LETTER TO EDITOR
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A Qualitative Study of Psycho Social Impact on Multi Drug Resistant TB (MDRTB) Cases: Experience from Ahmedabad City, India

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Sir,

Depression and tuberculosis (TB) are important public health concerns[1,2,3], contributing to 2.5–2.0% of disability adjusted life years (DALYs) worldwide in 2010, respectively.[4] Tuberculosis, especially DR-TB, is usually associated with adverse socioeconomic and psychological outcomes. This coupled with side effects of prolonged chemotherapy with multiple drugs increases the risk of depression,[5,6] which in turn affects adherence / compliance and treatment outcomes. An operational research (approved by IEC) was carried out with support from state TB Cell to study the depression among adult (> 18 years) MDR TB cases (registered at various TUs of Ahmedabad city), in which 185 cases were assessed on Hamilton Depression Scale[7] revealed 16.2% (n=30) prevalence of depression. During the study, we got the opportunity to explore the status of mental health of MDR TB patients and their familial and societal experiences during the course of treatment while conducting interviews. This communication deals with such experiences of psychosocial ill health faced by patients in their own words.

Experiences of adverse events during course of treatment: 161 (87.1%) experienced one or more adverse events. Verbatim of some of the interested narration observed were the emotional and psychological expressions like

"શરૂઆતમા એટલો ગુસ્સો આવતો કે, કોઈ વાત કરે તોય ના ગમે"

Initially I used to feel so angry that I would not like if someone talks to me. -**(42 years male)**

"શરૂ શરૂમા બહુ તકલીફ પડી. વોમીટ થઈ જાય, ખવાય નહી, કઈ કામ ના થાય"

Initially, it was very difficult. I used to vomit, was unable to eat, and could not do any work. -**(19 years newly married woman)**

"એકજ તકલીફ છે કે ચામડી કાળી પડી ગઈ છે. બીજી કોઈ તકલીફ નથી."

There is only one problem that the skin has become dark. No other issue. -**(33 years single female)**

"કોઈ આ દવા સહન ના કરી શકે. મગજ એટલું ભારે રહે. અધવચે દવા છોડીજ દે કારણ કે આ દવા સાથે કઈ કામજ ના થઈ શકે"

*Nobody can tolerate these medicines. Head feels so heavy and one would leave the medicines in between because one cannot work with these medicines***. -(50 years male)**

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Other patients' experiences: *A 21-year-old female with mild depression had* social and marital issues due to skin discoloration.

One of the participants, reported that before appearing in examination / interview, he avoids medicines because if he took medicines, he couldn't perform well.

Reactions and relationships with family members, friends and society: Discrimination was faced by 19 (10.3%) including from/at family (7), relatives/ neighbors (8), workplace (3) and friends (1). Issues faced within family include divorce, living alone, no sexual relations or strenuous relation with spouse. Experiences of few of subjects are cited below.

"कोई भी समाज में मेरे साथ बैठने के लिए तैयार नहीं था, इसलिए मुझे बुरा लगता था। कोई भी मुझसे मिलता है तो दूरी से बात करता है*"*

I felt bad since no one in the community was willing to sit with me.

People keep distance while talking to me. -**(22 years single male)**

"ટીબી લાગવાના ભય થી લોકો રૂમાલ રાખીને જ વાત કરે છે"

People will talk to me only after putting handkerchief in fear of getting TB. -**(35 years male)**

"शुरूमें, मैं पागल की तरह बन गयाथा। लोग कह रहे थे उसे मानसिक अस्पताल भेजें। इलाज के कारण, मैं काम करने योग्य हो गया हूं।"

Initially I almost went mad. People used to say that I should be sent to a mental hospital. But now I am able to do work because of treatment. -**(27-year-old single male)**

Experiences of Mental Ill-Health and Other Insightful Cases of Psychosocial Impact

24-year-old married, highly educated female had severe depression (HAM D score 20) had complaints of severe headache, fatigue and sleep difficulties. She had Feeling of guilt of having infected her sister-in-law who was unable to find a suitor due to her TB status.

33-year-old married housewife had severe depression (HAM D score32) had thoughts of death, constant crying, insomnia (despite the medication), inability to do any activity, severe headache and weakness. She had excessive worry and fear about the adverse events and treatment outcome. She felt depressed and was worried about the future of her children after her death. She was hypochondriac and addicted to watching YouTube videos on TB patients and would frequently ask for diagnostic tests.

40-year-old married female with 2 children had history of severe headache, uneasiness, itching & depression. She was a Loss to Follow Up case and felt the treatment was too long. She committed suicide by consuming poisonous substance.

27-year-old married male with severe depression (HAM D score 22) had severe insomnia, loss of interest in work, loss of libido and thoughts of death. He discontinued psychiatry treatment after few days, then and also refused counselor visit.

CONCLUSION AND RECOMMENDATIONS

Above case studies reflect that for the time bound goal of Tuberculosis Elimination, challenges such as stigma, discrimination and adverse event are there which not only affect physical but also mental health. One case of suicide or few severe cases of depression is the tip of the iceberg. Management of these challenges (due to the drug itself or social factors) should be the part of treatment algorithm which may in turn improve the treatment adherence and the outcome. Those experienced Adverse Events (AEs) or having stressors like family or financial issues were found at a higher risk for developing mental illness. PMDT guidelines have provision for mental health assessment but are usually ignored. Based on the interview with one of the Counsellors involved in the program, it was found that counselors can be helpful in screening and addressing mental health issues. Based on these experiences, it is recommended that, patients shall be counselled at the start of treatment regarding these issues.

There is the need for inclusion of a structured and systematic process for screening and evaluation of mental health as well as a strong referral mechanism with the nearest specialist services.

Adequate posts of counsellors need to be sanctioned at TUs (@ 1 per TU) who with special training can screen (for mental health) and address the related issues.

MO-TUs need to play a bigger role to play by counseling MDR TB cases at least once to screen for mental health issues.

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