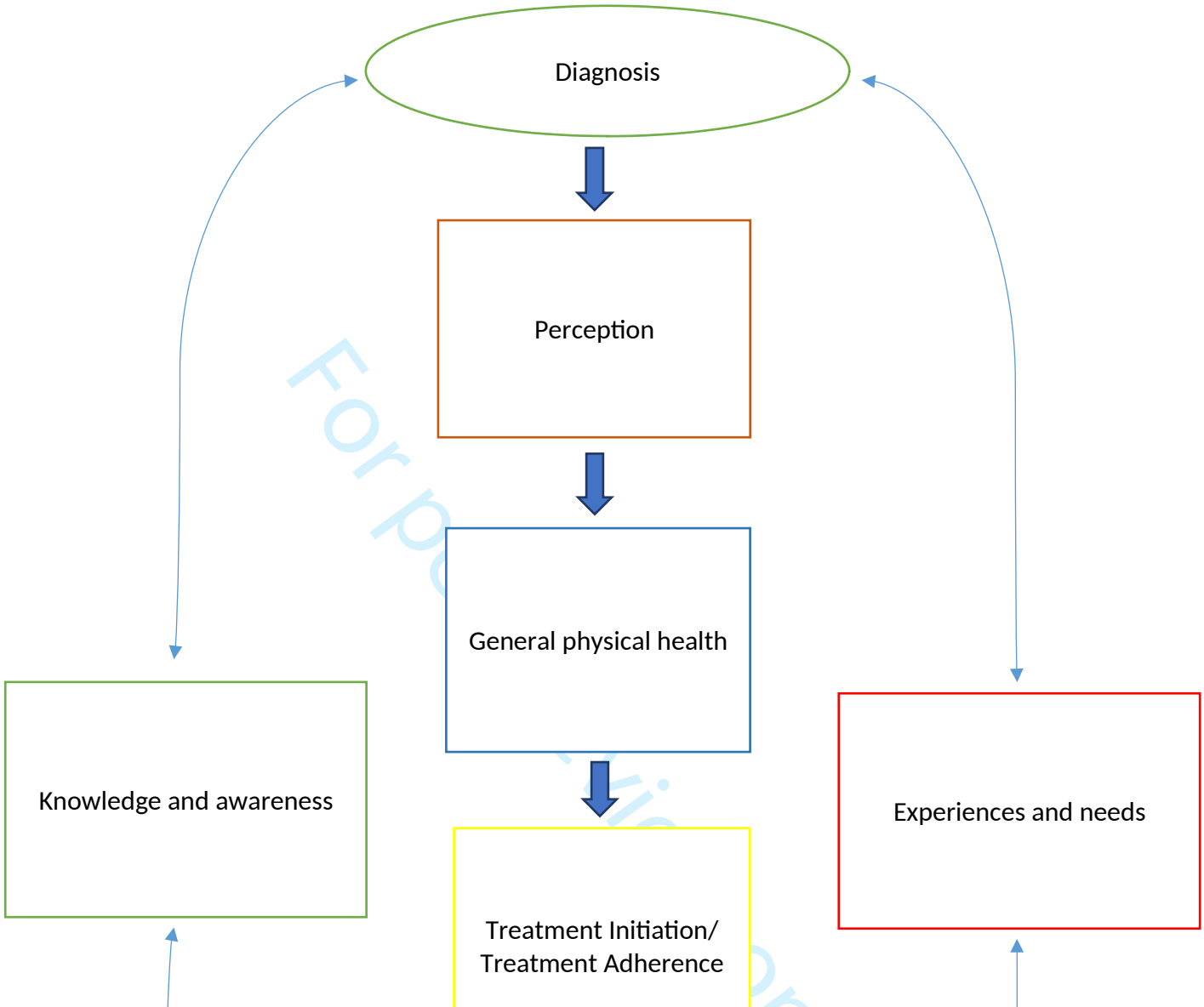
References:

1. World Health Organisation. Global Tuberculosis Report 2019. World Health Organisation, 2019. https://www.who.int/tb/publications/global_report/en/
2. World Health Organisation. The end TB strategy. World Health Organization, 2015. https://www.who.int/tb/strategy/End_TB_Strategy.pdf
3. World Health Organization. Drug-resistant TB: surveillance and response: supplement to global tuberculosis report 2014. World Health Organization, 2014. https://apps.who.int/iris/handle/10665/137095
4. Government of India. Annual Report 2017-18. Ministry of tribal affairs, Government of India 2018. https://tribal.nic.in/writereaddata/AnnualReport/AR2017-18.pdf
5. Rao VG, Gopi PG, Bhat J, *et al*. Pulmonary tuberculosis: a public health problem amongst the *Saharia*, a primitive tribe of Madhya Pradesh, central India. *Int J Infect Dis* 2010;14:e713–6.
6. Rao VG, Gopi PG, Yadav R, *et al*. Tuberculous infection in *Saharia*, a primitive tribal community of Central India. *Trans R Soc Trop Med Hyg* 2008;102:898–904.
7. Prakash R, Kumar D, Gupta VK, *et al*. Status of multidrug resistant tuberculosis (MDR-TB) among the Sahariya tribe of North Central India. *J Infect Public Health* 2016; 9: 289—297.
8. Jyothi Bhat, V. G. Rao, R. K. Sharma, M. Muniyandi, Rajiv Yadav & M K. Bhondley Investigation of the risk factors for pulmonary tuberculosis: A case– control study among *Saharia* tribe in Gwalior district, Madhya Pradesh, India. Indian J Med Res 146, July 2017, pp 97-104
9. Rao VG, Gopi PG, Bhat J, *et al*. Selected risk factors associated with pulmonary tuberculosis among Saharia tribe of Madhya Pradesh, central India. *Eur J Public Health* 2012; 22(2):271-3.
10. Rao VG, Bhat J, Yadav, R, *et al*. Pulmonary tuberculosis – a health problem amongst Saharia tribe in Madhya Pradesh. *Indian J Med Res* 2015; 141(5): 630-35.
11. Chakma T, Rao PV, Pall S, *et al*. Survey of pulmonary tuberculosis in a primitive tribe of Madhya Pradesh. *Indian J Tubec* 1996; 43: 85-9.
12. Ramma L, Cox H, Wilkinson L, *et al*. Patients' costs associated with seeking and accessing treatment for drug-resistant tuberculosis in South Africa. *Int J Tuberc Lung Dis* 2015;19(12):1513–19.

13. Foster N, Vassall A, Cleary S, *et al*. The economic burden of TB diagnosis and treatment in South Africa. *Soc Sci Med* 2015;130C:42–50.
14. Furin J, Loveday M, Hlangu S, *et al*. "A very humiliating illness": a qualitative study of patient-centered Care for Rifampicin – Resistant Tuberculosis in South Africa". *BMC Public Health* 2020;20:76 (https://doi.org/10.1186/s12889-019-8035-z).
15. Patel BH, Jeyashree K, Chinnakali P, *et al*. Cash transfer scheme for people with tuberculosis treated by the National TB Programme in Western India: a mixed methods study. *BMJ Open* 2019; 9(12): e033158. Published online 2019 Dec 29. doi: 10.1136/bmjopen-2019-033158.
16. Baral S, Aryal Y, Bhattrai R, *et al*. The importance of providing counselling and financial support to patients receiving treatment for multidrug-resistant tuberculosis: mixed method qualitative and pilot interventional study. *BMC Public Health* 2014;14:46.
17. Deshmukh RD, Dhande DJ, Sachdeva KS, *et al*. Patient and Provider Reported Reasons for Lost to Follow Up in MDR-TB Treatment: A Qualitative Study from a Drug Resistant TB Centre in India. *PLoS One* 2015;24:10(8);e0135802. doi: 10.1371/journal.pone.0135802. eCollection 2015.
18. Parmar MM, Sachdeva KS, Dewan PK, *et al*. Unacceptable treatment outcomes and associated factors among India's initial cohorts of multidrug-resistant tuberculosis (MDR-TB) patients under the revised national TB control programme (2007-2011): Evidence leading to policy enhancement. *PLoS One* 2018;11:13(4):e0193903. doi: 10.1371/journal.pone.0193903. eCollection 2018.
19. Jaiswal A, Singh V, Ogden JA, *et al*. Adherence to tuberculosis treatment: Lessons from the urban setting of Delhi, India. *Trop Med Int Health* 2003;8: 625–33.
20. Shringarpure KS, Isaakidis P, Sagili KD, *et al*. "When Treatment Is More Challenging than the Disease": A Qualitative Study of MDR-TB Patient Retention. *PLoS One* 2016; 9;11(3):e0150849. doi: 10.1371/journal.pone.0150849. eCollection 2016.
21. Harper M, Ahmadu FA, Ogden JA, *et al*. Identifying the determinants of tuberculosis control in resource-poor countries: Insights from a qualitative study in The Gambia. *Trans R Soc Trop Med Hyg* 2003;97: 506–10.
22. Khan A, Walley J, Newell J, *et al*. Tuberculosis in Pakistan: Socio-cultural constraints and opportunities in treatment. *Soc Sci Med* 2000;50: 247–54.

23. Greene JA. An ethnography of non-adherence: Culture, poverty, and tuberculosis in urban Bolivia. *Cult Med Psychiatry* 2004;28: 401–25.
24. Liefooghe R, Michiels N, Habib S, *et al*. Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan. *Soc Sci Med* 1995;41: 1685–92.
25. Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through ‘‘TB clubs’’ in rural north Ethiopia. *Soc Sci Med* 2003;56: 2009–18.
26. Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: Lessons learned from Vietnam. *Qual Health Res* 2002;12: 473–91.
27. Yellappa V, Lefèvre P, Battaglioli T, *et al*. Coping with tuberculosis and directly observed treatment: a qualitative study among patients from South India. *BMC Health Serv Res* 2016;19;16:283. doi: 10.1186/s12913-016-1545-9.
28. Tulloch O, Theobald S, Morishita F, *et al*. Patient and community experiences of tuberculosis diagnosis and care within a community-based intervention in Ethiopia: a qualitative study. *BMC Public Health* 2015;25;15:187. doi: 10.1186/s12889-015-1523-x.
29. Nathanson E, Lambregts-van Weezenbeek C, Rich ML, *et al*. Multidrug-resistant tuberculosis management in resource-limited settings. *Emerg Infect Dis* 2006;12(9):1389-97. doi: 10.3201/eid1209.051618.
30. Horter S, Stringer B, Reynolds L, *et al*. "Home is where the patient is": a qualitative analysis of a patient-centred model of care for multi-drug resistant tuberculosis. *BMC Health Serv Res* 2014;21;14:81. doi: 10.1186/1472-6963-14-81.
31. Hargreaves JR, Boccia D, Evans CA, *et al*. The social determinants of tuberculosis: from evidence to action. *Am J Public Health* 2011;101(4):654–62.
32. Lewis CP, Newell JN. Improving tuberculosis care in low income countries - a qualitative study of patients’ understanding of “patient support” in Nepal. *BMC Public Health* 2009;9:190.
33. O'Donnell MR, Jarand J, Loveday M, *et al*. High incidence of hospital admissions with multidrug-resistant and extensively drug-resistant tuberculosis among South African health care workers. *Ann Intern Med* 2010;19;153(8):516-22. doi: 10.7326/0003-4819-153-8-201010190-00008.
34. Pietersen E, Ignatius E, Streicher EM, *et al*. Long-term out- comes of patients with extensively drug-resistant tuberculosis in South Africa: a cohort study. *Lancet* 2014 5;383(9924):1230-9. doi: 10.1016/S0140-6736(13)62675-6. Epub 2014 Jan 17.

Figure 1:Thematic Representation:



Manuscript title: Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine, 89(9)*, 1245-1251.

No. Topic	Item
Title and abstract	
S1 Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended. **Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India** **Page 1**
S2 Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions **Abstract** **Page 2**
Introduction	
S3 Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement **Introduction Section** **Page 4 Line nos. 23-34**
S4 Purpose or research question	Purpose of the study and specific objectives or questions **Page 5** **Line nos. 1-3**
Methods	
S5 Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/ interpretivist) is also recommended **Methods section**

	Page 5, Line Nos. 13-15
S6 Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability. **Page 5, Line Nos. 23-34**
S7 Context	Setting/site and salient contextual factors; rationale[a] **Page 6, Line Nos. 1-8**
S8 Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[a] **Page 5, Line Nos. 23-34**
S9 Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues **Page 6, Line Nos. 11-14**
S10 Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[a] **Page 5, Line Nos. 13-15** **Page 5, Line Nos. 27-34** **Page 6, Line Nos. 1-3**
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study **Page 5, Line Nos. 27-34** **Page 6, Line Nos. 1-2**
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) **Page 6, Line Nos. 22-32**
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts **Page 6, Line Nos. 2-5**
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale[a] **Page 6, Line Nos. 2-8**
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[a] **Page 6, Line Nos. 2-8**
Results/Findings	
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory

	Pages 6-10
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings **Pages 7-10 & table 4**
Discussion	
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field **Page 10, line nos. 25 to page 12 line no. 8**
S19 Limitations	Trustworthiness and limitations of findings **Page 13, line nos. 5-7; 14-19**
Other	
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed **Page 14, line nos. 22-23**
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting **Page 14, line nos. 17-20**

[a]The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

BMJ Open

Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-044698.R2
Article Type:	Original research
Date Submitted by the Author:	17-Jun-2021
Complete List of Authors:	Nigam, Samridhi; ICMR-National Institute of Research in Tribal Health, Microbiology Sharma, Ravendra; National Institute of Medical Statistics Yadav, Rajiv; ICMR-National Institute of Research in Tribal Health, Microbiology Rao, Vikas; ICMR-National Institute of Research in Tribal Health, Community Medicine Mishra, Prashant; ICMR-National Institute of Research in Tribal Health, Microbiology Lingala, Mercy; ICMR-National Institute of Research in Tribal Health, Microbiology Bhat, Jyothi; ICMR-National Institute of Research in Tribal Health, Microbiology
Primary Subject Heading:	Infectious diseases
Secondary Subject Heading:	Qualitative research
Keywords:	Tuberculosis < INFECTIOUS DISEASES, PUBLIC HEALTH, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Samridhi Nigam[1], Ravendra K Sharma[2], Rajiv Yadav[1], VG Rao[1], Prashant Mishra[1], Mercy Aparna. Lingala[1] and Jyothi Bhat[1*],

1. ICMR-National Institute of Research in Tribal Health, Jabalpur

2. ICMR- National Institute of Medical Statistics, New Delhi

Corresponding author:

Dr. Jyothi Bhat, M.D.

ICMR-National Institute of Research in Tribal Health

Nagpur Road

P.O. Garha

Jabalpur 482003

Phone: +91 761 2370800

Email: drjyothibhat@rediffmail.com

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 drug-resistant tuberculosis patients of the Saharia tribe residing in Madhya Pradesh state of Central India to document their experiences, needs and to identify gaps for treatment adherence as it is known to be poor in this population because of migration and other factors.

Methods

We conducted sixteen in-depth interviews on purposively selected drug-resistant TB patients among the Saharia tribe using a pre-designed 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 sub-themes were extracted. The obtained qualitative data were subjected to thematic analysis.

Results

The study helped to understand the experiences and needs of the DR-TB patients in various stages from diagnosis to treatment. Also, the impact of factors like lack of education and awareness, poor living conditions, lack of healthcare facilities on pre-dominance 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 being it with diagnosis, treatment initiation, or treatment adherence.

Conclusion

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

Keyword

Tuberculosis, Drug resistant TB, MDR, XDR, Tribe, Saharia, India

Article Summary:

Strengths:

- The present study is a novel one exploring the needs and experiences of MDR/XDR TB patients belonging to the Saharia tribe in central India. This becomes particularly relevant since this population group falls in the Particularly Vulnerable Tribal Group (PVTG) 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, verbatims which would rather be impossible to be captured through a quantitative study

Limitations

- The sample was purposive and may not entirely represent the experiences and needs of MDR/XDR TB patients in this community.
- Though it is advisable to follow people prospectively, the DR-TB patients were interviewed for their perceptions and experiences about TB and the available treatment services retrospectively which may result in recall bias.

Introduction:

Tuberculosis (TB), caused by Mycobacterium tuberculosis, remains one of the top 10 causes of death worldwide. Globally, an estimated 10 million people fell ill with TB in the year 2018.[1] The burden of the disease varies enormously among countries, from fewer than five to more than 500 new cases per 100000 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, 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 or rifampicin-resistant TB (MDR/RR-TB).[1] Treatment success rate of DR-TB patients 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 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, 5, 6]

There are over 700 Scheduled Tribes (ST) notified in India, spread over different states and Union Territories of the country. The state of Madhya Pradesh accounts for 21.1% of the scheduled tribe 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 tuberculosis prevalence in the country ranging from 1270 to 3294 per 100000 population.[8-11]The Saharia tribe is among the most vulnerable population segments that suffer from poverty and unhygienic/ overcrowded living conditions. Most community members earn their livelihood as daily wage laborers or labour 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 amongst 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 DR-TB patients of Saharia tribe residing in Madhya Pradesh

state in central India to document their experiences, needs and to identify gaps for treatment adherence.

Methods:

Qualitative approach and research paradigm

The present qualitative research was conducted as a sub-study of the main ongoing 'Intensified TB control project (ITCP) 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 XDR/MDR tuberculosis in the particularly vulnerable tribal group. 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 August2019 among drug-resistant tuberculosis (DR-TB) patients belonging to this tribal group. As there is no well-established guideline for estimation of sample size as a prior for qualitative study and the study population is also very homogeneous that is MDR/XDR TB patients 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 sixteen 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 before the commencement of the interview from each participant

Data collection technique

All patients were interviewed by a senior researcher with having postgraduate degree in Public Health and 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 doesn't belong to the tribal community. Data from participants were acquired through pre-set of specific questions to get an insight into their socio-demographic details and living conditions.

Data Collection Tool

A pre-designed open-ended in-depth interview guide was drafted in consultation with subject experts, clinicians, and DOTS providers (available as supplementary 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 past/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 minutes 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. This included four main stages of familiarization, 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 verbatims. 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 a 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 w 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.

Ethics:

The present research is a part of an ongoing study that has been approved by the Institutional Ethics Committee (IEC) at ICMR NIRTH (approval reference number: NIRTH/IEC/2273/2016). The study objectives were explained to all participants and written informed consent for their participation and audio-recording were obtained.

Patient and Public Involvement

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

Results:

Interviewed participants comprised five extensively drug-resistant (XDR) and eleven multi-drug-resistant (MDR) cases. The participants ranging from 18 years to 65 years of age were interviewed using a pre-designed open-ended in-depth interview guide. Out of 16 patients, there were only two females as the majority of the DR-TB patients were males. 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 drug-resistant patient has to undergo from diagnosis to treatment and are summarized in Figure 1**.** The narratives of patients were broadly divided into six themes wherein, each theme is further underneath into two sub-themes – pre-treatment and during treatment. Six themes and sub-themes are presented in table 3, and important individual narratives are presented in table 4.

Pre-Treatment Phase

Perception about disease

Lack of education in the patients and their family lead 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 sukh kar 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 traumatizing 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 traumatizing experience for him. 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 drug-resistant 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 labours, construction workers, or farming-related works. 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 labours working with them, and thus the chances of getting an infection and infecting others increases. 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; 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 misbelieves 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 DR-TB patients. 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 stigmatization and family members took their care 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 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 to 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 practice their livelihood and support their families. The majority of patients are daily wage labours 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 even 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, 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 health care facility

Patients reported that they did not get medicine from the health facility/drug provider for continuing their treatment. Lack of access to the health care facility, long distances, and long durations to reach health care facility made it difficult for the patients to avail proper treatment. Patients are required to go to the DR-TB center for initiating XDR treatment which is around 120 to 240 km from the 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 center. 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 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 that "*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". – P5*

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 that "*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 years 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 globally [1]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 tuberculosis.[13,14]Drug-resistant tuberculosis 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 drug-resistant TB cases of the Saharia tribal community. Although the National TB Elimination Programme (NTEP; formerly Revised National Tuberculosis Control Programme -RNTCP) has been operational for more than 15 years along with programmatic management of drug-resistant TB (PMDT) from 2013 in this area, the findings of the study suggest that more concerted efforts are required especially at grass-root level. The study highlights several challenges faced by DR-TB patients 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 tuberculosis. 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 Rifampicin-Resistant Tuberculosis patients and households due to the loss of income and the expenses for transportation.[17]In India, although all notified TB patients are entitled to cash transfer of Indian Rupees (INR) 500 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 two 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 drug-resistant TB patients in this marginalised community.

The majority of DR-TB patients 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 counseling of the patients and their family members so that in the course of adverse effects the patient does not leave the treatment mid-way.

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 tuberculosis are reported by other authors.[23-26] The whole process of diagnosis and treatment of DR-TB is very tiring and traumatizing for the individuals, one has to undergo various phases comprising of physical fatigue and mental tiredness. Fighting with the disease condition and overcoming anxiety and fear poses the biggest challenge in patients' life. Most of the patients have seen their kith-and-kins 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 deep-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's 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 V et al (2016) mentioned the impact of disease in 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.

The most of the participants in the study reported that they never experienced any kind of stigma or discrimination by family members or their community. This is in contrast to the findings of other studies carried out among drug-resistant patients in India[5,21,24,] and abroad [28-34,]. This indicates social acceptance of TB patients in the community. However, patients noted that they choose to refrain from society and avoid social gatherings like marriages, religious functions, community meetings, etc. due to their physical weakness. The social acceptance of TB patients 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 demoralized 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 these 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 DR-TB patients 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 health care facilities and infrastructure. This emphasizes the importance of social factors that could affect individuals' ability to seek health care and adhere to a course of treatment.[30,31]The long-distance of the healthcare center and lack of infra-structure increases patient's struggle to reach the facility in time, especially due to their occupation or

other socio-cultural obligations.[32,33]The long-term outcomes in DR-TB patients especially in XDR patients 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 drug-resistant strains is one of the major challenges particularly in disadvantaged populations as in the present study. To address these factors, a systematic multi-pronged approach would be required with a specific focus on 'patient-centered care' for DR-TB patients as has been found useful in other studies.[17,31]

Few methodological limitations need to be discussed. Firstly, the sample was purposive and may not entirely represent the experiences and needs of MDR/XDR TB patients in this community. Secondly, 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 minimize the recall bias through interviewers' training in probing during interviews to facilitate precise replies. Though the findings of the study may not be generalized universally, these are relatable to any remote area and poverty-driven individual and can be generalized 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 DR-TB patients 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. Periodic counseling of patients is a must for proper treatment adherence and to gain their confidence in the treatment and medication process. Drug-resistant 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 emphasizes the need for 'patient-centered care' wherein patients' needs are to be comprehended and prioritized.

Contributorship statement

SN, RKS, JB designed the study, SN, PM, ML did data collection, SN, RKS, RY carried out the analysis, SN, VGR, RKS, and JB wrote the manuscript. All the authors read and edited the manuscript.

Acknowledgment

The authors would like to extend their gratitude towards the Director, ICMR-NIRTH, Jabalpur for the support in the study and also to all the participants who have given their time for the interview and believed in us for giving proper response. Last but not the least, thanks are due to all the district coordinators and field staff for their constant support.

Funding

It is a sub-study under the ongoing study on Intensified TB Control Project among the Saharia tribe, a PVTG in Madhya Pradesh. The main study is funded by the Government of Madhya Pradesh.

Competing interests

None declared

Availability of data and materials

Data supporting our findings are available with the investigators.

Table 1: Summary of XDR/MDR patients interviewed :

Sr. No.	Age	Sex	MDR/XDR	Education	Family Type	History of TB Patient 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

Table 2: Social-demographic characteristics of participants:

Characteristics	Category	N	Percent
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	One	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

Table 3: Representation of themes:

Themes	Sub-themes	
	Pre-treatment 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 emotionally, physically, or financially.	
Physical Challenges	• Physical symptoms discomfit normal activities of daily life. • Like household works or even taking care of personal chores.	• 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	• Healthcare facilities are difficult to reach because of distance. • The attitude of health facility personnel. • No proper channel or awareness about the facility.	• The facilities at DR-TB centres are not sufficient and the distance that one has to travel to reach the centre is about 120 to 240 km • The facilities like stay and food in the hospital ward are not proper. • The number of days to be admitted in a hospital for treatment initiation is also more (15 days).
Economic Challenges	• Loss of income as no work due to poor physical health.	• Till the time patient gets DBT money for treatment only, one has to pay the large amount out of his/her pocket for traveling, food, and daily necessities.
Emotional and psychological Challenges	• Due to physical ill health, he/she is dependent on others for the daily necessities, emotional state is devastated.	• Once a patient gets information about his tuberculosis disease particularly DR status, the hope of living just vanishes as they consider it to be a fatal disease with no cure.
Social Challenges	• Lack of involvement in social gatherings due to poor health conditions.	• Stigmatisation is not reported by the participants but they avoid social gatherings due to their poor health condition.

Table 4: Illustrative quotations of the study participants:

Pre–Treatment 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 neechai 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 use 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 - *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 use 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 withanything 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 myand 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 health care 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* - *The Patient's wife also said, "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 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). - 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 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 atnight. - P1*

Figure 1: Thematic Representation:

References:

1. World Health Organisation. Global Tuberculosis Report 2019. World Health Organisation, 2019.https://www.who.int/tb/publications/global_report/en/
2. World Health Organisation. The end TB strategy. World Health Organization, 2015. https://www.who.int/tb/strategy/End_TB_Strategy.pdf
3. World Health Organization. Drug-resistant TB: surveillance and response: supplement to global tuberculosis report 2014. World Health Organization, 2014. https://apps.who.int/iris/handle/10665/137095
4. Prakash R, Kumar D, Gupta VK, et al. Status of multidrug resistant tuberculosis (MDR-TB) among the Sahariya tribe of North Central India. J Infect Public Health 2016; 9: 289—297.
5. Deshmukh RD, Dhande DJ, Sachdeva KS, et al. Patient and Provider Reported Reasons for Lost to Follow Up in MDR-TB Treatment: A Qualitative Study from a Drug Resistant TB Centre in India. PLoS One 2015; 24:10(8); e0135802. doi: 10.1371/journal.pone.0135802. eCollection 2015
6. Parmar MM, Sachdeva KS, Dewan PK, et al. Unacceptable treatment outcomes and associated factors among India's initial cohorts of multidrug-resistant tuberculosis (MDR-TB) patients under the revised national TB control programme (2007-2011): Evidence leading to policy enhancement. PLoS One 2018; 11:13(4): e0193903. doi: 10.1371/journal.pone.0193903. eCollection 2018.
7. Government of India. Annual Report 2017-18. Ministry of tribal affairs, Government of India 2018. https://tribal.nic.in/writereaddata/AnnualReport/AR2017-18.pdf
8. Rao VG, Gopi PG, Bhat J, et al. Pulmonary tuberculosis: a public health problem amongst the Saharia, a primitive tribe of Madhya Pradesh, central India. Int J Infect Dis 2010;14:e713–6.
9. Rao VG, Gopi PG, Yadav R, et al. Tuberculous infection in Saharia, a primitive tribal community of Central India. Trans R Soc Trop Med Hyg 2008; 102:898–904.
10. Jyothi Bhat, V. G. Rao, R. K. Sharma, M. Muniyandi, Rajiv Yadav & M K. Bhondley Investigation of the risk factors for pulmonary tuberculosis: A case– -control study among Saharia tribe in Gwalior district, Madhya Pradesh, India. Indian J Med Res 146, July 2017, pp 97-104

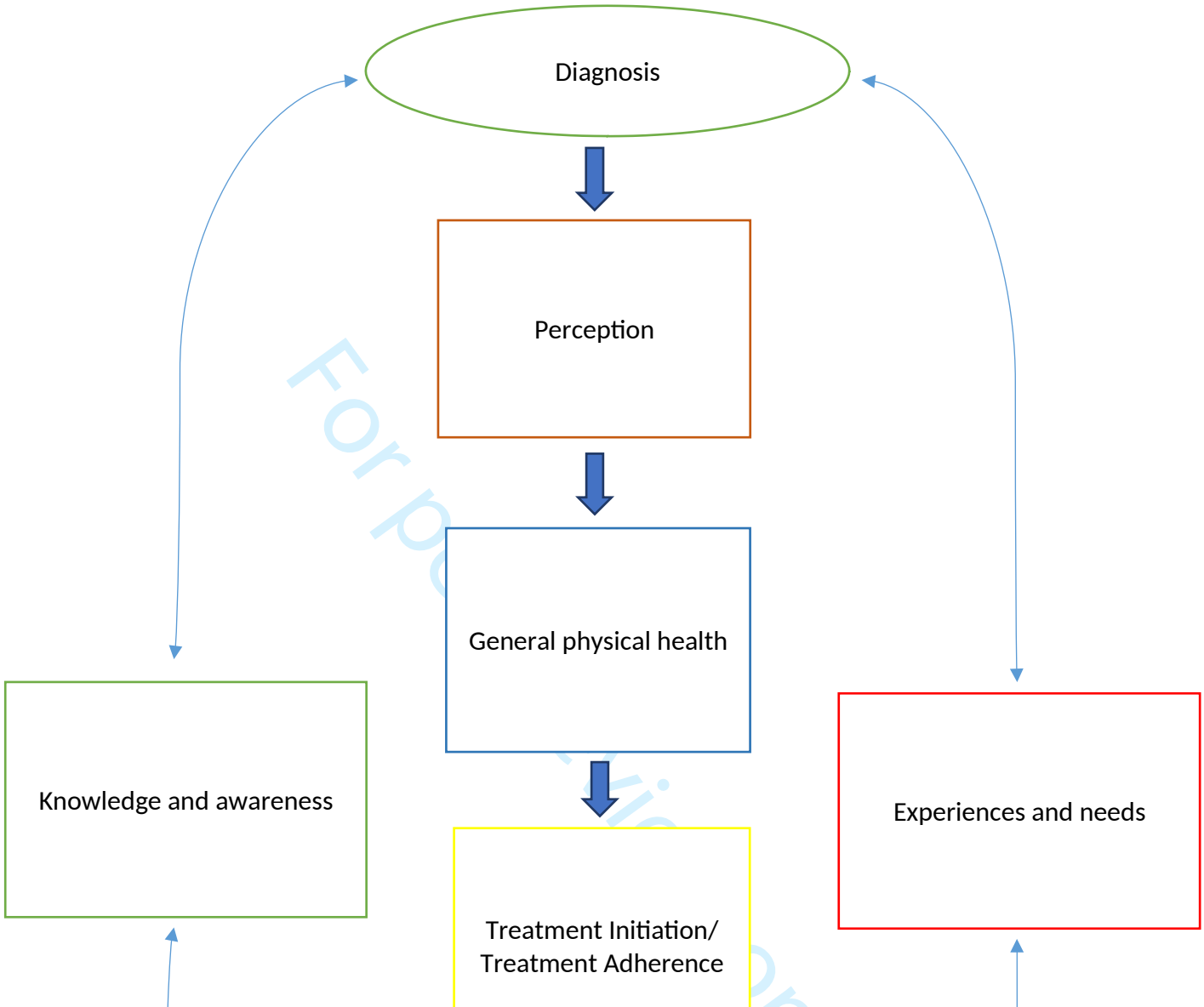
11. Rao VG, Gopi PG, Bhat J, et al. Selected risk factors associated with pulmonary tuberculosis among Saharia tribe of Madhya Pradesh, central India. Eur J Public Health 2012; 22(2):271-3.
12. Sharma RK, Rao VG, Yadav R, Mishra P, Lingala MAL, Nigam S, Bhat J. Comparative yield of pulmonary tuberculosis different symptoms among Saharia tribe of Madhya Pradesh, India. Indian J community Med. (In press)
13. Rao VG, Bhat J, Yadav, R, et al. Pulmonary tuberculosis – a health problem amongst Saharia tribe in Madhya Pradesh. Indian J Med Res 2015; 141(5): 630-35.
14. Chakma T, Rao PV, Pall S, et al. Survey of pulmonary tuberculosis in a primitive tribe of Madhya Pradesh. Indian J Tubec 1996; 43: 85-9.
15. Ramma L, Cox H, Wilkinson L, et al. Patients' costs associated with seeking and accessing treatment for drug-resistant tuberculosis in South Africa. Int J Tuberc Lung Dis 2015;19(12):1513–19.
16. Foster N, Vassall A, Cleary S, et al. The economic burden of TB diagnosis and treatment in South Africa. Soc Sci Med 2015;130C:42–50.
17. Furin J, Loveday M, Hlangu S, et al. "A very humiliating illness": a qualitative study of patient-centered Care for Rifampicin – Resistant Tuberculosis in South Africa". BMC Public Health 2020;20:76 (https://doi.org/10.1186/s12889-019-8035-z).
18. Patel BH, Jeyashree Jayashree K, Chinnakali P, et al. Cash transfer scheme for people with tuberculosis treated by the National TB Programme in Western India: a mixed methods study. BMJ Open 2019; 9(12): e033158. Published online 2019 Dec 29. doi: 10.1136/bmjopen-2019-033158.
19. Baral S, Aryal Y, Bhattrai R, et al. The importance of providing counselling and financial support to patients receiving treatment for multidrug-resistant tuberculosis: mixed method qualitative and pilot interventional study. BMC Public Health 2014;14:46.
20. Jaiswal A, Singh V, Ogden JA, et al. Adherence to tuberculosis treatment: Lessons from the urban setting of Delhi, India. Trop Med Int Health 2003;8: 625–33.
21. Shringarpure KS, Isaakidis P, Sagili KD, et al. "When Treatment Is More Challenging than the Disease": A Qualitative Study of MDR-TB Patient Retention. PLoS One 2016; 9;11(3):e0150849. doi: 10.1371/journal.pone.0150849. eCollection 2016.
22. Harper M, Ahmadu FA, Ogden JA, et al. Identifying the determinants of tuberculosis control in resource-poor countries: Insights from a qualitative study in The Gambia. Trans R Soc Trop Med Hyg 2003;97: 506–10.

23. Khan A, Walley J, Newell J, et al. Tuberculosis in Pakistan: Socio-cultural constraints and opportunities in treatment. Soc Sci Med 2000;50: 247–54.
24. Greene JA. An ethnography of non-adherence: Culture, poverty, and tuberculosis in urban Bolivia. Cult Med Psychiatry 2004;28: 401–25.
25. Liefooghe R, Michiels N, Habib S, et al. Perception and social consequences of tuberculosis: A focus group study of tuberculosis patients in Sialkot, Pakistan. Soc Sci Med 1995;41: 1685–92.
26. Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through ''TB clubs'' in rural north Ethiopia. Soc Sci Med 2003;56: 2009–18.
27. Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: Lessons learned from Vietnam. Qual Health Res 2002;12: 473–91.
28. Yellappa V, Lefèvre P, Battaglioli T, et al. Coping with tuberculosis and directly observed treatment: a qualitative study among patients from South India. BMC Health Serv Res 2016;19;16:283. doi: 10.1186/s12913-016-1545-9.
29. Tulloch O, Theobald S, Morishita F, et al. Patient and community experiences of tuberculosis diagnosis and care within a community-based intervention in Ethiopia: a qualitative study. BMC Public Health 2015;25;15:187. doi: 10.1186/s12889-015-1523-x.
30. Nathanson E, Lambregts-van Weezenbeek C, Rich ML, et al. Multidrug-resistant tuberculosis management in resource-limited settings. Emerg Infect Dis 2006;12(9):1389-97. doi: 10.3201/eid1209.051618.
31. Horter S, Stringer B, Reynolds L, et al. "Home is where the patient is": a qualitative analysis of a patient-centred model of care for multi-drug resistant tuberculosis. BMC Health Serv Res 2014;21;14:81. doi: 10.1186/1472-6963-14-81.
32. Hargreaves JR, Boccia D, Evans CA, et al. The social determinants of tuberculosis: from evidence to action. Am J Public Health 2011;101(4):654–62.
33. Lewis CP, Newell JN. Improving tuberculosis care in low income countries - a qualitative study of patients' understanding of "patient support" in Nepal. BMC Public Health 2009;9:190.
34. Craig GM, Daftary A, Engel N, O'Driscoll S, Ioannaki A. Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries. Int J Infect Dis. 2017 Mar;56:90-100.
35. O'Donell MR, Jarand J, Loveday M, et al. High incidence of hospital admissions with multidrug-resistant and extensively drug-resistant tuberculosis among South African

health care workers. Ann Intern Med 2010;19;153(8):516-22. doi: 10.7326/0003-4819-153-8-201010190-00008.

36. Pietersen E, Ignatius E, Streicher EM, et al. Long-term out- comes of patients with extensively drug-resistant tuberculosis in South Africa: a cohort study. Lancet 2014 5;383(9924):1230-9. doi: 10.1016/S0140-6736(13)62675-6. Epub 2014 Jan 17.

Figure 1:Thematic Representation:



ICMR-National Institute of Research in Tribal Health, Jabalpur

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 INFROMATION 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.

Manuscript title: Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India

Standards for Reporting Qualitative Research (SRQR)

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A., & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine, 89(9)*, 1245-1251.

No. Topic	Item
Title and abstract	
S1 Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended. **Experiences and needs of MDR/XDR TB patients: A Qualitative study among Saharia tribe in Madhya Pradesh, Central India** **Page 1**
S2 Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes objective, methods, results, and conclusions **Abstract** **Page 2**
Introduction	
S3 Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement **Introduction Section** **Page 4 Line nos. 23-34**
S4 Purpose or research question	Purpose of the study and specific objectives or questions **Page 5** **Line nos. 1-3**
Methods	
S5 Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., positivist, constructivist/ interpretivist) is also recommended **Methods section**

	Page 5, Line Nos. 13-15
S6 Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, or transferability. **Page 5, Line Nos. 23-34**
S7 Context	Setting/site and salient contextual factors; rationale[a] **Page 6, Line Nos. 1-8**
S8 Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[a] **Page 5, Line Nos. 23-34**
S9 Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues **Page 6, Line Nos. 11-14**
S10 Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[a] **Page 5, Line Nos. 13-15** **Page 5, Line Nos. 27-34** **Page 6, Line Nos. 1-3**
S11 Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study **Page 5, Line Nos. 27-34** **Page 6, Line Nos. 1-2**
S12 Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) **Page 6, Line Nos. 22-32**
S13 Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts **Page 6, Line Nos. 2-5**
S14 Data analysis	Process by which inferences, themes, etc., were identified and developed, including researchers involved in data analysis; usually references a specific paradigm or approach; rationale[a] **Page 6, Line Nos. 2-8**
S15 Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[a] **Page 6, Line Nos. 2-8**
Results/Findings	
S16 Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory

	Pages 6-10
S17 Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings **Pages 7-10 & table 4**
Discussion	
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field **Page 10, line nos. 25 to page 12 line no. 8**
S19 Limitations	Trustworthiness and limitations of findings **Page 13, line nos. 5-7; 14-19**
Other	
S20 Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed **Page 14, line nos. 22-23**
S21 Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting **Page 14, line nos. 17-20**

[a]The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.