

# Psychological profile of multi drug resistance TB patients: A qualitative study from a Tertiary care Centre of Kolkata

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## ABSTRACT

**Introduction:** There has been a new challenge to the already existing threat of tuberculosis (TB) and that is drug resistance TB (DR-TB). The causal relationships between mental disorders and TB are complicated and relatively unexplored. For this reason a qualitative study was done on DR-TB patients attending R G Kar Medical College. **Materials and Methods:** The study population consisted of the patients who are registered for the DR-TB regimen are followed up four times with General Health Questionnaire (GHQ). Those scoring poorly were sent for expert evaluation by psychologist, who counselled them, and followed them up after in-depth interviews. These records of in-depth interview were analysed as qualitative research inputs. **Results:** In our study out of 165 patients, (4.8%) needed interventions. The domains emerging from the study are worried about future and as well as family, disbelief about the diagnosis, embarrassment regarding the diagnosis, fear of death, blaming fate for the disease, stigma, suicidal ideation. **Conclusion:** This study finds out the important domains of psychological problems among the patients and also advocates a psychologist to remain at DR-TB centres.

**Keywords:** Fatalism, in depth interviews, stigma and discrimination, suicidal ideation

## Introduction

Even after 70 years of tuberculosis (TB) Control Programmes in India, it has still remained as a major public health threat in India. It is true that there have been improvements in many aspects, but along with that there have been new challenges poised at frequent intervals. Such a current challenge is the emergence of drug resistance TB (DR TB). This not only makes the treatment longer, costlier, less efficacious, and have adverse drugs reaction

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but also the treatment regime has a huge toll on the patient's life and the life of their caregivers.<sup>[1]</sup> Along with that there is risk of spread of disease to a person as primary DR-TB. Among the economic, social, and physical problems of such a situation, a looming problem is the mental problems which they have to face.

The causal relationships between mental disorders and tuberculosis are complicated. Many mental disorders are associated with high risk of tuberculosis contraction, transmission, and with poorer adherence to anti-TB treatment. Conversely, diagnosis with tuberculosis increases risk of mental disorders. Patients with TB have been reported with higher incidences of psychiatric morbidities before and after TB onset.<sup>[2]</sup> This not only leads to a poorer quality of life among

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these patients, but also it results in various other poor outcome measures like loss to follow-up, low treatment seeking, and also poor adherence to medications.<sup>[3]</sup> Studies report high prevalence rates of psychiatric comorbidity among patients with drug-resistant tuberculosis.<sup>[4]</sup> To add to this there are some drugs that treat DR-TB that are known to cause mental illness like cycloserine.

There has been a formation of a working group by Union namely TB and Mental Health Working Group<sup>[5]</sup> which is working to identify innovative ways of integrating TB and mental health care low-resource settings. As an innovative mode of qualitative research, they have made a film exploring Partners in Health (Socios En Salud) project in Peru that in 1996 began one of the first treatment programmes for individuals with drug-resistant TB in a low-resource setting. According to the World Health Organization in 1996, National Tuberculosis Programmes (MDR)-TB was 'untreatable' in these settings. But, among the first cohort of 75 patients, with TB strains resistant to a median of six drugs, 83% were cured. Integrated mental health care was pivotal for success of the programme. This experience highlights the factors that contribute to mental health issues for patients during treatment for MDR-TB, as well as the impact of providing mental health care on treatment outcomes.

Coming to evidences in India, Behera mentions in his study that,<sup>[6]</sup> persons affected by TB and their family members should be counselled at every opportunity, to address information gaps and to enable informed decision-making. In spite the sporadic evidences, mental health is yet to be linked to TB care or there has not been any serious effort of integrating mental health into TB control. National TB programmes currently do not address mental disorders as part of routine practice. Nevertheless, receptivity is high, which creates a ripe opportunity to integrate the management of TB and mental disorders into the policies and guidelines of National Tuberculosis Programmes (NTPs) worldwide.<sup>[7]</sup> Also, a systematic review mentions that data concerning factors affecting medication nonadherence among TB patients suggested that better management of comorbid conditions, especially depression, could improve the compliance rates.<sup>[4]</sup>

This may apparently seem that it is only pertaining to the specialist physicians, but this is of paramount importance to primary care physicians in two ways. Firstly, they have to identify the patients in primary care settings that the DR-TB patients are having psychological problems, as these patients are all treated in domiciliary manner after initial check-up. Also, the primary care physicians may be sensitised to the presence of mental health problems in other patients also, because many of these problems are not specific to DRTB patients but may be present in other patients too. The literature regarding the psychological profiles of DR-TB is rare in India, and more than that, comprehensive information has often lacked regarding psychological profile, as the matter requires information beyond the quantitative paradigm. The present study looked for various

psychological problems of DR-TB patients and suggested some recommendations coming from them. It also used a novel qualitative technique, as data regarding this was sparse and the domains were unknown.

## Methodology

The study population consisted of the patients who are registered for the Multi Drug Resistant/ Extensively Drug Resistant (MDR/XDR)-TB regimen are followed up four times, one at baseline, and then at 3 monthly interval. Those who are not giving consent for study and those people who have got diagnosed psychiatric illness at start of treatment were excluded from the study. The study population was enrolled for a period of 18 months (July 2016 -December, 2017) to follow-up for the intensive phase or extended intensive phase. Those patients already suffering from psychiatric illnesses were excluded from the study.

Data collection was done for three quarters. A baseline questionnaire was administered to all the patients diagnosed with DR-TB and admitted to the DR-TB ward of R G Kar Medical College for initiation of treatment of DR-TB therapy in the intensive phase. They were all from North 24 Parganas District. They were followed up at 3 months interval, some of them at R G Kar Medical College, the others at Barasat District Hospital, where trained interviewers screened them with General Health Questionnaire. Any score beyond 3 in GHQ<sup>[8]</sup> were sent to R G Kar Medical College Chest OPD where a trained psychological counsellor diagnosed them and did psychological interventions accordingly using a version of SCL-90.<sup>[9]</sup> A total of eight patients were included in the study. A total of five patients attended the counselling sessions as per requirement of the counsellor. One patient had a kanamycin-induced hearing loss thus was not able to be counselled. One patient died and another committed suicide. In total, 42 counselling sessions were done to the patients.

The counselling session included initial assessment by the psychologist determining the nature of problems. It was followed by psychological interventions that consisted of psychoeducation, supportive counselling, individual counselling, family counselling, and solutions focused therapeutic intervention. The psychologist also took an in depth interview of the patients with the help of a guide to reveal various issues of psychological domain. Notes were handwritten in notebooks after consent from the patient and interviews were done in an isolated room. The notes were then transcribed, and with immersive techniques it was coded to find out patterns emerging from the interviews. Thus, an in-depth Interview technique was used for the study, as there was paucity of existing medical literatures and the constructs were still ill defined.

All the processes were done after due clearance by Institutional Ethics Committee and Institutional Review Board. Before each interview, the participants were explained about the study, the

anonymity, confidentiality, and only after their consent were they included in the study.

## Results

In our study, there were eight patients included as requiring psychiatric intervention out of 165 patients who enrolled for receiving treatment in the said quarters. Thus, the prevalence of major psychiatric illness was 4.8%. Among these eight patients five deserves special mention as case studies.

Patient 1 (45 male) complained of aggressiveness, poor appetite, and isolating own self. The patient had a depressive state and also an aggressive nature towards the family. He felt worthless for his family and was unable to pursue his job (farmer). Supportive counselling, psychoeducation and family counselling were mainly performed for this particular patient.

After few months of counselling he became less aggressive and also started to involve himself into work and started socialising with other people. He started recovering, and stopped attending counselling sessions after 2 months before it has been terminated, due to his perceived wellness. But then the problems again triggered and he committed suicide.

Patient 2 (59 male) came with complains of disorientation, restlessness, violence and aggressiveness. The patient had main problem of disorientation with time, date, place and sometimes things. He was violent towards his wife and sometimes hit himself and also others. He did not want to stay in hospital as he thought that he will not live anymore.

He was started on orientation sessions by showing dates and things. Psychoeducation was done to help him of the self-blame and aggression towards his wife. Aggression control techniques were also used with him and his wife. He regularly attended counselling but unfortunately due to some medical condition (probably drug related ototoxicity) he lost his hearing and the session was discontinued. At the time of terminating sessions, he was in a better condition.

Patient 3 (37 female) complained of suicidal ideation, vomiting and insomnia. Psychoeducation and initial supportive counselling were done with her. She was also under psychiatric medication. After a few months she told that she was in a better condition and so she discontinued counselling sessions.

Patient 4 (45 female) complained of poor appetite and aggression. She was also seropositive for HIV. She attended only three sessions. Family counselling and psychoeducation were done. Patient was doing better after that.

Patient 5 (28 female) complained of speech decline, muscle weakness, isolation, suicidal ideations. At first the patient could not tell anything as she had a speech decline. After a few weeks she came for counselling. She also had a depressive state as her

husband left her. Family counselling could not be done because she did not have any family members with her. Supportive counselling and solution focused counselling were done. Previously, she felt worthless and helpless as she did not have any one with her. She also could not live with her daughter because of the medical condition. She attended regular counselling sessions and recovered gradually.

Patient number 6, a 16-year-old female required few initial counselling, after that she stopped counselling as she felt better and taking medicines regularly. The seventh patient, a 28-year-old female, received regular counselling from very beginning but she died 6 month after initiation of XDR TB regimen. She had bilateral extensive pulmonary disease. The last enrolled patient, 17-year-old female, received regular counselling and she improved. Also, cycloserine was removed from patients, which according to an experienced psychiatrist was causing the problem. Two patients were restarted on cycloserine.

The domains emerging from the study are worry about future and as well as family, disbelief about the diagnosis, embarrassment regarding the diagnosis, fear of death, blaming fate for the disease, stigma, suicidal ideation. Also, there was a major depressive state among the patients and also in their families. High stress also affects them psychologically as well as physically.

Worry is the most common factor that emerged in the interview or in counselling session. The worry is multidimensional in the patients and their care givers. There was worry about health or what will happen to their health, worry about outcome of the disease and the person, worry about family and worry about working life.

The next important domain that emerged was disbelief after their diagnosis. After a long period of treatment, as required in MDR/XDR TB patients, they perceived no changes occurred regarding their perception of treatment, the period of disbelieving started. In counselling session we found most of the patient belief that no one can help him/her. Because of that perception they started to disbelief in every aspect of treatment. This is an important cognitive error in the patients as the disbelief may lead to not having trust on the treatment and thus cause poor adherence to prolonged treatment.

There was also embarrassment regarding their condition in their mind. They were embarrassed by their condition, as friends, neighbours, near relatives did not go near them. In interview session patients told they feel bad when no one sits beside them and also they told other persons not to sit beside them. This creates a massive mental stress to the sufferer. This domain can also be interpreted as self-stigma.

The next important domain which they felt was fear about death. This was the most common aspect, which was found in

**The table shows quotes pertaining to the domains described in the results (after transcription)**

Domain	Patient	Family member
Worry about the future	I feel out of breath when I work more. I am unable to tolerate this pain farther. I just want to get better Every part in my body is aching. Even if I move slightly, it hurts. I do not enjoy life any more, I am worried about my future thinking how will I manage	He is suffering a lot. If a strong man becomes like him has such a fate, what can be done?
Disbelief about the treatment	I have lost trust on future. I take a lot of medicines every day, but do not get cured. I know that even you cannot help me. Nothing is going to happen even after coming here.	We have to come here from such a distance, but there is no progress.
Embarrassment about present condition Self -stigma	It feels awkward to visit any place. I have got examination after a few days, I cannot even go to my friend's house to collect notes. I feel alone even in midst of everyone. Nobody talks to me except my children and wife.	I have stopped going anywhere. Where will I keep him? My relatives do not want to come here.
Fear of death	First let me live. Only then I can work. The person besides my bed died recently. I will die surely.	We are all very scared. He almost died that day (regarding a suicide attempt.
Fate	I do not know in which of my previous births I have committed a sin. It was destiny, nothing could have been done.	Did he really commit any sin? He never harmed any person, even then why does he have to suffer?
Stigma	I hate wearing this mask any more. People look at me with differently. Everyone think that they will die if they even come near me. I cannot talk to my grandchildren properly. Everybody stays away from me.	Nobody from the neighbourhood comes to our house. He prefers remaining to himself closed in his room.
Suicidal ideation	I will not live even after such hardship, so what is the point? That is why I thought of ending my life by hanging. This is a fatal disease. I cannot bear this hardship any more. I was thinking of ending my life.	He tries to hang himself repeatedly and says he wants to die. I cannot withstand this anymore. He always says that you are suffering because of me. So kill me.

all the patients who were interviewed. Lack of information and education about adherence to TB treatment and the curability of the disease lead to this conclusion among the patients.

One of the important defence mechanisms emerging in the patients in this study was fatalism. They started believing their fate and their destiny for their present condition and were thus blaming external unknown factors for the disease. As the quotations suggest, the sufferer of TB believe that they done some sins, and thus they are suffering.

Stigma is another important aspect which is addressed in this research. People thought that MDR/XDR-TB is an incurable disease; people suffer from stigma thinking about the mask they wore, about their closeness to any persons, about their cloths and each and every thing belonging to them. Also there were instances when close neighbours and friends started to avoid them, and this avoidance created mental agony to the sufferer.

Like the fear of death, suicidal ideation is also a very important psychological determinant. Suicidal ideation occurs because of their depressive state and also because of the suffering, not only of their own self as well the suffering of the family members. They thought that whatever treatment they receive, they would die in the end, so there is no purpose of so much suffering and living. The above lines clear that ideation. Prolong duration of therapy is another reason for non adherence, loss of faith on treatment and depression.

## Discussion

In this study, major psychiatric illness was found among 4.8% of the population receiving medicines for DR-TB. This is lower than the prevalence of major depression as found by Ujaas Dawar<sup>[10]</sup> which found major depression in 16% of the patients. Multivariate analysis showed only marital status and nicotine dependence were associated with major depressive disorders. But they did not go deep into the cognitive domains that are affecting the depression.

The domains that were identified are similar to those obtained by another study which reports the psychological problems in tuberculosis patients to be stigma, isolation, lack of social support, helplessness. In this study, the domains obtained were worry about the future, disbelief about the positive outcome, embarrassment about present condition, self-stigma, fear of death, fate, social stigma and suicidal ideation.<sup>[11]</sup>

Stigma seems to be a common psychological domain in both HIV and TB literature that reduces the quality of life and treatment adherence too. It is mentioned to be a patient centred and can lead to social isolation of patients, as has happened in this study too.<sup>[12]</sup> Discrimination occurs when someone is treated unfavourable due to possession of a protected attribute, in an unreasonable manner. Looking at this study, the stigma was perceivable, with instances of isolation by society as well as family members. A study in Kolkata on TB stigma of female patients revealed that it mainly manifested through social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects and

neglect from family.<sup>[13]</sup> Consequences of stigma described by the women included non-disclosure, feelings of guilt and mental health issues including suicidal ideation. They also found negative coping activities as self-imposed social isolation and anger, which is in accordance with our study, where self-stigma and discrimination were seen.

Fatalistic view of a disease has been found as a coping mechanism of some diseases like cancer and HIV. Fatalism, the belief that an individual's health outcome is predetermined or purposed by a higher power and not within the individual's control, has been examined as an inhibitor to participation in health promotion programs and health care utilization. A person with fatalistic beliefs perceives health as being beyond one's control and instead dependent on chance, luck, fate or God. Our study finds that DR-TB patients often resort to fatalistic views to explain their disease.<sup>[14]</sup>

## Conclusion

Thus, this study gave valuable insights into the diverse psychological domains of patients suffering from DR-TB from their emic perspectives. Our study had the strength to conducting a qualitative research in a less explored topic by a trained psychologist. It also had the limitation of multicentric large samples that can be planned based on the findings of the current study. Probably this is the time an integration is required between Mental Health and RNTCP especially in managing DR-TB patients, to manage the psychological problems and increase better outcomes. At least a psychological counsellor can be planned at the centres of DR-TB with screening for mental illness at peripheral levels. In fact there is now increasing global evidence about the nature and extent of tuberculosis and mental disorders comorbidity in low-to-middle income countries. Despite the potential of person-centred interventions, evidence is limited. A pronounced need to address psychosocial comorbidities with tuberculosis in LMICs, where models of person-centred tuberculosis care in routine care platforms may yield promising outcomes.<sup>[15]</sup>

Total number of cases suffered from major mental illness during the study period is 4.8%, and especially one case of suicide points towards importance of this study and necessary action. Timely diagnosis and intervention for the psychological problems may both improve outcome of the patients and prevent unfortunate incidences like suicide of the patients. Thus, this study highlights to the presence of mental health problems among DRTB patients that may jeopardize the outcome among the patients, quick referral by primary care physicians and other staffs to centres when they see these problems, and the need to keep a psychological counsellor in house who can manage these problems.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other

clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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## Conflicts of interest

There are no conflicts of interest.

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