

INTERVENTION STRATEGIES TO MITIGATE PSYCHOSOCIAL CHALLENGES AND IMPROVE THE QUALITY OF LIFE OF MDR-TB PATIENTS – AN EVALUATION STUDY

Thiruvalluvan E¹, Sellappan S¹, Watson B², Muniyandi M³

¹ DSBR, ICMR-National Institute for Research in Tuberculosis (NIRT), Govt Rajaji Hospital, Madurai, India

² Department of Statistics (Epid), ICMR-National Institute for Research in Tuberculosis (NIRT), Chennai, India

³ Department of Health Economics, ICMR-National Institute for Research in Tuberculosis (NIRT), Chennai, India

ABSTRACT

Introduction: The psychosocial well-being and treatment outcome in MDR-TB is far undesirable as the treatment is characterized by a rigorous treatment regimen for a long duration, adverse side effects, lower cure rate, and high treatment costs. This study aimed to devise an intervention strategy and test its feasibility and effectiveness to ensure the patients' quality of life (QOL) and to promote adherence.

Methodology: The study population included all MDR-TB patients, of age 18 years and above registered in 16 tuberculosis units (TUs) under Chennai Corporation for treatment during the year 2014. Researchers have devised an intervention strategy package that included motivational interview (MI) module, counseling support as well as nutritional support. Participants were included in the study after getting informed consent. Motivational interviewing was offered at five times during the study period. Each participant received minimum 15 individual counselling sessions. All participants but two received nutritional flour packet weighing half kilogram every month.

Results: Of 35 participants enrolled in the study, one third was women. Poor QOL was experienced by 19 participants out of 35 at the start of treatment that came down to 2 after the study. QoL scores in all four domains were significantly high and depression level score was significantly lowered at the end of the treatment. At the start of the treatment twenty, four out of thirty-five participants were dissatisfied with their health that came down to five at the end of treatment.

Conclusion: Intervention strategy not only had a great impact on the QOL of study participants but also contributed to better treatment adherence and desirable treatment outcome. Therefore, researchers emphasize the need to adopt this Intervention Strategy through the provision of trained, professional MDR-TB counsellors. Further, larger studies of multi-state/ multi-site may be taken up to standardize the intervention strategies adopted in this study.

Key words: MDR-TB patients, intervention strategy, Quality of life, treatment adherence

INTRODUCTION

Tuberculosis (TB) remains one of the world's biggest threats despite the advances made in the management of the disease and nearly all TB

Correspondence:

Dr. Thiruvalluvan Elango
Senior Technical Officer - 3
Department of Socio-Behavioral Research (DSBR)
ICMR-National Institute for Research in Tuberculosis (NIRT)
62, Govt Rajaji Hospital, Madurai-625020
Mobile: +91 9442700551
E-mail: e.thiru@gmail.com

cases can be cured ⁽¹⁾. India has the highest burden of both TB and MDR-TB based on estimates reported ⁽¹⁾ in Global TB Report 2016. Globally in 2016, about 490,000 people were estimated to become ill with MDR-TB ⁽²⁾. In the same year, the estimated number of MDR/RR -TB cases among notified pulmonary TB cases (2.79 million cases of TB in India in 2016 by WHO) was 84,000 (72,000–95,000) with an incidence (MDR/RR-TB) 147 (95–199) per 100000 11 (7.2–15). While host genetic factors may probably contribute, MDR-TB has clinical as well as programmatic factors that include inadequate or poorly administered

treatment regimen/treatment failure^(3,4) or non-adherence⁽⁵⁾ to the prescribed regimen leading to the development of MDR-TB.

The community-based treatment program for MDR-TB (DOTS-Plus), specialized treatment using the popular Directly Observed Therapy Short Course (DOTS) initiative, has shown considerable success^(6, 7, 8, 9) in the management and treatment of MDR-TB in some parts of the world. However, management of MDR-TB is challenging due to its complex treatment that includes an elevated treatment cost⁽¹⁰⁾, the use of highly toxic anti TB drugs with potential adverse effects⁽¹¹⁾, longer treatment regimen^(12, 13) which often requires 24 months or longer, and it burdens an increased treatment failure and mortality^(14, 15) rate. As the treatment for MDR-TB is characterized by rigorous treatment regimen for a long duration, higher incidence of adverse side effects, lower cure rate, and high treatment costs, both psycho-social well-being and treatment outcome in MDR-TB is far negative than drug-sensitive TB. The current paper is to understand the psychosocial issues facing MDR-TB patients in terms of depression, stigma and social support; and to gain insight into the factors that influence treatment adherence and quality of life. Also to explore the feasibility and acceptability (effectiveness) of intervention strategies to promote adherence suitable for MDR TB Patients.

METHODOLOGY

This study was conducted in Chennai Corporation, covering 16 TUs. The study population includes all MDR-TB patients, 18 years of age and above registered for MDR-TB treatment from September 2014 to September 2016.

This was an intervention study conducted to understand the patients' experiences related to MDR-TB diagnosis and treatment and devise an effective and acceptable strategy to promote drug adherence. The study consisted of four individual assessments at 0, 6th, 12th and 18th and 24th month. During the assessment, investigators have identified patients' concerns that include awareness on MDR-TB, the disclosure of MDR-TB to family and their reactions, social stigma (perceived and enacted stigma), economic problem, psychological problems, and drug-related problems. Besides, the patients' lifestyle characteristics such as alcohol consumption and tobacco smoking were also assessed. Based on this assessment, we introduced the need-based intervention on 0, 6th, 12th, 18th and 24th month. Each assessment and intervention sessions were conducted for 30 to 45 minutes.

The interventionists were conducted by trained professional Medical Social Workers. Based on the phase-I findings an intervention strategy was devised that consist of motivational interviewing module, counselling module and nutritional support. The motivational interviewing intervention focused four main topics viz., Session-1: MDR-TB Management, challenges, nutrition; Session-2: Psycho-social issues intervention, Session-3: Alcohol, smoking, suicide thought; and Session-4: Rehabilitation. Study participants were met on five-time during the study period i.e., 0, 6th, 12th, 18th and 24th month over the study period (Table-1). Individual counseling sessions were organized based on the participants' psychosocial need.

Nutritional support in the form of nutritional supplement packets was provided to the participants as a part of the intervention program. This support addressed the indirect costs incurred by the study participants or in accessing the health

Table 1. Motivational interviewing intervention schedule

Activity /Time point	0 month			6 th month			12 th month			18 th month			24 th month		
Assessment/ Motivational/interviewing	√			√			√			√			√		
Counseling	1	2	3	4	7	8	9	10	13	14	15	16	19	20	21
Management/ challenges/ nutrition	√			√			√			√			√		
Psychological issues intervention		√			√			√			√			√	
Alcohol/smoking/suicide thought		√			√			√			√			√	
Rehabilitation			√			√			√			√			√

Motivational interviews were held as per the module developed before the intervention. Motivational interviews focused on 6 different issues mentioned in the table .

facility, or possibly, to mitigate the consequences of income loss related to the disease. Nutritional supplements including a variety of millets and legumes that have high nutritional value were provided to all the participants. Financial support in the form of financial incentives or transportation costs that would help the patients in undergoing preventive care, such as screenings or test, and for their periodical visits to the treatment facility was provided to the participants who needed financial assistance or too low-income participants.

The interview schedule was used to collect information on socio-demographic characteristics of patients. In addition Center for Epidemiological Studies Depression (CES-D) scale was used to measure anxiety; WHO QOL BREF scale was used to measure the quality of life; AUDIT scale was used to measure alcohol and drug abuse and Fagerstrom scale was used to measure smoking. Individual counselling sessions numbering 15 were held. During the study period, various psychosocial issues were addressed. Nutritional support was offered to all participants, but two participants who declined to accept nutritional support. Nutritional flour packet weighing half a kilogram was offered to participants every month.

Descriptive statistics like mean±standard deviation, median with Inter-Quartile Range and frequency with percentage were used, depending on the variable type. Comparison of the proportion who was depressed at baseline with those at 24th month follow up was done using the McNemar test. Paired t-test was used to compare the domain-wise score of the WHO-QOL scale. Statistical significance was determined at 5%. Statistical analysis was performed using SPSS Version 16.0.

This study was approved by the Scientific Advisory Committee and Ethics Committee of National Institute for Research in Tuberculosis, Indian Council of Medical Research (ICMR) Chennai. Written informed consent was obtained from the patients who were willing to participate in the study. Privacy and confidentiality were maintained over the study period.

RESULTS

Overall 35 participants were enrolled in the study. One-third of the participants were women (Table-2). One participant lost to follow-up and the other one died, remaining 33 participants were

included for analysis. Mean age of participants was 38 (SD+13). One-third of participants were educated up to 10th standard. More than half of the participants were married. Before the diagnosis of MDR-TB, only 4 participants were unemployed and after the diagnosis 23 participants become unemployed. Sixty-three per cent of the participants were tenants, living in line houses.

Socio-demographic characteristics		n (%)
Age	Mean ± SD	38 ± 13
Gender	Male	22 (66.7)
	Female	11 (33.3)
Education	Illiterate/no schooling	4 (12.1)
	Primary school	3 (9.1)
	Middle school	8 (24.2)
	High school	10 (30.3)
	College	4 (12.1)
	Professional education	4 (12.1)
Marital status	Single	10 (23.3)
	Married	20 (60.6)
	Separated	1 (03.0)
	Widowed	2 (06.1)
Family type	Nuclear	25 (75.8)
	Joint	8 (24.2)
Family size	Median (range)	3 (1,4)
Occupation	Before diagnosis	
	Salaried government sector	7 (21.2)
	Salaried private sector	10 (30.3)
	Daily wages earner	12 (36.4)
	Unemployed	4 (12.1)
	After Diagnosis	
	Salaried government sector	2 (05.9)
	Salaried private sector	5 (15.2)
	Daily wages earner	3 (09.1)
	Unemployed	23 (69.7)
Residence locality	Urban	28 (84.8)
	Semi-urban	3 (09.1)
	Slum	1 (03.0)
	Rural	1 (03.0)

Note: Removed one patient who was "lost" and the other one who died

Findings revealed that the majority of participants were unaware of 'MDR-TB'. Most of the TB patients have not disclosed their TB status (Table-3), even to their family members. Ninety per cent of participants found a government health facility as the primary source for treatment and an equal percentage of participants were aware of two years of the treatment period. As for depending on tobacco and alcohol, 9 participants had the habit of smoking and

12 participants had a history of drinking. However, the AUDIT scale suggested one participant with the drinking problem and Fagerstrom smoking scale suggested 6 participants as very low dependence and 3 participants with medium dependence.

Table 3: Status of disclosure and experience of stigma	
Reaction and experiences	n (%)
Informed of diagnosis	28 (84.8)
Reaction to diagnosis	
Shock	8 (24.2)
Worry	16 (48.5)
Disbelief	
Cried	2 (06.1)
Others	2 (06.1)
	5 (15.2)
The reaction of family members	
Rejection	3 (09.1)
Support	23 (69.7)
Agree	5 (15.2)
Not co-operative	
Other challenges faced	
Looked down by neighbours	5 (15.2)
Relatives refused to visit home	2 (06.1)
Loss of job	10 (30.3)
Neighbours do not interact	1 (03.0)
Others	10 (30.3)

The motivational interviewing intervention was offered to all 33 participants at 5 different time points and administered depression assessment scale and quality of life scale. At the initiation of treatment 27 MDR-TB participants had experienced depression. At the end of the treatment, only 7 participants had experienced depression.

Individual counseling sessions were held during the study period and various psychosocial issues were addressed. Psychosocial counselling sessions were conducted to help the participants in understanding MDR-TB and managing the impact caused by the disease in their psychosocial life. The counsellors educated the patients about MDR-TB prevention and transmission, and also about the course of the disease. These sessions not only helped the patients in preparing themselves to face any adverse outcome of the diagnosis but also helped them in alleviating their anxiety and depression level caused due to the illness. The counsellors also encouraged the participants to give importance on or value self-

worth, combat fear, on strengthening the patients' sense of responsibility and enabling them to adopt the changes that have occurred in their socio-economic life after diagnosing MDR-TB.

During the counselling sessions, the counsellors reiterated the pros and cons of the medications prescribed to the patient by treating physician. The patients were also counselled on the importance and need to adhere to the treatment and the effects of irregular treatment. The majority of the participants reported difficulties in adhering to the MDR-TB medications due to the severe side effects caused by the drugs or have a time conflict due to their daily schedule. For such cases, the counsellors suggested some feasible plan for drug adherence based on the patients' need and other related events. Such strategies include setting an accurate drug taking the time or forming the habit of stock-taking of drugs, or rescheduling drugs taking time depending on the participants' suitable time. Counselling was provided to those patients who reported substance use (alcohol and smoking) to deal with the issues underlying with substance abuse depending on then usage severity. The counsellors motivated them to keep them adhering to the MDR-TB treatment. Also, the counsellors helped the participants to set different possible ways of dealing with specific problem situations that prompt them to drink or smoke and taught them concrete techniques that would help them to quit or reduce intake. Besides, the counsellors also educated the family members of these participants in understanding about the ill effects of alcohol and smoking and provided them with some techniques during their visit to the treatment facility on how to better help them overcome their addiction.

Nutritional counselling was also given to the participants to assess their usual food intake and identify the areas where change was needed to help them develop a healthier lifestyle and strengthened their immune system. Nutritional awareness using visual aids (such as pictorial menus) and follow-up of their diet quality were done to help the patients make and maintain the needed dietary changes considering to each patient's situation and socio-economic background. For those patients who were having difficulties in maintaining the dietary changes, the counsellors helped them to set achievable health goals by developing a daily plan that promotes healthy eating while also

strengthening their motivation and taught them various ways of maintaining these goals.

Likewise, 19 participants had experienced poor quality of life at the start of treatment and at the end of treatment, only 2 participants had experienced poor quality of life (Table-4). Dissatisfaction with one's health condition was felt by 24 participants at the start of treatment which came down to 5 participants at the end of treatment. Quality of life scores in all four domains and depression level scores had significantly reduced from baseline to 24th month.

Depression and QOL at baseline	Baseline	24 th month	p-value
CESD depression scale			0.006*
No depression	6 (18.2)	14 (42.4)	
Depressed	27 (81.8)	7 (21.2)	
WHO-QOL scale			
Dissatisfied with his/her health	24 (72.7)	5 (15.2)	0.008*
Physical health (Mean ± SD)	11 ± 4	16 ± 3	<0.001 [§]
Psychological (Mean ± SD)	12 ± 3	17 ± 3	<0.001 [§]
Social relationships (Mean ± SD)	11 ± 4	15 ± 2	0.022 [§]
Environment (Mean ± SD)	13 ± 3	15 ± 3	0.002 [§]
Poor QOL	19 (57.6)	2 (6.1)	<0.001*

*McNemar Test & Paired t-test

DISCUSSION

This study highlights the positive impact of an intervention package that includes MI module, counselling module and nutritional support. One of the most common concerns raised by the study participants was rejection or exclusion from their loved ones that led them to deliberately separate or isolate themselves from their families and social activities. Feeling of guilt and shame, fear of transmitting the infection to their loved ones^(16,17,18,19,20) were also expressed as one of the common causes for self-isolation. Social stigma or discriminatory behaviour unleashed by health providers^(18, 20, 21) and family members had a far negative impact on the patients' treatment adherence. Study participants had expressed a dislike in making visits to the facility for the reason that they have been reprimanded or being humiliated by the health providers which they

found it very disheartening. This may be triggered by many forces including lack of understanding and knowledge of the disease, and myths and misconceptions that are deeply rooted in the society. Because of the stigma attached to this disease, patients experienced a lack of social and emotional support from their family members that undermined their ability to protect themselves or confidence to seek help and care. Research carried out in India that assessed Quality of Life (QOL) of MDR-TB patients found out that the social areas such as personal relationships, social support and sexual activity of MDR-TB patients were low compared to other areas (physical, psychological and environmental) that had an impact in their QOL⁽²²⁾.

Low level of psychosocial support, especially from family, during the treatment also underscored in several other studies which were found to be a factor affecting treatment adherence among MDR-TB patients^(18, 23, 24). Fears of death due to the disease or about their future and family have been yet another concern raised by most of the study participants. Moreover, one of the significant challenges raised consistently by the participants was issues related to MDR-TB therapy. Dealing with severe side effects of MDR-TB drugs like many other studies proved to be very challenging for most of our study participants^(18, 25, 26, 27, 28, 29) which they considered as an additional issue to cope with along with the symptoms of the disease itself. Adding to the adverse effects of MDR-TB drugs is the long MDR-TB treatment course that not only brought changes in the physical ability of the patients to perform their individual routine life but also resulted in the inability to go for work that eventually cost them their job. Our finding is corroborated with the study conducted in India, which reported that five out of ten MDR-TB patients could not resume work even after one year of treatment and had to force reductions in salary due to absenteeism from work⁽³⁰⁾.

Study participants consistently cited financial burden as a barrier as documented in a study conducted in Indonesia, which reported that the financial impact was higher among MDR-TB patients than that of TB (77% vs 50%)⁽³¹⁾. Similarly, financial issues were reported as the most prevalent issue to care or default among MDR-TB patients in several studies conducted in

China, India, Dominican Republic, Kazakhstan and Nepal^(25,32,33,34,35) Some participants managed this issue by borrowing money from family members, which often strained relationships. Many of our study participants reported losing their individuality and self-esteem since they lost their job and became financially dependent on their family members or relatives. Loss of job coupled with the financial crisis led to a more psychological impact on the patients as well as their families during the treatment course.

The psychosocial intervention not only supported treatment adherence for the patients but has also determined the need for a holistic approach to strengthening MDR-TB care and management of the TB control program. The outcome of our intervention was encouraging with improved treatment adherence observed among the participants and in pacifying their unpleasant emotions caused by MDR-TB. Psychosocial support programs have been considered as a successful component to help patients in enduring the long and unpleasant treatment, and thereby resulting in better treatment outcomes and reductions in default among MDR-TB patients. However, the benefits of psychosocial support in MDR-TB should not be limited only to increased adherence to treatment.

Even with the significant medical advances in patient management, psychosocial intervention remains an integral part of the holistic management and care for MDR-TB patients and their family. Our intervention that included psychological counselling, motivational interviewing and nutritional supplementation has shown the conducive result to both emotional and social rehabilitation of MDR-TB patients as well as treatment adherence. Most of our study participants were very positive about the counselling sessions and considered it very helpful during the long treatment journey. An intervention study in Nepal⁽³⁶⁾ showed improvements in cure rates with 76% among MDR-TB patients who received counselling with financial support. The present study also comprehends the vital and effective role of trained counsellors in enhancing the quality of life of MDR-TB patients through counselling. The impact of psychosocial interventions has also been underscored in some studies which showed significant reductions

in depression and default rates and improved adherence to MDR-TB medications. ^(19, 25, 35, 37, 38)

While (MDR) TB patients have an ethical duty to complete treatment, health providers' obligations to the patients and their caregivers also becomes a moral duty to support patients' ability to adhere to treatment. The current effort in psychosocial intervention for MDR-TB management is understood crucial; however, innovative patient-centred support mechanisms that are accessible and stigma reduction activities are scarce. There is a need not only to standardize an intervention module but also ensure the adoption of the same in the program becomes essential. Therefore, the researchers suggest an intervention package that consists of motivational interviewing, counselling and material support to aide MDR-TB Patients to complete treatment and to stop spreading the disease.

CONCLUSION

The important outcomes of this intervention study were improved Quality of life (QOL), a substantial increase in satisfaction with the health condition, reduction in the experience of depression and treatment adherence. Psychosocial support is a crucial component of MDR-TB treatment to ensure completion of treatment regimens and in enabling psychosocial rehabilitation after treatment. This kind of support will also help the patients endure the long and unpleasant treatment, thereby improved treatment compliance resulting in better treatment outcomes. This study emphasized the need to strengthen the psychological wellbeing and social relationship of MDR-TB patients using proper and consistent psychosocial support interventions and counselling in the TB control program. Furthermore, there is a need to include peer support groups for patients undergoing treatment and transitioning back into the community after treatment. Further, multi-state/ multi-site larger studies may be taken up to standardize the intervention strategies adopted in this study.

CONFLICT OF INTEREST

None

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