TB: A Neglected Mental Health Issue?

A resource for journalists

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The relation between TB and mental health:

Tuberculosis has emerged as a grave public health challenge in several countries. India is a major contributor to the global burden of TB. In 2015, there were 2.8 million new cases, and 4.7 lakh deaths due to TB in India, according to the WHO global report. Apart from the physical suffering, TB has an impact on the mental well-being of the patient. This is often an ignored aspect of TB management. Loss of employment, stigmatization by spouse, family and friends, and the physical distress that TB patients undergo often takes a toll on their mental health with serious consequences. Patients tend to give up treatment and some of them are lost to follow-up as a result. TB patients are prone to depression and there have been several instances of TB patients committing suicide.

The psychological effect of TB on patients:

The stigma surrounding TB and the misconceptions about TB have a psychological impact on patients. Patients come under mental distress when they lose their jobs or are unable to work because of TB. At this stage, patients suffer from low self-esteem and are more vulnerable to depression and anxiety. Patients tend to develop a sense of helplessness as a result of the combined onslaught of physical discomfort, perceived or real loss in the capacity to work and the stigma attached to TB. Some think that TB cannot be cured or that their lives are in danger and this further contributes towards an increased level of stress, anxiety and depression. Alcohol-dependent patients, who are required to abstain from alcohol during the treatment period, generally experience withdrawal symptoms that add to the already increased levels of anxiety. Self-stigmatization is particularly high among those who are co-infected with HIV. Many of them are ostracised by their own family members and this takes a toll on their mental well-being. The mental health of those undergoing treatment for MDR-TB is subjected to protracted stress, as the treatment is long and frequently painful.

TB and Depression:

Studies have shown that adults with chronic diseases are more likely to suffer from depression. Depression has been stated as a frequent common co-morbid condition for those affected with TB. Patients who are depressed tend to discontinue treatment prematurely and can be lost to follow-up. Interruptions in anti-TB treatment could lead to the person developing drug-resistant TB. The reasons for depression can vary among patients. Loss of employment and the subsequent financial burden, the stigma attached to TB, substance and alcohol abuse, a sense of helplessness as a result of their weak body condition and misconceived notions surrounding TB are few of the reasons behind depression in TB patients. When those with TB experience depression, it is important that they are given counselling and are motivated to complete their treatment. The mental well-being of those affected with TB is just as important to overcoming the disease as other factors such as adhering to treatment and eating nutritious food. Family members and friends should also be counselled on the need to be supportive and caring towards those with TB.

In cases of severe depression, psychotic episodes or suicidal behaviour, it is extremely vital that the patients consult a psychiatrist and undergo appropriate treatment for depression as well. Those with MDR-TB need to be given additional importance as the treatment for MDR-TB takes a long period and has side effects. A study in Peru found rates of depression at 52.2% among MDR-TB patients. Chances of depression are higher among those with MDR-TB and those co-infected with HIV.

Suicides related to TB:

Occasionally severe depression can be seen especially among those with MDR-TB. This is due to the acute physical effects of MDR-TB, a high level of stigma associated with this form of the disease and the long duration of treatment. Patients are in constant distress and require assistance in performing simple, routine

activities. This makes them very vulnerable to depression and they develop suicidal tendencies as well. There have been instances of suicides, reported all over India among TB patients. These are not limited to MDR-TB patients alone. Suicides were also reported among those co-infected with HIV. Sometimes, suicidal ideation may be the result of the side effects of the treatment. One of the drugs in the treatment regimen for MDR-TB, Cycloserine, can induce depression and suicidal thoughts, and this has to be carefully monitored.

Stigma and its psychological impact:

Stigma among TB patients is prevalent irrespective of gender or social backgrounds. However, stigma has had a greater impact on women than men.

Stigma and its psychological impact on women: Studies have shown that while men find it hard to cope with the physical effects of TB and its impact on their ability to work and earn a living, women consider stigma as the most difficult effect to cope with. Women are ostracised by their own family members and isolated by their community. They are forced to take their treatment in secret and live in constant fear of people around them finding out about their condition. Married women are often driven out of their homes and are forced to stay away from their children. According to a multi-country research study on Gender and Tuberculosis conducted in Bangladesh, India, Malawi and Columbia, a few women in India and Bangladesh had stated that their husbands and in-laws encouraged suicidal thoughts. The research also stated that according to certain estimates, one-third of the women in the Indian study sample reported psychological and emotional distress as a result of the disease. Women are asked to stay away from their children and the inability to provide proper care for their children often resulted in them developing a sense of worthlessness and, the fear of leaving their children behind as orphans. In unmarried women, their prospects of getting married are compromised as a result of the stigma associated with TB, leading to emotional distress and depression. Another important consequence of stigma is that it may prevent the individual from seeking care.

Government schemes:

The Indian Standards of TB Care (STCI) has underlined the importance of counselling in the overall management of the TB problem. The RNTCP has included in its Guidelines on Programmatic Management of Drug Resistant TB (PMDT) in India, counselling and social support services for MDR-TB patients. The government also has a voluntary counselling programme for HIV-TB patients. A counselling tool has been developed for this purpose. In addition, several civil society and community organisations have integrated counselling with patient care and support for those affected by TB.

Importance of counselling and role of family members:

Patients are often in denial when they are diagnosed with TB. Counselling can help mitigate the fear and misconceptions surrounding TB and help patients and family members realise that TB is curable. Providing psycho-social support in the form of counselling can improve treatment adherence. During this period, the patient needs the support and care of his or her family members and friends. Counselling can help in establishing a good support system and prevent the patient from spiralling towards depression and anxiety.

Where's my story?

- Are there any case studies on the impact of TB on one's mental well-being in your district/city/state? What are the challenges patients face when it comes to seeking care and completing the treatment?
- Do TB patients in your district/city/state experience any stigma? If so, how has the stigma affected them? How does it impact women and men differently?
- Any instance of severe depression or suicides among the TB patients in your locality/district/city/state? If so, are measures being taken to prevent such incidents?
- Is any form of psycho-social support made available to TB patients? If so, who provides these services? How is it done and how has it affected treatment?
- Are counsellors, social workers trained to provide psycho-social support to TB patients? Are these services extended to the family members as well?
- Are there any case studies on the perception and experience of a family member caring for someone with TB and the challenges faced by them?
- Are there any examples of when provision of counselling has helped TB patients in a particular locality?

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If you have any questions, please write to us at trisha.reach@gmail.com

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