

Psychosocial Problems In Multidrug Resistance Tuberculosis (Mdr-Tb) Patients: A Qualitative Study

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Abstract

Multi-Drug Resistant Tuberculosis (MDR-TB) is a condition of resistance to isoniazid and rifampicin simultaneously with or without other first-line drugs. TB is still a serious public health problem in Indonesia. Treatment for MDR-TB is generally carried out with strict treatment regimens for long periods, a higher incidence of adverse side effects, lower cure rates, and high treatment costs. It can lead to psychosocial problems that affect medication adherence. This study aims to explore the psychosocial impact of MDR-TB patients in Indonesia. Data collection was carried out by interviewing 10 MDR-TB patients and a doctor who has expertise in the treatment of MDR-TB. Then conclude from the results of the interviews obtained. The psychosocial condition of MDR-TB patients greatly influences their treatment adherence. Support from family, health workers, and the community can motivate patients to remain enthusiastic and obedient in undergoing treatment. There is a need for psychosocial support for MDR-TB patients and their caregivers to reduce the negative effects of stigma, and to manage the patient's psychological stress.

Keywords: psychosocial, multi-drug resistant, tuberculosis.

INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis*, the organism that is most often transmitted through droplets released by the cough of a person suffering from TB (Herchline & Bronze, 2019). Despite the availability of effective treatment, TB is still a serious public health problem (WHO, 2010). WHO states that Indonesia is included in the 30 countries with the highest burden of tuberculosis in the world and is the third-highest ranking in the world regarding the incidence of tuberculosis in 2018 the incidence of tuberculosis in Indonesia was 316 per 100,000 population or it is estimated that around 845,000

people suffer from tuberculosis (Rumende, 2018). The increasing number of TB cases requires serious treatment. One condition that requires more attention is the emergence of resistance to anti-tuberculosis drugs or MDR-TB.

Tuberculosis (TB) Drug resistance is a condition where the bacteria *M. tuberculosis* can no longer be killed with anti-TB drugs. Meanwhile, MDR-TB is a condition of resistance to isoniazid and rifampicin simultaneously with or without other first-line drugs (Rumende, 2018). Drug-resistant TB is an important problem because its impact on public health is getting worse. Without

successful completion of treatment and achieving cure, a TB patient will become a source of transmission of infection with more lethal strains to others (Ahuja et al., 2012). Treatment for MDR-TB is generally carried out with strict treatment regimens for long periods, a higher incidence of adverse side effects, lower cure rates, and high treatment costs (Oladimeji et al., 2016). It can lead to psychosocial problems that affect medication adherence (Thiruvalluvan et al., 2017). The existence of potential problems following MDR TB treatment encourages the Indonesian government to optimize intervention comprehensively, including paying attention to the handling of psychosocial factors (Kemenkes, 2020).

Research on the psychosocial impact of MDR-TB treatment has been carried out in several countries such as India (Thiruvalluvan et al., 2017) and Mexico (Morris et al., 2013). Soedarsono et al's research was conducted in Indonesia to find the determinants of LTFO (loss to follow-up) in drug-resistant TB patients (Soedarsono et al., 2021). In contrast to these studies, this study aims to explore the psychosocial impact of MDR-TB patients in Indonesia.

RESEARCH METHODS

This qualitative study was conducted through an online interview process with 10 MDR-TB patients. In addition to conducting interviews with 10 respondents, interviews were also conducted with doctors who are experts in related fields. Several questions were asked to the respondents by referring to the interview guide that had been prepared based on a theoretical review. The first-time questions were asked regarding demographic data which included age, gender, education level, marital status, and occupation. Furthermore, questions were asked related to the journey of MDR-TB illness experienced, physical reactions experienced after undergoing MDR-TB treatment, psychological impacts experienced, economic impacts, experiences of the stigma that have been received, and perceptions of health services that have been obtained.

The results of data collection through interviews were then processed for analysis using content analysis and interpretation of theoretical themes. The verbatim transcription process is carried out on the results of the interviews, then the process of grouping similar data is carried out, and ends by finding the themes of the data.

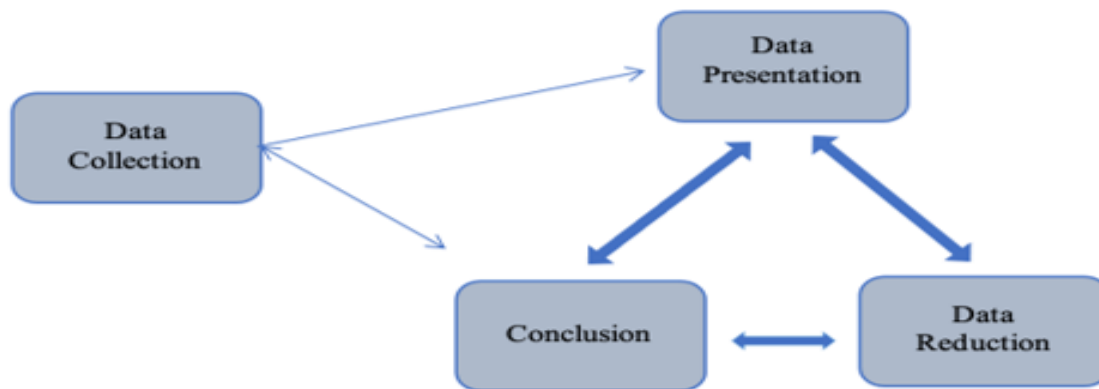


Figure 1. Research Flow

RESEARCH RESULT

Respondent Demographics Data

The respondents of this study were 10 people with a ratio 4 women, and 6 men. Nine people are MDR-TB survivors and members of the “Panther” community which is a community support group for MDR-TB sufferers, while 1

respondent is still in the MDR-TB treatment process. The members of the “Panther” community on average work as motivators in the community, although there are 4 out of 9 people who also work outside the community. Meanwhile, 1 respondent who is still under treatment has not returned to work because the effects of the treatment are still being felt.

Table 1. Demographic data of research respondents

Initial	Age	Gender	Educational Status	Marital Status	Employment
OG	46 yo	Male	Senior High School	Single	-
DL	26 yo	Female	Senior High School	Married	Housewife
MI	40 yo	Female	Junior High School	Married	Tailor
IN	28 yo	Male	Senior High School	Single	At Honda Dealers
KN	60 yo	Male	Junior High School	Married	Panther Community
RR	33 yo	Female	Senior High School	Married	Panther Community
HL	51 yo	Female	Bachelor degree	Married	Panther Community
MU	39 yo	Male	Junior High School	Married	Odd Job
SR	37 yo	Male	Junior High School	Married	Online Motorcycle & Panther Community
TP	40 yo	Male	Senior High School	Single	Panther Community

Research Data Findings

The findings of this study will be presented according to the grouping of respondents' answers based on 7 things: 1) the reaction of the respondents when they found out they were exposed to MDR-TB, 2) the reaction to physical treatment, 3) the psychological impact, 4) the economic impact, 5) the experience of stigma, 6) perception of health worker services, 7) providing support. Next, the results will be presented one by one.

1) Reaction when diagnosed with MDR-TB

Almost all of the subjects were shocked and confused when they first found out they were exposed to MDR-TB. They are in shock because of the length of the treatment process, the effects of illness, the body's reaction to drugs, and the impact of treatment-related to living conditions such as stopping work and difficulties in interacting with family. Some respondents also feel inferior.

"I'm inferior. I am afraid of infecting my family. I am shy to go out and communicate with other people. I stigmatized myself and limited my activities" (Mrs. HL, 51 yo)

"I was in shock at the thought of taking such a long treatment and knowing that several people had died from it. It drops even more when my body can't accept certain types of medicine" (Mr. OG, 46 yo)

"I was in shock because I was told to be outpatient and I was confused because there was a small child at home. I thought about who would take care of him. I asked for some time and ended up being hospitalized for 3 days, then outpatient for 1 month and every day to the hospital for injections and taking medicine" (Mrs. MU, 40 years old)

2) Physical reaction to treatment

All subjects complained of nausea, vomiting, dizziness, and no appetite so the majority also stated that their weight had decreased drastically. Some said that there was a sense of aches, and the majority also experienced an increase in uric acid levels. Two out of 10 people stated that they had hearing loss, the other two people also complained of visual disturbances. Two out of 10 people stated that they had hallucinations, then one subject, namely OG, who is still in the process of undergoing treatment, said his skin had darkened.

"I have mild nausea, vomiting, dizziness, and uric acid up to 12. If I walk, the joints in my ankles hurt a lot. There is also a disturbance in the eye. If hallucinations there is no doctor, only eyes and high uric acid" (Mrs. HL, 51 years old)

"Nausea and want to vomit. I'm sorry, I feel like I need to urinate and defecate frequently, my body feels like it's been stomped on, and I feel like I'm going to die" (Mrs. RR, 33 years old).

"When I did the second treatment, I started to feel dizzy, nauseous, vomiting, feeling achy, having no appetite" (Mr. IN, 28 years old)

"Nausea, Vomiting, and increased uric acid. For about 20 months I often went to the hospital because of side effects" (Mr. SR, 37 years old)

"2 hours after taking the medicine, the body is very cold for several hours, nausea, after that I am dizzy and have no appetite. after that, the side effects of the medicine appeared on my skin, it became scorched" (Tn. OG, 46 years old)

Mr. OG experienced a fairly severe impact of treatment because when he was diagnosed with tuberculosis for the first time, the doctor advised him to continue to take the medication given even though his body was refusing to take the drug. Finally, he was referred to a specialist and given a new drug, starting the treatment all over again thus prolonging the treatment. Tn. OG was the only respondent who experienced the most drug reactions, including scorched skin.

3) Psychological impact of treatment

The subjects reported feelings of anxiety, stress, a sense of wanting to give up on the condition, hopelessness, depression, and wanting to die, and some even wanted to commit suicide. Undergoing treatment with all its effects is felt to be very heavy, causing feelings of helplessness, anger, fatigue due to too many drugs, and long times for treatment. In addition, it has an impact on economic conditions which also strengthens the anxiety and depression they feel.

"I am depressed, stressed, often think about suicide, and often intend to discontinue treatment" (Mrs. DL, 26 years old).

"Yes, definitely (stressed), it's because we have a baby. It's getting harder because I have decent (debt) dependents and yesterday I had the chance to go to that expensive doctor" (Mrs. RR, 33th)

The answer from Mrs. RR above is a experience of the respondent who had to spend a lot of money to go to a doctor when he was first diagnosed. Once he came he had to pay Rp. 150.000, and he has to see a doctor every other day for 6 months straight. However, in the process of treatment, she developed resistance and drug poisoning appeared, so he had to switch to alternative medicine. Because his condition did not improve, he finally moved to a pulmonologist and was declared to have MDR-TB. The economic burden arising from previous treatment and having to undergo another treatment for 2 years made stress on the subject. Plus other stressors related to her role as a mother with a child who is not yet 1 year old.

4) Experience stigma

Six people stated that they experienced stigma, and 4 others did not experience stigma from the environment. Subjects who said they did not experience stigma from the environment kept their distance and limited interactions because they were worried that other people would be infected.

"I limit it for fear of infecting others" (Mrs. HL, 51 years old).

Stories of subjects who experience stigma or discrimination not only from the community in their environment but also from health workers (nurses and doctors).

"At the public health center, health workers (who are discriminatory) but at home, it is the neighbors who discriminate" (Mrs. MI, 40 years old)

"I've experienced discrimination when I was on the train going home from Malang. (I) stories with people and someone listens. He who heard immediately asked all the people around him to stay away. Even though I already wear a mask" (Mrs. DL, 26 years old)

"People have different opinions. Some still think that the disease is dangerous and contagious, so it gets a stigma, but some understand that this disease has a cure and can be cured. If I meet people who don't understand, I feel a bit inferior" (Mr. MU, 39 years old)

There is also a family attitude that is felt to put pressure on the subject because his family feels embarrassed if there is a family affected by MDR-TB so it is forbidden to convey it to other people.

"It was my parents who were embarrassed. Maybe they knew I had a contagious disease, so they were embarrassed and said that they shouldn't let other people know. If other families had time to stay away while I was sick" (Mrs. RR, 33 years old).

5) Economic Impact

All subjects said the length of treatment had an economic impact, even though the medicine they received was free. As they say that during their illness they automatically cannot work so they only rely on help from their family.

"I was not working at that time (while undergoing treatment), but there are still daily needs. So I sold what I had to make ends meet" (Mr. MU, 39 years old)

"What I was able to work before ended up not working, plus the pandemic. Everything is a burden to the family, even though the family doesn't mind but still feels bad" (Mr. OG, 46 years old)

Although OG does not yet have the responsibility

to provide for his family, when he is sick and has to depend on his family, he feels uncomfortable.

The female subjects also felt the economic impact, and even her husband had to go out of work to take care of her.

“I experienced a lot of sadness (because of economic problems). So when I was sick and during the treatment period, my husband resigned to focus on caring for her. It made me cry because the economy was disrupted” (Mrs. HL, 51 years old)

The existence of assistance during MDR-TB treatment was quite helpful for the subjects while they were still patients. However, they also have to bear other costs themselves, so they are still not able to adequately help their economic condition.

“Yes. During the treatment I did not work. There is assistance but only 100 thousand during treatment” (Mr. KN, 60 years old)

6) Knowledge of tuberculosis and perceptions of health workers

Based on the experience of the subjects in undergoing treatment, there are two groups of subjects in terms of assessing the quality of health care services. The majority of 6 subjects stated that the doctor's explanation was very good, and the doctors and nurses were very good in providing assistance. Some even felt that they were given a lot of motivation to recover.

“Yes, tell me first how good and bad. Something important was explained. The timeframe is also explained. (The doctor and nurse) are sociable and like to joke” (Mr. TP, 40 years old)

“When I entered the examination room there were photos of people who had recovered. So that I am motivated to recover. And I also encourage my friends during the treatment period” (Mrs. HI, 51 years old)

“Alhamdulillah. family, doctors and nurses gave the best motivation and support to continue until he recovered” (Mrs. MI, 40 years old)

There are also respondents who stated that information about the disease had been given quite clearly but in fact it was more severe than that.

“Yes, the doctor explained in detail the side effects. But it turns out that the effect is more severe than I expected” (Mr. KN, 60 years old)

One subject, RR, even said that he had to pay Rp. 150,000 every two days to go to the doctor at the first diagnosis of TB for a period of several months. In fact, TB treatment is provided free of charge by the state. The subject of RR only found out about it when he referred to a pulmonologist and was declared to have MDR-TB. In line with RR's experience, OG subjects also said that they had an unpleasant experience during the treatment of pneumonia.

“Honestly, for me some doctors are just robots, when we are sitting opposite each other, the doctor checks as needed, writes a prescription, then we go out. Maybe not all patients should be talked to more, but what if the patient feels tired, dropped, and somewhat different from the others. Maybe I use BPJS so it's natural to be treated like that and finally I encourage myself” (Mr. OG, 46 years old)

7) Providing Support

One of the themes that emerged in all the interviews with all subjects was the strong support they received. All subjects without exception reported strong family support, both economic and emotional support. Some also expressed support from friends, from health workers who took care of them, as well as support from the MDR-TB survivor's community, namely the “Phanter” community.

“Family support is very important to me, so it's my family's turn to take care of me. I am very grateful that God has given a caring family, although it is not excessive but I feel it is enough” (Mr. OG, 46 years old).

“Alhamdulillah, the family is supportive. My family wears masks and I keep my distance from my first child. They are supportive, family, and also neighbors” (Mr. MU. 39 yrs)

“When Phanter community was formed in 2010. So, it was already there but not as intense as it is now. There is also assistance from Aisiyah Hospital and there is food support such as eggs and milk but not in the form of money” (Mrs. HL.51 years old)

In addition to interviewing 10 respondents, the researcher also conducted interviews with a doctor who has expertise in the treatment of MDR-TB. The Doctor in an interview with researchers said about: 1) drug reactions that can be felt by MDR-TB patients, 2) other factors that affect drug reactions to patients, 3) related to patient-physician communication in the MDR-

TB treatment process. The results will be explained one by one.

1) Side Effects of MDR-TB Drugs

Treatment of MDR-TB initially does take a long time, up to 24 months. However, in the latest treatment approach, based on research results, it has been found that the Short Therapy Regimen only takes about 9 months.

Generally, drugs for MDR-TB are heavy drugs and also have high doses. Some drugs that are included in the MDR-TB therapy regimen can have quite severe side effects. For example, the drug clofazimine can have side effects in the form of blackened skin. Side effects of other types of drugs that are included in the MDR-TB therapy regimen, for example, can cause heart problems, peripheral neuropathy, hearing loss, gastrointestinal, arthritis to the psychological side in the form of mild to severe depression.

2) Factors influencing drug reactions in patients

The desired MDR-TB drug reaction is to suppress bacteria so that the patient is expected to improve. However, drugs can also give side effects of drugs. Drug side effects as described in point 1 can appear and interfere with the patient's condition. However, in addition to drug factors, other factors that also affect drug side effects are mental, physical, religious, social, and economic.

Mental factors are related to the patient's readiness to undergo treatment. Before treatment, the patient is usually given informed consent as evidence of the patient's willingness to undergo treatment with all the risks. In addition to mental, physical factors are also things that can influence so that inspections of all-important organ functions in the patient's body are carried out regularly to provide monitoring.

Social factors are very important, especially from the family. It is hoped that the family can be cooperative so that they can help patients undergo the treatment process completely. There is the term Drug Swallowing Companion as a form of attention from medical personnel to the patient's family to assist during treatment. The patient's religious strength also plays a role in counteracting the severity of drug

side effects. In patients who can accept their illness and the treatment process as an effort to recover, sincerely undergoing the process can strengthen the patient's mentality so as not to give up.

Economic conditions are the last factor that influences the patient's condition during treatment. If the economic situation of the patient's family is not supportive, it can be a stressor in itself that can worsen the patient's condition.

3) Doctor-patient communication

The management of MDR-TB patients has special standards. Three components become the standard of treatment in MDR-TB cases. The first is professional standards according to their respective professions. This means that health workers, both doctors, and nurses, must be health workers who have received education in the medical field legally and according to their respective qualifications. Second, doctors and nurses specifically for MDR-TB patients must participate in competency improvement, namely a kind of service training for pneumonia patients. In addition to the training, in the patient care process, patient handover briefings were also conducted. Training and work meetings between the nursing team and the hospital providing treatment and their satellite services (public health center) are also routinely carried out. Third, as a monitoring step for evaluating drug side effects, there is a daily checklist form that must be filled out to monitor patients.

Based on this explanation, it can be concluded that the standard of care for MDR-TB patients already has a clear standard operating procedure. However, when in the field sometimes things still happen that are not optimal for the health service provider, other factors such as socio-cultural conditions can influence. For example, language barriers, or educational level barriers that make the delivery of information less understandable.

DISCUSSION

This qualitative study was conducted to explore the experiences of MDR-TB patients undergoing their treatment and to identify psychological, social, and economic problems. Based on the results of interviews with both MDR-TB patients and their survivors as well as interviews with

doctors, it was found that there are psychological, social, and economic problems that accompany MDR-TB treatment. The results of this study are in line with (Morris et al., 2013) and (Thiruvalluvan et al., 2017) regarding the psychosocial and economic impact on MDR-TB patients. The results of the current study have implications for the need for a more comprehensive intervention plan to improve the patient's quality of life.

The dominant theme found was drug side effects in patients undergoing MDR-TB treatment, especially on the physical aspect. For all research subjects, drug side effects become things that can affect their daily functioning. Their mental function, economic function and social function can all experience problems as a result of the treatment they are undergoing. As noted by dr. Rahmat, the side effects of drugs are unwanted and unwanted things that occur at regular doses. The side effects of this drug can be influenced by its appearance from external factors other than the drug itself and the patient's physical condition in general. These factors are mental, physical, religious, social, and economic (Zard et al., 2021).

The mental aspect is one of the things that affect the patient in dealing with the side effects of the MDR-TB drug. But on the other hand, there are also drugs given to MDR-TB patients which have side effects in the form of depression. This means that even if the patient has shown readiness and strong motivation to undergo treatment, side effects of drugs that lead to mood disorders are still likely to appear. Moreover, at the same time, patients also experience physical side effects of drugs which are very uncomfortable, some even say that they are very depressed to experience it all, so that it can worsen the patient's mental condition. The patient's further deteriorating mental condition can also affect his physical endurance. These results are consistent with several studies on depression as a condition that is commonly experienced by MDR-TB patients (Javaid et al., 2017; Naidu et al., 2020; Redwood et al., 2021).

The existence of a circle of interaction between one aspect and another reinforces the need for a comprehensive intervention plan. Interventions for mental aspects can be done with supportive counseling, stress management, or providing group support (Thiruvalluvan et al., 2017). Like several other studies, this study also shows that social support is an important supporting factor for MDR TB sufferers (Deshmukh et al., 2018; Puspitasari et al., 2016; Saqib et al., 2019).

The social aspect is the stigma and discrimination felt by more than half of the respondents. Even among the pressures related to discrimination on some subjects also came from the family. This shows that there is still a lack of knowledge about TB disease among the community, especially families of TB sufferers. Knowledge about disease is an important component that helps individuals and their families to obtain, communicate, process and understand basic health information (Thiruvalluvan et al., 2017). Knowledge is also an important component in treatment, especially related to medication adherence in TB patients (Fitri, 2018). The results of several studies also provide evidence that education and prevention can increase knowledge and reduce community stigma against TB sufferers (Hidayati, 2015).

The results of this study also indicate that less than optimal communication between doctors and nurses with patients is one of the obstacles to understanding patients with their illness. Even though there are already standards of service from health workers in providing special services to MDR TB patients, the monitoring and evaluation is still not optimal. Factors in the patient's condition were also found to influence the communication between health workers and patients. There were 3 respondents who complained that it was still difficult to understand the doctor's explanation regarding their illness. It is possible that the lack of education in the patient is a factor in the difficulty of understanding the doctor's explanation. Including socio-cultural factors such as language barriers. These results are in line with research which states that communication and education are associated with concordance attitudes of patients with pulmonary TB, hypertension and asthma (Patriani & Ayuningtyas, 2013). The implication is the need to improve doctor-nurse communication with patients.

CONCLUSION

Based on the results obtained from this study, it can be concluded that there are psychological and socio-economic challenges for MDR TB patients and their families. MDR TB patients need assistance and support to deal with the negative effects of MDR TB treatment and manage their psychosocial stressors.

Considering the side effects of drugs felt by MDR TB patients greatly reduce their quality of life, preventive measures are recommended in order to suppress the increase in cases of TB and MDR TB. Socialization programs can be carried out to

the community, including health workers in service satellites about TB disease and its prevention. In addition, to prevent the development of TB to MDR TB, it can be done by providing knowledge to patients and their families. Furthermore, MDR TB patients need to be provided with assistance in the form of e-counseling services to provide support and help relieve pressure while undergoing treatment. This e-counseling can be accessed in their homes and can minimize transmission. Assistance through support groups from survivors such as the Panther community still needs to be continued. However, members of the support community also need to be given development programs related to the support services they provide to patients.

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