

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 INFORMATION OF PARTICIPANT:

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

In-depth-Interview:

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

Opening question

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

Disease condition

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

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

Health care facility

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

Treatment and drugs:

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

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

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

Perception about TB

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

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

Financial burden

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

26. How you managed these expanses?

Social/ Psychological impact

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

28. Have you ever felt depressed?

Physical health

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

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

Lifestyle / behavior

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

Closing question

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

THANKS FOR YOUR PARTICIPATION IN THE STUDY.