A QUALITATIVE STUDY ON THE PSYCHOSOCIAL CHALLENGES FACED BY MRD TB PATIENTS

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ABSTRACT

Background & objectives: In light of the challenges posed by MDR-TB, the 'DOTS Plus' guidelines for a comprehensive strategy to the treatment of this disease. This study aimed to investigate the psychosocial factors that adversely affect medication adherence in MDR-TB patients diagnosed and registered for treatment. **Methods:** This qualitative study employed focus group discussions and interviews involving 72 participants, comprising 57 MDR-TB patients and 14 healthcare workers, who were diagnosed with MDR-TB. All FGD sessions were audio recorded, and the recorded information was transcribed verbatim in Hindi and subsequently translated into English. **Results:** The majority of the individuals involved in the study chose not to reveal their tuberculosis status, even to those in their own families. Most patients were unaware of their diagnosis of MDR-TB and the extended treatment duration. The majority of patients have encountered stigma from their families, communities, and health providers. Patients and their families expressed concerns about the potential loss of economic stability, which was already fragile due to the illness. **Conclusion:** This qualitative study has identified a variety of problems faced by patients with MDR-TB and their family. Psychosocial support is essential to alleviate stigma and address the related psychological pressures.

Key words: Psychosocial support, psychosocial factors, MDR-TB, family.

INTRODUCTION

The treatment for MDR-TB is characterized by a stringent regimen of prolonged length, a higher frequency of unpleasant side effects, a reduced cure rate, and elevated treatment expenses.[1] This may result in various psychosocial issues that affect treatment adherence. In light of the challenges posed by MDR-TB, the 'DOTS Plus' guideline established by the Ministry of Health and Family Welfare, Government of India, advocates for a comprehensive strategy to the treatment of this disease.[2,3]

The DOTS Plus strategy comprises a multidisciplinary team of providers, including physicians, nurses, social workers, community health workers, and volunteers, who deliver a variety of services for MDR-TB patients, encompassing psychosocial and community support.[4] Although numerous studies in India and other nations have explored the

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psychosocial issues related to TB patients, there remains a scarcity of research focused specifically on MDR-TB patients within this context.[5,6] This study aimed to investigate the psychosocial factors that adversely affect medication adherence in MDR-TB patients diagnosed and registered for treatment under NTEP.

MATERIALS AND METHODS

This qualitative study employed focus group discussions and interviews involving 72 participants, comprising 57 MDR-TB patients and 14 healthcare workers, who were diagnosed with MDR-TB and registered under the DOTS Plus program between the fourth quarter of 2022.

Patients who shown desire and provided informed written consent were invited to participate in focus group discussions. Each focus group discussion consisted of six to eight participants, both male and female. Efforts were made to optimize patient comfort levels. Focus Group Discussions (FGDs) typically aligned with the patients' medication collection day, during which participants were provided an amount of Rs. 100/- to cover their lunch and local transportation expenditures.

A qualitative focus group discussion guide was developed based on the literature study and the team's prior experience (Box-1). The guidelines encompassed thematic areas related to the physical issues faced by MDR-TB patients (pain, breathlessness, fatigue, dizziness, somnolence), psychological disturbances (anxiety, fear, tension, denial, depression), social challenges (issues of disclosure, rejection, enacted stigma, perceived stigma, discrimination from family and community), and economic difficulties (inability to work, absenteeism, loss of income, indebtedness). Moreover, the challenges encountered during treatment and the subsequent pursuit of a normal life were addressed.

All FGD sessions were audio recorded, and the recorded information was transcribed verbatim in Hindi and subsequently translated into English. Qualitative data that were transcribed and translated were inputted into the NVIVO software tool.

Content analysis and theoretical thematic interpretation have been conducted utilizing both deductive (top-down) and inductive (bottom-up) coding, along with the integration of codes. A flow chart was created based on the discovered contextual psychosocial themes from the investigation. The transcribed data were categorized into five distinct themes.

i) Knowledge regarding the diagnosis of multidrug-resistant tuberculosis (MDR-TB).

ii) Preliminary response to sickness,

iii) Challenges pertaining to disclosure problems iv) Experience of stigma and

V) Economic challenges encountered by MDR-TB patients.

RESULTS

The study participants ranged in age from 19 to 73 years, with over fifty percent being married. The majority possessed a school-level education. With the exception of one patient, all were initiated on treatment under the Category-II regimen under RNTCP, subsequently diagnosed with MDR-TB, and transitioned to the DOTS Plus Category-IV regimen. Participants exhibited homogeneity in age across three of the five focus group discussions. Two focus group discussions included participants of a slightly older demographic. Nonetheless, all participants in the five focus group discussions were daily wage earners.

i) Understanding the diagnosis of multidrug-resistant tuberculosis (MDR-TB)

One-third of participants were unaware of their MDR-TB status, the causes of MDR-TB, and the necessity for an extended treatment duration. Participants indicated they were diagnosed with 'muthina TB' (advanced tuberculosis) and 'Valarntha TB' (excessive tuberculosis). Several others stated that healthcare providers advised them to undergo daily injections for six months and to continue medication for 24 months. However, participants felt that the rationale for these treatments was not adequately communicated. One male participant remarked, “I was informed that I need to take 12 tablets per day for two years with daily injections for six months; no one informed me that I have MDR TB” (Male, age 36 years).

ii) Primary response to illness

A significant concern raised by the participants was fear. Participants, comprising both men and women, had fears of transmitting infections to family members, dread of mortality, and concerns for the future of their relatives.

Upon learning about the prolonged treatment time and the quantity of medication required, the participants internalized the problem's scope and had a sequence of first emotions. Over fifty percent of individuals experienced guilt, since they were informed that their non-adherence to tuberculosis treatment was the cause of their sickness. I am unable to ingest tablets, and I find it exceedingly difficult to consume 12 tablets. I expel one or two tablets through vomiting. I perceive the dosage as excessive; following the administration of the prescription, I experience drowsiness and encounter unwarranted dreams and nightmares.” (Male, 35 years old)

In addition to dread, other psychological concerns such as disbelief, denial, and depression were consistently stated by all participants in the focus group discussions. MDR-TB has also affected sexual life. A female participant forfeited her family life due to the apprehension of transmitting an infection to her spouse, stating the following. “I refrain from sexual contact with my husband to avert the transmission of MDR-TB to him” (Female, 21 years old).

I wept. I was unable to focus on my examinations. “I contracted this disease at a young age” (Male, 19 years).

Participants experienced self-pity regarding their sickness status and associated issues due to their sadness. Self-blame for the events that transpired was a decision made by many. As this disease deteriorates, suicidal thoughts emerges. Disbelief and denial frequently resulted in sadness and suicidal ideation. Participants expressed denial and amazement with statements such as, “I felt like killing myself.” How was I to ingest tablets for a duration of two years? "I lack adequate food." (Male, 36 years)

I am prepared to undergo two years of treatment. "If I am not cured this time, there is no alternative, and I will have to die." (Female, 29 years)

iii) Challenges pertaining to disclosure matters

The majority of participants indicated that they did not reveal their MDR-TB status to family members, since the disclosure of tuberculosis was regarded as a sensitive matter, resulting in potential rejection at home. A young male participant, aged 21, expressed his worry regarding future marital prospects. “I was apprehensive about revealing my MDR-TB status to my relatives, particularly to my aunt, due to

concerns regarding my future." (Male, 21 years old)

Another concern regarding disclosure was the potential adverse effects it could have on the neighborhood. One participant (male, 35 years old) reported that his neighbors have designated him as a 'chronic sick person.' Consequently, he hardly ventured outside his residence to evade confronting difficult inquiries from neighbors. "I am inquired about my slenderness and the persistence of my cough." What is the reason for my consumption of tablets?.... I infrequently exited my residence to evade responding to such inquiries" (Male, 35 years).

"I am apprehensive about social interactions, avoiding gatherings and outings, and have now acclimated to residing alone in a separate room." (Male, 45 years).

iv) Encounter with stigma

Both men and women commonly expressed that MDR-TB patients experienced prejudice both at home and in the community due to the extended therapy necessitating many hospital visits.

The majority of respondents indicated experiencing discrimination within their families. This was seen in aggressive comments either being expressed externally or confined within the family unit. Few individuals have chosen to maintain their possessions separately within the residence. In some cases, inmates have disregarded an MDR-TB patient entirely, perceiving him/her as a liability to their family. Household prejudice, in particular, complicates life significantly for MDR-TB sufferers. A male participant articulated this sentiment. I have lost my parents. My siblings have not accepted me since they learned of my tuberculosis diagnosis and the necessity for a two-year treatment regimen. I am currently remaining on the platform." (Male, 31 years old).

Occasionally, the patient's family responded positively, something the patients yearn for. In certain instances, family ostracized the sick to the extent of relegating him/her to the dirtiest and most isolated area of the house, severely restricting any form of socialization.

Fifty percent of the participants indicated that their friends and neighbors mistreated and shunned them. Participants reported experiences of heartedness both directly and indirectly. Several individuals also reported negative reactions from their neighbors. Two respondents indicated that they were requested to leave their residence owing to their medical condition. A multitude of participants encountered discrimination in public venues as well. Two responders were requested to depart their residence due to their chronic sickness. The account of two participants is conveyed as follows: "Shortly after my discharge from the tuberculosis hospital, my landlord compelled me to vacate the premises." I was resting on the platform." (Male, 21 years old).

v) Economic challenges encountered by MDR-TB patients

Patients frequently constituted the sole earners in their households, while the majority of women bore the dual task of managing the home and caring for children. Patients and their families feared the loss of economic stability, which was already tenuous due to illness. This concern has frequently induced significant stress. I ceased attending work and remained at home, therefore unable to contribute to household expenses. My siblings would infrequently visit me and provide a sum of Rs. 200 to 300 before departing. I experienced financial repercussions, which led to feelings of worry and guilt." (Male-35 years)

I must traverse 4 to 5 kilometers daily to obtain medication. I am the primary financial provider for the family. I was unable to attend daily due to work commitments. When I take tablets alongside injections, I am unable to engage in any activities and cannot keep regularity." (Male-31 years).

DISCUSSION

This study has identified several barriers encountered by MDR-TB patients, including disclosure, stigma, psychological issues, and economic difficulties. These findings validate previous research that has emphasized the psychological, social, and economic challenges faced by MDR-TB patients. This outcome necessitates a comprehensive intervention strategy to systematically address these issues, thereby improving treatment adherence and quality of life for MDR-TB patients.

A notable finding from this study was the deficiency of knowledge regarding the diagnosis of MDR-TB among patients enrolled in the DOTS Plus program. From a public health standpoint, understanding sickness is a crucial element that enables individuals to acquire, convey, process, and comprehend fundamental health information. This underscores the necessity of educating affected individuals about MDR-TB. Participants indicated that healthcare staff have not provided information regarding MDR-TB. This may be attributed to the inadequate understanding of MDR-TB among healthcare professionals. The findings indicated that fewer than half of healthcare workers possessed accurate knowledge regarding tuberculosis (TB). Similarly, a study conducted among healthcare workers and TB patients in Southern Nigeria revealed that 38% of healthcare workers and 82% of TB patients exhibited inadequate knowledge about multidrug-resistant tuberculosis (MDR-TB). This underscores the necessity for training and retraining healthcare workers on MDR-TB to ensure they provide appropriate health education to patients.[7,8]

The ideas of motivational interviewing, demonstrated to enhance treatment adherence in India, could be further investigated among MDR-TB patients. In addition to educating patients, their families, and employers about MDR-TB, it is crucial to assist patients in comprehending their issues and to aid them in overcoming both perceived and performed social stigma.[9,10]

Both the morbidity and treatment of MDR-TB resulted in an economically precarious condition for patients. Many people with MDR-TB have suffered from physical problems associated with their condition, including dyspnea, fatigue, cachexia, cephalalgia, gastritis, depression, and peripheral neuropathy.[11] These physical ailments impaired their capacity to engage in productive labor. The bulk of participants in this study were from a low socioeconomic class, specifically wage laborers. They experienced an incapacity to work and were anxiously attempting to surmount thoughts of 'uselessness' and being 'a burden' to their families.[12]

CONCLUSION

This qualitative study has identified substantial psychological, social, and economical obstacles faced by patients with MDR-TB and their family. Psychosocial support for MDR-TB patients and their caregivers is essential to alleviate stigma and address the related psychological pressures. Our findings also

highlight numerous policy-relevant challenges in the management of MDR-TB within the community. Policy debates and reforms are necessary to innovate intervention options that assist MDR-TB patients in managing their psychosocial problems, hence enhancing treatment adherence and decreasing default and TB transmission rates. Additionally, there is an urgent necessity to assess patients' financial apprehensions regarding elevated therapy expenses, transportation costs, and income loss.

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