Quality of Life of Multi Drug Resistant Tuberculosis Patients: a Study of North India

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Abstract- Tuberculosis is still one of the leading causes of mortality and morbidity. Besides clinical impact, the disease affects the quality of life (QOL) too. With the rise of 21st century, multi-drug-resistant TB (MDR TB) has risen as a significant public health problem due to emergence of resistance to anti-tuberculosis therapy (ATT) drugs. This study was planned to analyze the impact of MDRTB on QOL. It was a six month analysis, with a sample size of 60 cases each of MDRTB and PTB. It was based on a pre-designed, pre-tested questionnaire using WHOQOL BREF scale. Out of each group, 38 (63.33%) and 36 (60.0%) were in the 21-40 years of age groups, more than 60% married and were residing in the urban/urban slums. It was found that QoL of MDRTB patients was worse than PTB counterparts. The psychological and environmental domains (MDRTB vs. PTB 17.46 vs. 15.23 and 22.00 *vs* 18.91) were more affected as compared to physical and social domains (19.03 *vs* 20.05 and 7.88 *vs* 9.61) in MDRTB and PTB. Financially, MDRTB patients were worst suffers as compared to PTB as former were not being covered under any program, while both groups are affected socially due to social stigma attached with the disease. Thus, there is a need to design an applicable, reliable measure to better address the quality issues methodologically. This would further enable the health care professionals and management to devise relevant interventions to improve the quality of the patients, as well as the programme.

Introduction

Tuberculosis remains a major public health problem worldwide. Tuberculosis is one of the leading causes of mortality and morbidity around the world, infecting approximately 8 billion people, with an annual death rate of close to 1 million1. India shares one third of the global tuberculosis burden and out of the 2 million incident cases approximately, half a million deaths occurs annually. Henceforth, tuberculosis is certainly an enormous public health problem in this country (1,2). Tuberculosis in India also carries a social stigma due to the perceived consequences of infection.

With the emergence of resistance to drugs used to treat Pulmonary TB (PTB), and particularly multi-drug-resistant TB (MDR TB), has become a significant public health problem and an obstacle to effective TB control (3). When there is a selective growth of resistant mutants in the presence of drugs, it is manifested as drug resistance. Resistance to a single drug is "mono resistance" while resistance to two or more drugs is termed as "poly resistance."

As MDR-TB (multi-drug resistant TB) describes strains of tuberculosis that are resistant to at least the two first-lines TB drugs, Isoniazid and Rifampicin. XDR-TB is MDR-TB that is also resistant to three or more of the six classes of second-line drugs. XDR-TB leaves patients (including many people living with HIV) virtually untreatable with the currently available anti-TB drugs. Recent findings from a survey conducted by the World Health Organization (WHO) and the Centre for Disease Control and Prevention had stated that XDR-TB is prevalent in all regions of the world but is more prominent in former Soviet Union and Asian regions

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and is even more difficult to treat than MDR-TB. And further to add, treatment is destined to fail, reason being, very few drugs will be left to which these patients still respond.

Tuberculosis patient, in addition to clinical symptoms has, to deal with several physiological, financial, and psychological problems. The symptoms and clinical burden of disease often extend beyond the duration of treatment. Also, the treatment itself may be related with several side-effects. All these aspects of the disease and its management have a huge impact on the overall well-being of the patient and burden of these factors can equal and even exceed the physical impact of illness (4).

However, there is no state-represented surveillance data of drug resistance among patients with TB and a major limiting factor in conducting drug resistance studies is the lack of state level Quality Assured Culture and Drug Sensitivity (DST) laboratory facilities. In a study done by Indian Council of Medical Research (ICMR) in India in nine centers, it was found that MDR TB varies from 0.6% to 3.2% with respect to initial drug resistance and 6% to 30% in respect to acquired drug resistance5. Also, Tuberculosis Research Centre and National Tuberculosis Institute findings show that MDR TB levels are less than 1% to 3% in newer cases and rises to about 12% in re-treatment cases (3).

According to the World Health Organization (WHO), health is defined as a state of complete physical, mental, and social well-being and not a mere absence of disease or infirmity. Thus, in an individual the impact of any disease, especially chronic illness is all-encompassing, not only his physical health but also ones psychological, economic, and social well-being.

Physical functioning reflects the capacity of the patient to carry out basic day-to-day activities. Some forms of Tuberculosis like Tubercular arthritis is well associated with long-term disability (6).

Psychological health takes into account several facets of the individual's mood and emotional well-being. Most patients are worried, frustrated, or disappointed by the diagnosis, and almost a quarter do not initially accept their diagnosis (7-9). The economic burden of the disease and distress of spreading the disease to others might impair the psychological health (10,11). These negative emotions generally decline and reduce over the course of successful anti-tubercular therapy (7).

Social functioning includes a patient's interaction with other people around him at home, work, and society. The marital impact of a diagnosis of tuberculosis is well known. It is difficult to arrange the marriage for boys and more commonly, girls, suffering from this disease. In many instances, knowledge of diagnosis has resulted in divorces or second marriages. Among patients admitted to isolation facilities, many feel lonely, bored, confined, or abandoned (12,13). In other instances, unfriendly health care workers made some patients feel frustrated, threatened, unwelcome, or uncomfortable (12,14). After discharge from the health care facility, many patients are not received back into their homes (15).

Even after successful completion of treatment, many patients inhibit to visit their acquaintances and from revealing their diagnosis to colleagues or even to their spouses (7). Such discriminations with the tuberculosis patients are a key determinant of non-adherence to ATT treatment (16). Patients are seen of even providing wrong addresses at ATT centers to avoid stigmatization to them and to their entire family (8,9). Patients are also afraid of informing their employers about their diagnosis to avoid losing job or wages (17). Women participation is lessened in household activities and they avoid seeking treatment unless and until the disease is far advanced and beyond control (11,18). In India, it is also common for women with tuberculosis to be rejected by their husbands or be sent away until cured (18).

Though in medical practice, the method of assessing patient health status and disease is by laboratory or clinical tests and but it becomes impossible to separate the disease from the individual's personal and social context, especially in chronic and progressive diseases with the tests.

Therefore, for a comprehensive assessment of patients' health status, it is very much essential to assess the overall impact of TB on health and patients' perception of well-being, besides routine clinical, radiological and bacteriological assessments (19). This assessment can be done by measuring the Quality of Life (QoL) that has several dimensions.

Measurement of health-related quality of life is gaining popularity and can be used to demonstrate the importance that an individual places on certain aspects of their health or disease process. This information may be potentially useful in developing more appropriate therapies and to assist in planning comprehensive strategies of care, which are important objectives in many chronic diseases.

The effect of disease on ones each dimension can be done by using certain instruments, which are either generic or specific. The assessment of chronic diseases like hypertension, leprosy and asthma and depression,

has been studied using such instruments. In the present study, WHOQoL (27) (BREF), which has the four domains, was used to assess the impact of TB on the QOL and to have an in-depth understanding of the effect of disease on various dimensions of patient's health. This would enable the health care professionals and management to devise relevant interventions to improve the quality of the programme.

So, the present study was an attempt to analyze the impact of MDRTB and PTB and the associated treatment on patients' QOL.

Materials and Methods

The study was conducted in a multispecialty tertiary level Hospital of North India, with an annual IPD of 40,000 and OPD load of about 4.5 lakhs. The OPD s the pulmonary wing has a TB clinic where patients with TB are examined and managed. The average annual enrolment of patients in TB clinic is 400 and 1800 for MDRTB and PTB respectively.

It was a three month analysis conducted in the TB clinic itself. The sample size was 60 cases each of MDRTB and PTB, who met the inclusion criteria, were interviewed at the TB clinic. The patients who were on MDR medication (from last six months minimum) and on Anti tubercular Treatment (ATT) (relapse/ failure cases) were enrolled for the study sample. The patients, who have been on ATT first time, were not taken in the

study sample. Also, the patients transferred from the study hospital to other health centres, IPD patients, subjects with co-morbidities (HIV, malignancy, diabetes or with underlying cardio-respiratory disease, rheumatic disease, psychiatric disease) were excluded from the study.

A pre-designed, pre-tested questionnaire about HRQOL using WHOQOL BREF, a 26-item scale was used to assess the Quality of life. The questionnaire has four domains i.e. physical health, psychological health, social relationships and environment.

Data were entered in MS excel and analyzed using SPSS. The overall QOL was assessed using specific questions and the mean scores for it were the average of the mean scores of the domains. One-way ANOVA was used for comparison between mean group scores. Ethics approval was obtained from the authorities, and informed consent was taken from each subject to participate in the study.

Results

Out of the 120 patients (MDRTB = 60, PTB = 60), who were included in the study, 69 (57.5%) were males and 51 (42.5%) were females. In each group (MDRTB and PTB; n=60), 38 (63.33%) and 36 (60.0%) were in the 21-40 years of age group respectively, while 51 (85.0%) and 38 (63.33%) of the patients were married. In each group, about 35.0% were housewives. (Table 1)

Table 1. Socio demographic profile

Factors	Variable	MDR n (%)	ATT n (%)	Control n (%)
Sex	Male	37	32	28
	Female	23	28	32
Age (Years)	0-20	3	2	0
	21-40	38	36	42
	41-60	13	14	17
	More than 60	6	8	1
Education	Illiterate	19	9	14
	Undergraduate	31	30	31
	Graduate	10	21	15
Marital status	Married	51	38	35
	Unmarried	9	22	25
Occupation	Laborer	12	10	14
	Housewife	20	25	20
	Others/ Pvt.	28	25	26
Locality	Urban/ Urban slum	37	32	35
	Rural	23	28	25
Total		60	60	60

In comparison to controls, PTB patients fared significantly better than the scores of MDRTB patients in psychological and environmental domains (MDRTB vs PTB 15.23 vs 17.46 and 18.91 vs 22.00) respectively, while scores for physical and social domain were lesser

(19.03 vs 20.05 and 7.88 vs 9.61) (Table 2). The mean differences in scores for the cases (MDRTB and PTB) were highly significant for all the domains and the overall QoL; (mean difference RTB 6.83; PTB 4.81).

Table 2. Mean table

	MDR Mean	ATT Mean	CONTROL Mean	F-RATIO
Domain-I Physical Health	19.03	20.05	24.08	28.902**
Domain-II Psychological	15.23	17.46	22.35	49.201**
Domain –III Social Relationship	7.88	9.61	12.45	28.837**
Domain –IV Environment	18.91	22.0	29.5	65.311**

**significant at 0.01 level

Results have shown that there is significant impact ($P > 0.01$) on Psychological (F-ratio = 49.201) and Environmental domain (F-Ratio = 65.311) (Table 2, 3). The respondents reported the wide range of psychological reactions viz. negative feelings of their survival, poor health and self-esteem. There were reports regarding restrictions towards their freedom of movement, participation in home and day to day recreation / leisure activities. Most patients claim that with the passage of time they have developed constraint relations with their family and friends as they get lesser support from their wards. The environmental domain related to the sense of safety, security, home environment, transport and financial security was also negatively affected in MDRTB and PTB patients.

Table 3. Analysis of Variance (ANOVA)

	SS	df	MS	F
Domain 1 (PHYSICAL HEALTH)				
Between	856.08	2	428.04	28.902**
Error	2621.37	177	14.81	
Domain 2 (PSYCHOLOGICAL)				
Between	1589.63	2	794.82	49.201**
Error	2859.32	177	16.15	
Domain 3 (SOCIAL RELATIONSHIP)				
Between	637.73	2	318.87	28.837**
Error	1957.22	177	11.06	
Domain 4 (ENVIRONMENT)				
Between	3555.28	2	17777.64	65.311**
Error	4817.58	177	27.22	

**Significant at 0.01 level

Financially, MDRTB patients were worst suffers as they were not been given any sort of medication from any Government, NGO or funded organization, while PTB patients have been covered under Revised National Tuberculosis Program (RNTCP). They are managing to health care organization of their own, and some (12.4%) are not being helped from their family members.

Tuberculosis is a disease with social implications due to the stigma attached to it. The mean scores of cases in social domains were (MDRTB *vs* PTB; 7.88 *vs* 9.61), while the impact on physical functioning that involves one's ability to carry on normal physical activities had almost similar impact on both MDRTB and PTB (19.03 & 20.05) patients. The respondents had

complaints of the early fatigability, regular body ache, and lack of sleep, unrest and decreased working capacity.

It can be inferred that the QoL of MDRTB patients was lower than the PTB and controls and all domains of QoL are affected.

Discussion

The present study was an attempt to analyze the impact of MDRTB and PTB and the associated treatment on patients' QOL. The QOL of MDR TB and PTB patients when compared with controls helped in the evaluation of the impact of TB on Quality of life. Still no such studies have been conducted to assess the QOL of MDRTB patients. To our knowledge, this is the first study that elicited the QOL of MDRTB and PTB patients.

Results have shown that MDRTB patients had significantly lower mean scores than PTB patients and the later has lesser scores in comparison to control the group for overall QoL and its domains. The worst affected were Environmental domain followed by the psychological domain.

In the present study, patients have reported wide range of psychological reactions and had developed negative feelings of their survival, poor health, and restrictions towards their freedom of movement, participation in recreation / leisure activities. These findings were similar to the study (22) where participants complained of boredom, frustration and isolation with their initial hospitalization. Even, some participants had expressed frustration with their primary care physicians for the lack ofprompt diagnosis or inappropriate management. There was a common perception among many of the participants that health care providers needed more extensive education regarding TB which is contrary in the present study. In the present study respondents were found to be complaining negative feelings of their survival, suffering from depression and results of the study were found to be consistent with the study conducted by Mirza (26) and others in Karachi in 2004.

In a study in Baltimore, it was found that the

financial well-being of some of the participants was adversely affected through loss of income and health care expenses whereas our study strongly support this issue as MDRTB patients are worst suffers as they have to manage their own treatment expenses, even not getting support from their families. A few of the respondents in our study have left job, especially doing private jobs, due to their health status or social stigma, which were similar to the findings to the studies of Raneswarj R and Kahn A (8,11).

The present study shows that, in both MDRTB and PTB patients, social functioning was affected through isolation; variable social support by family and friends, and inability to continue with social and leisure activities. This is in coherence with the other studies20, 21 which point out that TB affects all the predicted domains of QOL. i.e. psychological, health perceptions and social role functioning. Furthermore, a few qualitative studies (9,23-25), have shown that the social stigma attached to the diagnosis of TB in some cultures is significant. People with TB feel isolated from their family and friends or experience the fear and anxiety of being known by others about their diagnosis.

In China, a study conducted on TB patients using SF-36 questionnaire also showed that HRQoL declines in patients having TB with physical scales the most affected21, while, in our study, the physical scales are comparatively less hampered in comparison to other domains.

The study had certain limitations. We had enrolled a self-selected group of MDRTB and PTB patients who may not be representative of the entire population of North India affected by TB. In fact, we have attempted to select individuals from different geographical and socioeconomic groups, with a belief, that the responses that we received are likely indicative of the areas of QoL, which are affected by MDRTB.

The present study shows that Quality of life of patients with the history of MDRTB and PTB was worse than healthy subjects as measured by WHOQoL methods. Our review suggests that a further step in the future would be to design an applicable, reliable and valid TB-specific HRQL instrument, which can better address quality of life issues methodologically.

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