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## QUALITY OF LIFE OF MULTI DRUG RESISTANT TUBERCULOSIS PATIENTS IN INDIA



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### ABSTRACT

**T**uberculosis remains as a major public health problem and one of the world's deadliest communicable diseases. In 2013, globally around 9 million people were estimated to have developed TB and 1.5 million died of TB. India accounts for 24% of world TB cases. Quality of life refers to a subjective evaluation which is embedded in a cultural, social and environmental context. 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.

The researchers have studied the Quality of Life (QOL) that has several dimensions. The effect of disease on each dimension can be assessed using instruments, which are either generic or specific. The impact of various chronic diseases like hypertension, leprosy and asthma and depression has been studied using this WHO QOL BREF scale instrument. In this present study, WHO QOL (BREF) which has the four domains was used to assess the impact of MDR TB on the QOL. It is required to incorporate the measurement of QOL of MDR TB patients to have an in-depth understanding of the effect of disease on various dimensions of health.

**Objective:** To study the Quality of Life of MDR TB patients in three states of India. **Methods:** The study population were the MDR TB patients from three States of India Bihar, Andhra Pradesh and New Delhi. The universe of the study were the MDR TB patients who were undergoing treatment before the year March 2015 and have at least completed six months of treatment under the Revised National Tuberculosis Control Programme (RNTCP) and above 18 years of age. A total of 610 patients were interviewed. In this research the researcher describes the characteristic of persons affected by MDR TB and their quality of life. Hence the researcher adopted the descriptive research design to study the QOL of MDR TB patients. A structured interview schedule was instrumented to collect the data along with WHO QOL BREF; a 26-item scale was used to assess the Quality of life. **Findings:** It is identified that among the four QOL domains Social domain remains low, which means the Personal relationships, Social support and Sexual activity of the MDR TB patients are affected. Male MDR TB patients QOL was comparatively higher than the female MDR TB patients. The young MDR TB patients

in the age group of 18 to 30 years had higher QOL and MDR TB Patients above 60 years had low quality of life when compared to other MDR TB patients. Among the three States, Bihar, Andhra Pradesh and New Delhi QOL among MDR TB patients in Andhra Pradesh was comparatively higher. Among the major religions Hindu, Muslims and Christians, MDR TB patients among Muslims had higher quality of life except in the environmental domain. Conclusion: The quality of life of MDR TB patient study has revealed that among the four WHO BREF QOL domains Social domain remains much low which means, the Personal relationships, Social support and Sexual activity of the MDR TB patients are affected. The study reveals that among the MDR TB patients especially the young patients in the age group of 18 to 30 years have higher QOL when compared to other age groups. The QOL of male MDR TB patients is comparatively higher to females MDR TB patients. Thus, there is a much scope that awaits for the health fraternity, health care professionals and policy makers to devise and incorporate a systematic approach to study the quality issues of TB and MDR TB patients which would pave way for a timely and relevant intervention for the MDR TB patients.

**KEYWORDS:** *Quality of Life, Health study, MDR Tuberculosis, Drug Resistant TB Physical, Psychological, Social, Environment.*

### INTRODUCTION :

Tuberculosis remains as a major public health problem and one of the world's deadliest communicable diseases. In 2013, globally around 9 million people were estimated to have developed TB and 1.5 million died of TB. India accounts for 24% of world TB cases. Multi drug resistant tuberculosis (MDR-TB) is a contagious disease, which spreads through droplet nuclei. Multi drug resistant tuberculosis is a type of TB that often develops in patients who do not adhere to or complete the proper treatment for TB. Most of the strains of Mycobacterium Tuberculosis are sensitive to first line anti-TB drugs. Multi Drug Resistant (MDR) TB is caused by strains resistant to Rifampicin & Isoniazid, two key first line anti-TB drugs. In 2013 alone, around 4, 80,000 people were estimated to have developed MDR-TB. It is estimated that around 61,000 people in India have developed MDR TB during the year 2013, as stated in the reports (12, 13 & 14).

Patients with drug sensitive TB require 6-8 months of treatment with less toxic drugs. Studies have shown that patients with drug sensitive TB face stigma and discrimination within their family, neighbourhood and also in work places. Beside this they face catastrophic health expenditures, loss of productive man days and they are further pushed into poverty. When a woman suffers from TB, the household loses the activities that the woman routinely performs. In some societies, TB patients are seen as injured for life or unmarriageable. 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. Such discrimination can result in anxiety, depression, and reduction in the quality of life. A person who is diagnosed with MDR TB would have already taken treatment for 6-8 months with first line drugs, besides this he needs to further undergo MDR TB treatment for another two years, leading to worst socioeconomic consequences among the MDR TB patients.

### II) LITERATURE REVIEW:

WHO defines; Quality of life is defined as individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. This definition reflects the view that quality of life refers to a subjective

evaluation which is embedded in a cultural, social and environmental context. 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.

Global TB Report 2014 of WHO states that India and China alone accounted for 24% and 11% of total world TB cases, respectively.

TB India Annual Report 2014 of Central TB Division RNTCP Programme states that there are 230 suspects per lakh population among which there are 75 new sputum positive cases among which 2 to 3 percent are diagnosed for MDR TB.

Morris et al (2013), has conducted a qualitative study in Mexico and used in-depth interviews which revealed an intense perception of social isolation, coupled with the inability to work and the uncertainty of how MDR-TB would affect their future ability to earn a living and therefore re-integrate into society, appeared to decrease patients' sense of worth.

Sharma R et al (2013), in their study done in north India found that the quality of life of MDR TB patients was worse than drug sensitive TB patients.

Khan et al, had found in a study conducted in Pakistan on socio-cultural constraints in treatment that while both male and female TB patients face social and economic problems, female patients are more affected.

Meera Dhuria et al (2008), in their study in Impact of Tuberculosis on the Quality of compared the QOL scores in patients of TB with that in normal population showing lower mean scores than the controls worst affected were physical domain followed by psychological domain.

Hansel NN, Wu AW, Chang B, et al. (2004), The purpose of this study was to describe the impact of TB on patients' QOL by using focus groups to assess the domains of QOL that are affected. The QOL domains and three elements of treatment specific to TB which substantially impact QOL were identified. While patients and clinicians both identified issues in many areas of QOL, only patients mentioned the impact on sexual function, spirituality and improved life perspectives.

Chamla D (2004), In China, a study conducted on TB patients using SF-36 questionnaire also showed that health-related QOL declines in patients having TB with physical scales the most affected.

The WHO QOL facets and domains incorporated within domains of Physical aspects are the Activities of daily living, Dependence on medicinal substances and medical aids, Energy and fatigue, Mobility, Pain and discomfort, Sleep and rest and Work capacity. With regard to the Psychological aspects covered are the Bodily image and appearance, Negative feelings, Positive feelings, Self-esteem, Spirituality/religion/personal beliefs, thinking, learning, memory and concentration. The Social aspect covers the relationships which are Personal relationships, Social support and Sexual activity. The factors in Environment involves the Financial resources, Freedom, physical safety and security, Health and social care, Accessibility and quality Home environment, Opportunities for acquiring new information and skills, Participation in and opportunities for leisure activities, Physical environment (noise, pollution, climate, traffic) and Transportation, which are considered as important factors.

Chow SP, Yau A, in the study on Tuberculosis of the knee-- A long term follow-up sated that Physical functioning reflects the capacity of the patient to carry out basic day-to-day activities. Liefoghe R, Michiels N, Habib S, et al. in their study stated that Psychological health takes into account several aspects of the individual's mood and emotional wellbeing. Patients are worried, frustrated, or disappointed when it comes accepting of the TB / MDR TB diagnosis; the economic burden of the disease and distress of spreading the disease to others is also a cause to leading to psychological factors. Social functioning includes a patient's interaction with other people around them at home, work, and society. Patients are many a times isolated therefore they feel lonely, bored, confined, or

abandoned. The environmental aspect covers the living standards and compatibility towards a conducive environment & well being of the MDR TB patients.

The researcher has studied this by measuring the Quality of Life (QOL) that has several dimensions. The effect of disease on each dimension can be assessed using instruments, which are either generic or specific. The impact of various chronic diseases like hypertension, leprosy and asthma and depression has been studied using this WHO QOL BREF scale instrument. In the present study, WHO QOL (BREF) which has the four domains was used to assess the impact of MDR TB on the QOL. It is required to incorporate the measurement of QOL of MDR TB patients to have an in-depth understanding of the effect of disease on various dimensions of health.

### III) METHODOLOGY:

The methodological aspects of the research study includes Aim, Objectives, field of study, Research Design, Sampling Design, Sources of Data, Tools for Data Collection and Data Analysis plan are discussed in this area.

#### a)Objective:

To study the Quality of Life of MDR TB patients in three State of India.

#### b) Study Population:

The universe of the study were the MDR TB patients who were undergoing treatment before the year March 2015 and completed six months of treatment under the Revised National Tuberculosis Control Programme (RNTCP) and above 18 years of age. The patients below 6 months of MDR TB treatment were not taken in the study sample. The patients were interviewed at their residence and also during their visits to DOT's centre and DOT providers.

#### c)Sampling Frame and Sampling Design:

The study was conducted in 3 States of India, Bihar, Andhra Pradesh and New Delhi. Twenty two districts were selected for the study, 15 districts from Bihar 6 districts from Andhra Pradesh and one district from New Delhi. Proportionate stratified random sampling method was adopted for this study. A total of 610 patients (272 from Bihar, 295 from Andhra Pradesh and 43 from New Delhi) were interviewed.

#### d)Research Design:

In this research the researcher describes the characteristic of persons affected by MDR TB and their quality of life. Hence the researcher adopted the descriptive research design to study the QOL of MDR TB patients. A structured interview schedule was instrumented to collect the data along with WHO QOL BREF; a 26-item scale was used to assess the Quality of life. Data were entered 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. The informed consent was taken from the patient to participate in the study.

### IV)RESULTS:

Out of the 610 MDR TB patients who were included in the study, 423 (69.3%) were males and 183 (30.7%) were females. The patients in the age group of 10 to 30 years were 44.6%, 31 to 40 years were 5.4%, 41 to 50 years were 15.2%, 51 to 60 years were 11% and above 60 years group were 3.8%

respectively, while 420 (68.9%) of the respondents were married, 152 (24.9%) were not married and others were either separated or widow or widower.

**Table 1. Gender and Age wise distribution of Patients QOL**

Domains	Physical Mean (SD)	Psychological Mean (SD)	Social Mean (SD)	Environmental Mean (SD)
<b>Gender wise distribution</b>				
Male	55.4289 (12.10)	54.6395 (13.09)	52.4035 (18.14)	58.4072 (16.21)
Female	53.1131 (13.25)	52.6961 (12.35)	47.6827 (19.18)	56.9853 (16.86)
<b>Age wise distribution</b>				
18 to 30 Years	56.0530 (12.12)	56.5104 (12.54)	54.6569 (17.27)	58.8580 (16.18)
31 to 40 Years	53.0415 (14.19)	52.2043 (13.78)	49.7312 (20.81)	56.0484 (16.66)
41 to 50 Years	55.0691 (11.06)	53.4050 (11.62)	50.0000 (17.97)	58.9382 (16.11)
51 to 60 Years	53.7313 (12.09)	51.8035 (12.05)	43.9055 (16.64)	58.6754 (16.69)
60 & above Years	51.7081 (10.20)	46.3768 (12.51)	39.8551 (14.20)	54.4837 (17.77)

It is evident from Table 1, that in gender wise distribution of domains, male MDR TB patients' scores were higher when compared to female MDR patients. Higher the mean domain score higher the quality of life of MDR TB patients. It is observed that among the four domains both male and female MDR TB patients have obtained lower mean score in Social domain when compared to other domains. It is also observed from the age wise distribution that among the four domains scores the young people in the age group of 18 to 30 years have obtained more mean score when compared to other age groups, therefore young MDR TB patients in the age group of 18 to 30 years quality of life is comparatively higher than other age groups. The MDR TB patients above 60 years secured less scores which indicates their quality of life is low when compared to other age groups.

**Table 2. State wise distribution of patients QOL**

State	Physical Mean (SD)	Psychological Mean (SD)	Social Mean (SD)	Environmental Mean (SD)
Bihar	51.9695 (13.88)	52.8339 (13.80)	49.0196(19.54)	50.7583 (14.62)
Andhra Pradesh	58.5351 (9.08)	56.8362 (10.70)	51.9209(17.44)	66.9174 (12.69)
New Delhi	45.9302 (14.69)	42.5388 (13.41)	56.5891(18.68)	42.2238 (15.76)

In table 2, the distribution of State wise QOL is presented with four domains. The MDR TB patients QOL in three States Bihar, Andhra Pradesh and New Delhi were compared among which the QOL among Andhra Pradesh patients were comparatively higher except in the social domain aspects. Secondly the QOL of Bihar was higher when compared to New Delhi MDR TB patients. New Delhi being a capital and metropolitan city it was observed that the MDR TB patient’s scores in Physical, Psychological and Environmental domain scores were very low except Social domain scores when compared to Bihar and Andhra Pradesh.

**Table 3. State wise distribution of patients QOL**

Religion	Frequency	Valid Percent	Physical Mean (SD)	Psychological Mean (SD)	Social Mean (SD)	Environmental Mean (SD)
Hindu	470	77.0%	53.9286 (13.01)	53.6082 (13.50)	51.0638 (18.94)	57.0678 (16.89)
Muslim	105	17.2%	57.0068 (10.75)	55.8333 (10.39)	52.5397 (17.06)	60.1190 (15.09)
Christian	33	5.4%	57.4675 (7.48)	53.5354 (10.31)	45.4545 (16.93)	63.1629 (11.71)
Others	2	0.3%	75.0000 (.00)	70.8333 (5.89)	33.3333 (23.57)	71.8750 (.00)
Total	610	100.0	(54.72)	(54.04)	(50.96)	(57.97)

The MDR TB patient’s religion and faith wise distribution is categorised in table 3. It is observed that 77% were Hindu, 17.2% Muslim, 5.4% Christian and 0.3% belonged to other faith. The MDR TB patients those who belonged to other faith had high mean score and except in social domain when compared to other religions. Among the MDR TB patients from Hindu, Muslim and Christian religion it is observed that MDR TB patients among Muslim religion had a higher mean score in all the domain except in environmental factor, where the Christian domain score remained high.

**V) DISCUSSION:**

This study was an effort to analyse the impact of QOL among the MDR TB patients from 3 State of India, South (Andhra Pradesh), North (Bihar) and Capital of India (New Delhi). To our knowledge, this



is the first kind of its study that has been elicited on the QOL of MDR TB patients with A cross comparison of MDR TB patients from the three States in India.

The results of this study has revealed that the QOL among the MDR TB patients in the four domains, Physical, Psychological, Social and Environmental scale, Social domain scores remained low, which means the Personal relationships, Social support and Sexual activity of the MDR TB patients were affected. This is in coherence with the other studies (1,2) 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 (3, 4,5), 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.

The study has revealed that the male MDR TB patients the entire four domain scores QOL was comparatively higher than the female MDR TB patients. These findings were similar to the study of Meera Dhuria, et al. on impact of Tuberculosis on the Quality of Life (6,7) where the females are economically and socially affected when compared to male. In this study it was identified that young MDR TB patients in the age group of 18 to 30 years had higher QOL when compared to other age groups and the MDR TB patients above 60 years have lower QOL among all.

New Delhi being a country capital and a metropolitan city it was observed that the MDR TB patient's quality of life was comparatively lower in Physical, Psychological and Environmental domain except in Social domain when compared to Bihar and Andhra Pradesh. This is in lines with the study (11) where the Psychological health takes into account several aspects of the individual's mood and emotional wellbeing.

Among the three States, Bihar, Andhra Pradesh and New Delhi QOL among MDR TB patients in Andhra Pradesh was comparatively higher except in the social domain where New Delhi was first and second stood Bihar. The MDR TB patients those who belonged to other faiths had higher QOL except in the social domain scores when compared to other religions. Among the three major religions Hindu, Muslims and Christians, MDR TB patients among Muslims had higher quality of life except in environmental domain.

There are some limitations in the present study that may have some potential impacts on the results. As part of sampling process all the MDR TB were not available for interview due to various practical reasons, so the available and willing MDR TB patients for the interview from the proportion were included for the study.

### **VI) CONCLUSION:**

In the quality of life among the MDR TB patients in the four domains Social domain remains much affected which means, the Personal relationships, Social support and Sexual activity of the MDR TB patients are affected. The study reveals that among the MDR TB patients especially the young patients in the age group of 18 to 30 years have higher QOL when compared to other age groups. The QOL of male MDR TB patients is comparatively higher to females MDR TB patients. Thus, there is a much scope that awaits for the health fraternity, health care professionals and policy makers to device and incorporate a systematic approach to study the quality issues of TB and MDR TB patients which would pave way for a timely and relevant intervention for the MDR TB patients.

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