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## RESEARCH ARTICLE

### PSYCHO- SOCIAL ISSUES AND WELLBEING OF MULTI DRUG RESISTANT TUBERCULOSIS (MDR TB) PATIENTS - A REVIEW ON SOCIAL WORK INTERVENTION

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#### ABSTRACT

Multi Drug-Resistant Tuberculosis (MDR-TB) is a type of drug resistant TB. It defined as strains of Mycobacterium tuberculosis resistant to at least isoniazid and rifampicin, i.e., the two first-line anti-TB drugs. MDR-TB poses a major threat to public health worldwide, particularly in low-income countries and it represents a major obstacle towards successful TB control programme. The current long (24 months) and arduous treatment regimen uses powerful drugs with side-effects that include mental ill-health. It has a high loss to- follow-up (25%), higher case fatality and lower cure-rates than those with drug sensitive tuberculosis. Global TB strategy aims to end the global TB epidemic, to reduce TB deaths by 95% and to cut new cases by 90% by 2035, hence the management of MDR-TB is much more difficult than drug-susceptible TB. **Aim & Objectives:** To understand the psychosocial issues faced by MDR-TB patients and their wellbeing through published articles and conference reports to find out the social work intervention methods to strengthen the Programmatic Management of Drug-Resistant Tuberculosis (PMDT). **Methods :** Based on the PubMed for studies published from January 1995 to November 2018, with the terms: Tuberculosis, MDR TB, and Psychosocial problems / issues/challenges/ wellbeing. A total of 87 published articles were retrieved, of which 53 articles were chosen for full text review and presented in this review. **Findings :** This review has captured the psychosocial issues and wellbeing of MDR patients. Number of issues for their psycho social and economic issues due to long duration of treatment, high pill burden, drug adverse effects. Psychological disturbances (worries, fear, tension, denial, depression), social problems (disclosure issues, rejection, enacted stigma, perceived stigma, discrimination by family members, community, lack of social support) and economic problems (inability to go for work, work absenteeism, loss of income, borrowings) In addition, challenges they faced during treatment and further to lead normal life. **Conclusion :** The social workers strive to eliminate discrimination, to reduced Psycho-Social issues and to promote the drug adherence by using the Social Case Work and Group Work method for intervention among MDR TB patients. Social workers engage in direct practice with patients in such roles as counsellor, enabler, case manager, and advocate. It is recommended that the social worker will work as a bridge between TB patients and Health professionals for psychological intervention.

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#### INTRODUCTION

India has the highest TB burden of any country in the world, accounting for an estimated one-fifth of global TB cases worldwide. Drug-resistant TB continues to be a public health crisis. Globally, 3.5% of new TB cases and 18% of previously treated cases had MDR/RR-TB. The best estimate is that, worldwide in 2017, 558 000 people (range, 483 000–639 000) developed TB that was resistant to

rifampicin (RR-TB), the most effective first line drug, and of these, 82% had multidrug-resistant TB (MDR-TB). Three countries accounted for almost half of the world's cases of MDR/RR-TB: India (24%), China (13%) and the Russian Federation (10%). Globally, 3.5% of new TB cases and 18% of previously treated cases had MDR/RR-TB (Global Tuberculosis Report, 2018). The Revised National Tuberculosis Control Programme (RNTCP) has notified 1.94 million patients in 2016 (1). India has been locating and treating MDR-TB patients since 2007 and achieved complete geographical coverage of programmatic management of drug-resistant TB (PMDT) services in 2013. Tuberculosis (TB) is a leading cause of infectious disease deaths in the world, with developing nations accounting for 95% of TB

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mortalities globally (Zazueta et.al, 2009). Multidrug-resistant TB (MDR-TB), however, is caused by *Mycobacterium tuberculosis* (Mtb) strains that are resistant to both INH and RIF, which has a significant impact on the clinical course and outcome of the disease (Furin, 2007). Drug-resistant Tuberculosis (TB) is today a major threat worldwide – and in some settings up to one third of new cases are multidrug-resistant at first diagnosis. Failure to control MDR-TB may lead to progression to XDR-TB, a virtually untreatable form of TB. (Chakaya *et al.*, 2006) Treatment for MDR-TB and XDR-TB is prolonged, expensive, associated with heightened adverse drug reactions and low cure rates. It is also not widely available in resource-limited countries. Due to the above reasons patients has undergone lot of psychosocial problems and the patient have to face many challenges during the entire course of treatment. The side effects of the drugs were a challenge to treatment.

**Burden of TB:** India alone accounts for nearly one-third of the global tuberculosis (TB) burden (Global Tuberculosis Report, 2019). TB population in the Indian state of Tamil Nadu alone is found to be 1,04,917; of this 75,415 are notified in public and 29,502 in private. In Tamil Nadu's capital city, Chennai, 14,370 cases are notified, of which 9,005 and 5365 patients are diagnosed and treated both in public and private sectors (India TB Report, 2019). India leads the world in the burden of tuberculosis (TB) according to the new report of the World Health Organization (WHO) on the disease. According to the WHO's 2018 Global TB Report, released in the United Nations (UN) headquarters in New York, two of the primary routes to reducing TB incidence and death are diagnosis and treatment, areas where "large and persistent" gaps remain. Of the 10 million new and relapsed cases in 2017, only 6.4 million (64 per cent) were officially reported to national authorities and the WHO. Ten countries accounted for 80 per cent of the 3.6 million gap, led by India (26 per cent), Indonesia (11 per cent), Nigeria (9 per cent). The gap is suspected to be caused by a combination of under-diagnosis and under-reporting. Overall, the report revealed that while the number of new TB cases continued to decline in 2017, and fewer people died from the disease, efforts to make the world's deadliest infectious disease a "disease of the past" needed to be ramped up. While an estimated 54 million deaths have been averted since 2000, the burden of TB remains high in many low- and middle-income countries, and WHO officials say ending TB as a major global health problem by 2030 will require countries to pick up the pace. The report estimates that 10 million people developed the disease in 2017, including 5.8 million men, 3.2 million women, and 1 million children. That is down from 10.4 million in 2016. Globally, the TB incidence rate is falling by roughly 2 per cent a year, with annual reductions of 5 per cent and 4 per cent in Europe and Africa, respectively. But the global incidence rate needs to be falling by 4-5 per cent every year to meet the first milestone of the "End TB" strategy—a 20 per cent reduction by 2020 (compared with 2015). The strategy aims to cut TB incidence by 80 per cent by 2030.

**Psychosocial Problems:** The term 'psychosocial' is a broader term and widely used in the literature with regard to health outcome. The roots of psychosocial health lie in the World Health Organization's (WHO) definition of health as – "a state of complete physical mental and social well-being and not merely the absence of disease and infirmity". This

WHO definition of health has been criticised on several grounds, but researchers using health outcomes based on such definitions need to guard carefully against circular arguments. The psychological problems of MDR-TB patients are multi-dimensional as worries, fear, tension, denial, depression, anxiety, suicidal tendencies, treatment side effects, productivity loss, hopelessness due to MDR-TB were some of the common issues reported in various studies.

**Aim & Objectives:** To understand the psychosocial issues facing by MDR-TB patients and their wellbeing through review published articles, reports and to find out the social work intervention methods to strengthen the Programmatic Management of Drug-Resistant Tuberculosis (PMDT).

## METHODS

We searched PubMed for studies published from January 1995 to November 2018, with the terms: Tuberculosis, MDR TB, and Psychosocial problems / issues/challenges/wellbeing. A total of 87 published articles were retrieved, of which 56 articles were chosen for full text review and presented in this review.

## Literature Review

**Psychosocial Problems:** Vega *et al.* (2004), examined with Psychiatric issues in the management of patients with multidrug-resistant tuberculosis, it was observed, baseline depression and baseline anxiety were respectively 52.2% and 8.7% of this cohort. Most individuals with baseline depression experienced improvement of depressive symptoms during the course of TB therapy. The incidence of depression, anxiety and psychosis during MDR-TB treatment was 13.3%, 12.0% and 12.0% respectively. Baral *et al.* (2007), a study conducted in Nepal to find out cause of stigma and discrimination associated with TB, and the findings were suggest that causes of self-discrimination identified included fear of transmitting TB, and avoiding gossip and potential discrimination. Causes of discrimination by members of the general public included: fear of a perceived risk of infection; perceived links between TB and other causes of discrimination, particularly poverty and low caste; perceived links between TB and disreputable behaviour; and perceptions that TB was a divine punishment. Furthermore, some patients felt they were discriminated against by health workers.

Fazlul Karim *et al.* (2007) on their study in Bangladesh Stigma, Gender, and their Impact in their life of rural Tb patients, outcome revealed that in case of stigma, Female patients emphasised psychosocial and marriage or family related indicators more than men. Women said that they thought less of themselves due to TB, and felt ashamed or embarrassed. Anita S. Mathew *et al.* (2007) said that in India, patients with TB often experience rejection and social isolation, Because of the lack of awareness about the disease and fear of being ostracized, persons with TB often hide their symptoms and fail to receive appropriate treatment - a stumbling block in the control of the disease. A common belief is that TB is incurable and that the drugs for treatment of TB can harm the patient. Siddiqua Aamir *et al.* (2010) a study conducted in order to find out Co-Morbid Anxiety and Depression among Pulmonary Tuberculosis Patients in Pakistan & the findings revealed that forty seven out of 65

(72%) TB patients had severe/moderate level of anxiety and depression according to Hospital Anxiety and Depression Scale (HADS). Fourteen (22%) TB patients with co-morbid anxiety and depression showed multi drug-resistance (MDR-TB).

Basu G, *et al.* (2012) in their study on Prevalence of depression in tuberculosis patients: An experience from a DOTS clinic & they found that 62% patients were depressed, two third of the depressed patients were suffering from mild to moderate depression whereas 5.5% patients were severely depressed. Elderly were most affected. The prevalence of depression is high in TB patients currently on DOTS. Karl Peltzer *et al.* (2012) On study of Prevalence of psychological distress and associated factors in tuberculosis patients in public primary care clinics in South Africa and the findings highlighted that overall prevalence of psychological distress (32.9 % and 81 % according to the K-10 score 28 and K-10 score 16, respectively) was found in this large sample of tuberculosis public primary care patients in South Africa.

Venkatraju *et al.* (2013) conducted a study in Nalgona District Andhra Pradesh to find out psychosocial trauma of TB patients & they find out that Six major themes emerged from the analysis of data which were considered to be of major importance in the lives of respondents: worry/depression (37.3%), disbelief/shock (23.6%), embarrassment/shame (16.4%), fear of dying (12.7%), fate/God's act (9%) and relieved that it was just TB (0.9%). Aydin IO and Ulusahin (2001) on their studies shown that people infected with TB are more likely to develop mental and psychological problems than people not infected with the disease to be afflicted with pulmonary, tuberculosis is a unique and painful experience in the bio psychosocial history of an individual, and the emergent stress contributes to psychiatric morbidity. Depression, posttraumatic stress disorder (PTSD), and acute stress disorder are the most common stress-related conditions of TB patients. Reactions to the stressful situation brought about by the illness negatively affecting an individual's ability to work, in conjunction with social and respiratory isolation lowered self-esteem, fear of spreading the illness to others, helplessness brought out by incapacitation due to chronic illness, and social stigma attached to this illness, are all plausible causes that one can postulate for depression and anxiety. (Argiro Pachi *et al.* 2013).

**Stigma and Discrimination:** A number of studies (Atre *et al.* 2004; Uplekar & Rangan 1998; Liefoghe *et al.* 1997) have reported that people with tuberculosis, especially women, have low esteem and encountered number of social problems. In India, married women expressed a concern that their husbands and in-laws would subject them to harassment and discrimination because of their illness (Rajeswari *et al.* 2005). Stigma has been reported as a major concern facing MDR-TB patients (Vega *et al.* 2004), Stigma in the context of MDR-TB negatively impacts the patient in accessing healthcare facilities in their neighbourhood (Isaakidis *et al.* 2013). The effects of stigma include experiences of social seclusion or rejection from family members, friends, neighbours, and/or health providers; internalised shame; financial instability; discrimination; and its repercussions (Acha *et al.* 2007). One study among health care providers highlighted that the major barriers for the MDR-TB patients were social resulting from stigma rather than medical. Social

acceptance and support were not present for MDR-TB, unlike other diseases (Isaakidis *et al.* 2013). It has also been reported that MDR-TB patients would voluntarily separate themselves from their family for fear of spreading infection to other members ((Morris *et al.* 2013). The impact of stigma reported has led to divorce, cancellation of impending marriages, breakdown of family relationships and also isolation within the family (Baral *et al.* 2014). Several studies suggest that health-care providers and at-risk community members perceive TB stigma to have a more substantial impact on women's health-care-seeking behavior than on men's (Thorson, 2004, Johansson *et al.* 1999). Balasubramanian *et al.* (2004), however, found that although women in south India felt TB stigma more strongly than men, they were more likely to access health services. Rajesawri *et al.* (2005), found that stigma is major cause of concern for TB patients in South India, and it interfered with social interactions, such as visiting friends and relatives.

**Socio-Economic Challenges:** MDR-TB has a huge adverse economic impact on patients due to the long duration and complexity of treatment. The socioeconomic barriers include inaccessibility of treatment, distance, transport costs and costs incurred during hospitalization (Horter *et al.* 2014). One study found that 23% of MDR-TB patients had defaulted on treatment due to financial constraints (Kalaikbarova, 2013). There was also a reduction in salary due to work absenteeism and some income had to be spent on costs associated with treatment (Sharma *et al.* 2014). Several research studies have suggested that a number of factors were associated with patient delays including poor socio-economic condition, alcoholism, domestic preoccupation, and distance (Rajeswari *et al.* 2002); traditional disease causation beliefs (Long *et al.* 1998); gender, stigma (Ngamvithayapong *et al.* 2000); old age, lost work and income (Needham *et al.* 2001); illiteracy, treatment cost, attribution of symptoms to less serious illnesses (Liefoghe *et al.* 1997) and self-treatment (Rubel & Garro 1992). In a study conducted by Zhang *et al.* (2007), in rural Mongolia, China, respondents reported that that people delay decision to seek proper treatment for TB for the following reasons: i) lack of knowledge of the important signs and symptoms of TB, its transmission and its curability; ii) fear of social stigma; and iii) socio-economic reasons.

General health seeking pattern of chest symptomatic clearly suggest that private practice is the most important source of first contact for majority of patients, including people from poor socio-economic strata (Uplekar *et al.* 1996; Wandwalo & Morkve 2000; Sudha *et al.* 2003). A majority of patients basically switch from private health care services to government health services for economic reasons. Several studies (Saunderson 1995) clearly established that TB patients incurred considerable direct costs (such as consultation fees, transportation and hospitalization charges, treatment and medicine costs, etc.), before diagnosis of TB in the private sector. These direct costs placed a heavy economic burden on the individual patient and his/her family. Ngamvithayapong *et al.* (2001), found that patients sold assets such as land, cows, gold, houses, etc., in order to meet treatment expenses. Patients also borrowed money from their relatives and neighbors to meet the expenses.

**Family and Community:** Kleinman *et al.* (2006) argue that patients and family explanatory models of illness are

influenced by a number of socio-cultural factors such as social class, cultural beliefs and perceptions, education, occupation, religious affiliation, and past experience with an illness episode and health care providers. Kleinman contends that to provide care that effectively meets the patient's and family member's needs, health care workers must elicit patients' and family members' explanatory models of illness. Rajeswari *et al* (1999) found that 15% of the married women (n=120) were rejected by their family members because of their TB. Studies found that women may suffer violence, verbal abuse and abandonment once their TB positive status becomes public. In India, about 100,000 women are abandoned by their families because of their TB every year (RNTCP Status Report, 2005). Anita *et.al* (2007) reported that the stigma has taken a greater toll on women than on men. Many of the patients who start receiving therapy, frequently in secrecy, stop as soon as they start to develop adverse effects, such as orange discoloration of the skin (seen with rifampicin, a first-line drug for TB therapy), which reveals to the community that the patient has TB. Discontinuation of therapy can lead to emergence of multidrug-resistant TB and extensively drug-resistant TB, which are difficult to treat and can be fatal.

## RESULTS AND FINDINGS

This review has captured the psychosocial issues and wellbeing of MDR patients. Number of issues for their psycho social and economic issues due to long duration of treatment, high pill burden, drug adverse effects. Psychological disturbances (worries, fear, tension, denial, depression), social problems (disclosure issues, rejection, enacted stigma, perceived stigma, discrimination by family members, community, lack of social support) and economic problems (inability to go for work, work absenteeism, loss of income, borrowings) In addition, challenges they faced during treatment and further to lead normal life.

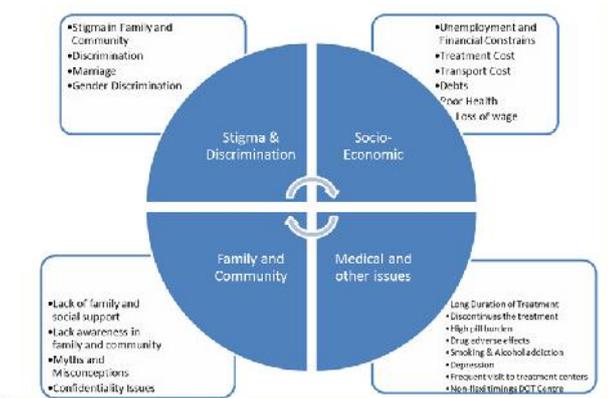


Figure 1. Conceptual Framework of MDR-TB Patients

## DISCUSSION

The psychological problems of MDR-TB patients are multi-dimensional and broadly classified in four aspects namely stigma and discrimination, socio-economic problems, family and community and other medical and other issues. The social issues relate to the family and community of the patient may persist throughout the disease course, sometimes even after the disease ceases. Involvement of family, community in the disease management was found to be one of the ways to overcome the social issues like stigma and

discrimination while also improving treatment outcomes. Economic and financial challenges also affect patients and their families throughout the disease course, especially because treatment costs accrue during the long duration of treatment.

Stigma and discrimination is always attached to the disease like tuberculosis. Women were facing lot of discrimination in family and community. Unmarried female patients experienced psychosocial problems due to rejection in marriage and family related indicators more than men. RNTCP in India has initiated counselling services in dealing with MDR-TB patients. In 30 districts, counselling services have been provided to over 8000 MDR-TB patients resulting in a significant reduction in loss to follow up and death amongst the MDR-TB patients by nearly two thirds. Over 200 personnel working with RNTCP have been trained in on key thematic areas (TB India, 2017). This is a good initiative of RNTCP to provide psychosocial support for the welfare of TB patients.

WHO Global Tuberculosis Report heightened that the need for expanded policy and legal frameworks, financing and programme strengthening to ensure that support is available on a systematic and sustainable basis. In addition, examples were provided of social support in the context of TB treatment services, such as transport, vouchers, food packages, and psychosocial support, and cash-transfer schemes (including those in which TB patients are linked to general schemes). Documentation on social protection for TB patients is increasing.

## Social Work Intervention

- ) Advocacy for psychosocial support and access to basic health services (Using wide publicity propaganda in social media about TB) functioning governance systems, into which psychosocial support needs to be mainstreamed, and the assurance of security in order to re-establish wellbeing and mitigate further psychosocial harm.
- ) A smaller percentage of the population, with particularly stressful reactions, will require more focused and specialised support interventions with attention to the individual, family or group (e.g. psychosocial first aid by health workers, Medical Social workers).
- ) Good channels of communication should be established within the general hospital and with community services with regard to psychiatrics as well as physical health.
- ) Social worker will work as a bridge between TB patients and Health professionals; she / he will help the doctors in psychological intervention.
- ) Advertisement and educational references through Advocacy, Communication and Social Mobilization for TB.
- ) Addressing psychological factors to ensure compliance is critical so the patients should be monitored for adverse drug reactions, which are common.
- ) Psychological, social and economic support interventions need to be included as a regular part of MDR-TB care.

## Conclusion

This review highlights the serious psychosocial challenges experienced by MDR-TB patients both due to disease and its treatment complexities. Depression during MDR-TB treatment needs particular attention. Health care professionals involved in management of MDR-TB patients should be properly skilled to execute proper mental health assessment tools, in particular at baseline, so that presence of depression can be identified on earlier basis. The social workers strive to eliminate discrimination, to reduced Psycho-Social issues and to promote the drug adherence by using the case work and group work social work intervention method among MDR TB patients. Social workers engage in direct practice with patients in such roles as counsellor, enabler, case manager, and advocate. It is recommended to regularly monitor the mental health status of MDR-TB patients by skilled Medical Social Worker/ Counsellors using simple, validated and cost-effective tools which will result in adherence and cure rate in MDR-TB patients. It is observed that the psychosocial and economic interventions reported in these studies suggest improvements in both treatment adherence and cure rates among MDR-TB patients.

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