Original Research Paper

Volume-8 | Issue-3 | March-2018 | PRINT ISSN No 2249-555X

Community Medicine

CHANGES IN FAMILY DYNAMICS OF PATIENTS WITH MDR-TB AND ASSESSMENT OF THE COPING MECHANISMS ADOPTED BY THE FAMILIES- A QUALITATIVE STUDY.

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ABSTRACT The social impact of TB extends beyond TB patient to household members and the larger community. MDR-TB poses greater burden than drug sensitive TB. Understanding the effect of MDR-TB on family and mechanisms adopted by families to overcome them will help in devising strategies for comprehensive care. A qualitative study was conducted in the family members of MDR- TB to assess the effects of diagnosis and treatment of Tuberculosis on the family dynamics and to assess the mechanisms resorted to by the family members to overcome the burdens. In-depth interviews were conducted. Data was coded inductively. Thematic analysis was done using grounded theory. 4 main themes emerged from data. 1. Family members lack appropriate knowledge on MDR-TB, 2. MDR- TB has regressive effects on life of patients 3. Daily Life of family members was impacted 4. Social Networks play important role in coping positively.

KEYWORDS : MDR-TB, Family dynamics, Coping mechanisms

Introduction:

The social impact of TB extends beyond the TB patient to household members and the larger community. At the household level, TB has a considerable impact in terms of income, health, education and nutrition (Grede, Claros, de Pee, & Bloem, 2014). MDR-TB poses greater burden than drug sensitive TB. Stories like that of Dr. Samidha Khandare ("Mumbai News - Times of India, Death of 24-year-old doctor at Mumbai hospital due to MDR-TB |," n.d.) are glaring examples for effects of MDR-TB .

Families may adopt different strategies to cope with the changes. A positive coping strategy helps to access timely diagnosis of TB and helps to preserve quality of life of the family. Negative coping strategies fail to preserve assets and reduce production and income levels, thereby increasing the risk of collapse for the household or deepening impoverishment.

Understanding the effect of MDR-TB on family and mechanisms adopted by families to overcome them will help in devising appropriate strategies to provide comprehensive care to whole family.

Objectives

1. To study the changes in family dynamics of patients with MDR-TB
2. To assess the coping mechanisms adopted by the families

Methodology

Qualitative (In depth interviews) were conducted in the family members of persons diagnosed with MDR-TB and taking treatment from the DOTS center under UHTC, department of Community Medicine, Seth G S Medical College and KEM Hospital, Mumbai. Standard WHO case definition ("WHO | What is multidrug-resistant tuberculosis (MDR-TB) and how do we control it?," 2017) was used to define MDR-TB. Family was defined according to definition of Sharma et.al (Sharma, 2013). Convenient sampling was used and data was collected till the data saturation is reached. Diagnosed cases of HIV positive were excluded from the study. Total number of interviews conducted was 13. Transcripts were prepared depending on the notes of interviews and memos. Coding of all relevant data was done by inductive method. Thematic analysis was used. Data was analyzed by grounded theory using atlas.ti software version 7.5.7

Results-

Table 1: Distribution of participants according to religion and relation with patient.

Relation/ Religion	Hindu	Muslim	Total
Husband	1	1	2
Wife	2	1	3
Mother	4	3	7
Father	1	0	1
Total	8	5	13

Many of the participants belonged to Hindu religion and were mothers of patients.

4 main themes emerged from the data.

1. Family Members lack appropriate Knowledge

Most of the family members lack correct knowledge about MDR-TB. While all of the participants knew TB to be air borne, there were gaps in knowledge with respect to other activities such as sharing of food. Many of the participants knew MDR-TB to be severe than drug sensitive TB but did not know the reasons for emergence of same.

"People when they have TB and they share same food and water it might have happened. People who have TB should know to be separate"

There was ignorance about the effects and infectivity of MDR- TB on one hand and in appropriate fears on the other. Some of the participants described MDR-TB as the most dangerous disease one can get.

One of the patients was staying away from home and his family since the day he was diagnosed with MDR-TB and was determined to stay alone till he is declared cure. Remaining family of the patient was staying at relatives' since one and half years and has not met the patient even once. Lack of knowledge about appropriate preventive measures and personal protective measures had led to broken families.

2. Regressive effects on life of patients

MDR-TB was found to have regressive effects on the life of patients. These were due to both deleterious effects of disease and side effects of treatment.

a) Missed educational opportunities

Some of the patients who were students had discontinued their studies. Lack of energy, side effects of drugs was quoted as reasons for low

school performance. Recurrent visits to health care facilities often led to absenteeism and eventually students stopped attending school.

"She was to attend 11th standard this year but then she feel sick. We could not get her admission in the college. We were shifting between doctors and hospitals. All her friends are in college. She keeps lamenting about not being with friends but it was inevitable."

b) Lost working opportunities

There was difference in the effect of disease on men and women. Men mainly lost opportunity to earn. While some of them had shifted to lesser paying jobs, few of them had stopped working. This had led to mainly economic burden on the family.

"He was a mechanic but since he got the disease he is not able to work so he was not working for almost one year"

Patients were choosing to do jobs requiring lesser travel and lesser physical strain. This often included working from home.

In case of women, inability to take care of daily chores and domestic responsibilities was the most quoted problem. When the mother was affected, care of children was affected. Nuclear families had the most brunt as the whole responsibility fell on the husband alone.

3. Daily Life of family members was impacted

a) High stress

Most of the participants informed to have high stress. Stresses had psychological, physical, emotional and cognitive components.

" *I am always filled with tension. I am constantly thinking of ways to run the house, earn money pay the bills and to feed him (husband) good food. I am always tired."*

Stress and worry about the health of patient was added on with pressures to manage daily living and compensate for the lost man power and productivity.

b) Families with MDR-TB are stigmatized

TB is still a taboo as quoted by some of the participants. Some of the families opted to hide the MDR-TB status of patients from relatives and friends. Fear of being stigmatized and isolated from society was the main reason quoted.

"*People will stop coming to home if they know about TB"*

Spoilt prospect of marriage was the main concern in case of young girls, while same was not a concern for a boy of same age.

"We have not told anyone as she is a girl and it may spoil her chances of marriage"

One of the patients was engaged to get married and the family had advised against disclosing information to the fiancée.

c) Interruption of daily work

Diagnosis of MDR-TB disrupts the work schedule of not just patient but of whole family. Many of the families had to change the roles and were multitasking to compensate for the loss of working of patient. Some of them were working for lesser hours than before as they had to spend time in caring for the patient.

"I am an auto driver. I used to work for 10 hours on some days. Since the time my wife has fell sick, it's been very difficult. I have to take her for clinic every day for her injectable. I hardly work for 3-4 hours and there are times where I do not work the whole day."

d) Increased economic burden

Families often suffered financial difficulties following diagnosis of MDR-TB. Economic burden was both due to costs in assessing health care and loss of earning capacity and wages. Indirect costs posed more burden than direct costs.

It was quoted that before the patient was diagnosed as MDR-TB, Patient often made multiple visits to various private practitioners and often shifted doctors. This often prolonged the period of illness and in turn increased the financial difficulties.

"We did not know it was MDR-TB, we were getting treatment from outside. We did not know that we can get TB tablets for free. She was treated for many months but she went on being sick. We visited many doctors. Later we came here and she was diagnosed as MDR-TB."

4. Social Networks play important role in coping.

Social networks in the form of extended families and relatives were the first point of support for coping with the adversities of MDR-TB.

a) For day-today activities

"*My mother in law takes care of the kids, sends them to school and then look after my wife. She (wife) is too week to work."*

In most of the families there was relocation. Either the patient was sent to a relative's house or some of other family members had relocated to village. Children were sent to the homes of grandparents in case mother had TB. Grandparents were quoted as the first support.

b) Moral support

There were contradicting views regarding the moral support received. In many instances relatives and neighbors were the source of motivation and support for the families. They supported families to stay strong.

"They are very good and supportive. Neither I have problem with neighbors, They are always there to console me when I am over-whelmed."

In some instances relatives were seen as a threat and source of negative motivation. Fears about being stigmatized and loosing ties were quoted as the main reasons for hiding TB infection status.

"My niece and nephew used to play at our house. My daughter like a fool told my sister about her treatment and the children have stopped visiting us since then. Neither my sister visits us now."

c) Financial support

All the families were trying to tide over financial burdens through money borrowed from social networks. None of the families had taken any loans from bank or from any other money lender. None of the families had any health insurance. There was no instance of selling assets.

"I don't like much to borrow money from friends. But since she (wife) got ill, I have to ask them."

d) Praying and faith play an important role

Faith in god and praying were found to be the most important defense mechanism adopted by families. Acts of good deeds in past were seen as reasons for hope to get cured of disease and stay health.

"I pray day and night that he should get well. I am sure he will save my family and that's my only hope."

Discussion-

Total 13 participants were studied. Families of MDR-TB patients lack adequate knowledge about the disease. Some of the families had false beliefs which often led to stigmatization of patient in the family.

Social roles like domestic chores, care of children and prospects of marriage were the most impacted for women. Loss of wages was the main concern of men. Similar results were found by D M Nair et al (Nair, George, & Chacko, 1997). While men worried about loss of wages, financial difficulties, reduced capacity for work, poor job performance, and the consequences of long absence from work. Women were concerned about rejection by husband, harassment by in-laws, and the reduced chances of marriage.

MDR-TB has high economic burden on families. Indirect costs lead to more burden than direct costs. Loss of man power and decreased productivity were the main reasons. Pantoja et al (Pantoja et al., n.d.) found that the average cost incurred by patients before treatment in the Revised National TB Control Program (RNTCP) was USD 145, and during treatment it was USD 21. Families had high stress. Stresses had psychological, emotional, physical and cognitive components. Zhang et al (Zhang, Meikle, & Trumble, 2003) found that parents had high psychological pressures when their children were diagnosed with tuberculosis.

Social networks plays vital role in defending against the disease. Social networks help in managing day today activities and in financial management. Contradictory role was seen in case of moral support. Social networks acted as both positive and negative motivators. Liefooghe R et al, (Liefooghe, Michiels, Habib, Moran, & De Muynck, 1995) found that TB leads to stigmatization and social isolation of TB patients and their families. Pantoja et al (Pantoja et al., n.d.) Found that TB households borrowed from relatives and friends; 8.3 % borrowed from banks; 45 % sold productive assets.

Faith and spirituality plays a pivotal role in coping with adversities caused by MDR-TB.

Conclusions-

Families of Patients with MDR-TB are under high psychological, social and financial pressure.

Assistance from social networks and faith are the most important coping mechanisms used by the families.

Recommendations-

1. Family should be the unit of interventions and counselling. SOPs for Comprehensive counselling of families should be made part of MDR-TB treatment protocol.
2. Social Assistance and Social transfers (aid) should be made available to the families as and when required. Different models can be developed for same including PPP and social security schemes.
3. Provision of social and vocational rehabilitative services should be integral part of MDR-TB treatment.
4. MDR-TB patient and family networks in the lines of alcoholics anonymous should be encouraged.
5. Spirituality and faith should be used strategically in motivating patients to adhere with treatment.
6. IEC and BCC activities should be strengthened with special focus on medication and curability of TB.

Limitations- Studying about condition of family prior to disease onset was beyond the scope of present study but could be looked as factors that may influence their coping strategies.

Conflict of Interest- None
Funding- None

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