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Original Research

The complexity of treatment discontinuation behavior in Drug-Resistant Tuberculosis (DR-TB) patients during Covid-19 pandemic era: A qualitative study in special region of Yogyakarta

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Abstract: In 2017, there were 82 instances of drug-resistant tuberculosis in the Special Region of Yogyakarta, which is one of the regions with the highest incidence of tuberculosis (3,770 cases). Increases in mortality and Lost to Follow Up (LTFU) are affected by age, knowledge, psychological, and economic factors. TB and COVID-19 symptoms are nearly same, however there have not been as much research on COVID-19 infection in TB patients as during the COVID-19 epidemic. The purpose of this study is to determine the reasons why TB drug-resistant patients who are currently undergoing treatment abandon their regimens. A qualitative design with 5 respondents of TB drug-resistance discontinuation in the Special Region of Yogyakarta over the treatment period of 2022. Interviews, observations, and documentation were used to collect the data. Guidelines for interviews and observations, as well as documentation, are employed as instruments in this research. The data was examined using the seven coalition steps: transcripts, repeated readings, quotation, marking lines, codes, categories, and themes. There are 77 codes, 16 categories, and 4 themes as a consequence of the study. The psychological, spiritual, and economic element that is affected by psychological, spiritual, and economic management. Acceptant stage, function of roles, rewards, and assessment-based diagnosis influence the support system factor. The side effect of part is influenced by alternative treatments, biopsychology post-treatment, safety predominance, and the decision-making premise. The adaptability element is determined by the ability to decide one's own beliefs, the capacity for prevention, one's level of comfort, and the objectives of government programs. The termination of treatment in tuberculosis drug-resistant patients in the Special Region of Yogyakarta is influenced by psychosocial and economic factors, support networks, treatment side effects, and adaptation.

Keyword: Tuberculosis Drug Resistant; Treatment Discontinuation; COVID-19 Pandemic.

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1. INTRODUCTION

World Health Organization (WHO) declared Tuberculosis (TB) as a public health emergency and ranks as the 10th highest cause of death in the world which is a top priority in the Sustainable Development Goals (SDGs)[1]. Currently, the success rate of Drug Resistant Tuberculosis (DR TB) treatment has not meet the overall treatment criteria which is still bellow than 50% [2]. Estimated DR TB cases in Indonesia are around 2,8% from the new TB cases and 16% from the re-treatment TB cases [3]. WHO estimated there are 23,000 cases of DR TB in Indonesia, with the highest cases reported from province with large populations such as Special Region of Yogyakarta (DIY). The Case Notification Rate (CNR) in DIY is 99 cases per 100,000 population. While the Case Detection Rate (CDR) in DIY is 33,9%. Based on a study conducted by Widiastuti (2017), the number of positive DR TB patients in Yogyakarta is quite high about 82 people in 2017. The increase of DR TB cases will occur in TB group such as the TB patient who failed the TB chronic treatment, relapsed TB, and TB drop out cases [4].

The success rate for DR TB is still relatively low at 45%, while the estimated treatment discontinuation or Lost To Follow Up (LTFU) is 30% [5]. This is still far from the government's target

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in the Integrated Management of Drug Resistant Tuberculosis (MTPTRO) program, which is to prevent DR TB from becoming public health problem by breaking the chain of transmission [6].

The low success rate of DR TB treatment will lead to high mortality and LTFU. Many countries have been tried to control LTFU. The efforts in finding potential factors problem that influencing DR TB treatments have been done in many studies in the world. The studies shown there is a greater chance for the older patients in getting the treatment, while the patients who less than 45 years will have a better chance of recovery than the elder ones [7, 8, 9]. Besides of that, the insufficient knowledge about DR TB and anti-TB therapy will lead to drug discontinuation in DR TB patients and affecting the outcome of their treatment in the future because patients with high severity are more likely to give up the treatment and patients with poor knowledge of TB treatment are 4x more likely to discontinue the treatment [10].

Another influencing factor is psychological factor. Patients who tend to felt depression, despair, and lack of social support can also affect the TB treatments. Emotional burden increased by the existence of social discrimination, this can cause ashamed and depression that can make the patient inadequately doing the treatment [11]. Therefore, emotional support such as family support should be provided by people around the patients [12, 13, 14].

Financial problems can also affect the treatment adherence of DR TB patients. Patients need to pay for accommodation even though the medicines have been provided free of charge by the government. The quality of live and the financial situation especially for the poor and marginalized people are even worsen by the disease due to the adverse side effect caused by the treatment [15, 16].

Indonesia is one of the countries facing the Coronavirus Disease-19 (COVID 19) and Tuberculosis (TB). The symptoms of COVID-19 and TB are nearly identical like cough, fever, and difficulty breathing. However, the rate of spread and transmission of COVID-19 is several times faster than TB transmission. Currently, information about COVID-19 infection in TB patients is still limited [17]. Until now, there has been no research on DR TB treatment assistance during the COVID-19 pandemic based on the treatment problems seen from the both experiences of the recovered patients and patients who failed treatments by taking a closer look at the treatment journey to recovery. Hence, this study will examine the factors of treatment and healing which seen from the patient's point of view. This will raise new problems that may have not been discussed before and open the opportunity to develop a new model based on the patient's opinion. This study was conducted in Special Region of Yogyakarta (DIY) in 2020. The number of positive patients for DR TB in DIY was 110 people per year and most of the patients had received previous TB treatment. DIY also still have the low success rate of TB treatment about 85,1% which it supposed to be targeted at > 90%.

2. MATERIAL AND METHOD

This is a qualitative descriptive study with case study approach method that aims to understand, examine, and interpret the meaning of the treatment discontinuation risk factors in DR TB patients using depth interview. The sampling technique used in this study was purposive qualitative snowball, the sample of this study was the DR TB patients who had experience in completing DR TB treatment and were declared cured, willing to participate, and had the ability to communicate both of their experiences and opinions expressively, reflectively, and articulately [19, 12]. There were 5 participants of DR TB patients in 2022 treatment period.

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The data were collected using in-depth interview techniques [21]. The instruments used in this study were interview guidelines, observation sheets, and documentation. The validity of the data was tested using triangular techniques (source, technique, and time) and the data were analyzed according to Colaizzi [22] steps by processing the data into 77 codes then grouped into 16 categories and resulting 4 themes.

3. RESULT AND DISCUSSION

Participant's Characteristics

Tabel 1. Drug Resistant Tuberculosis (DR TB) patient in Special Region of Yogyakarta (DIY) (n=5).

Code	Initial	Age	Treatment Status	Regimen
P1	AS	54	Cured	ITR
P2	PS	40	Cured	ITR
P3	RO	36	Cured	ITR
P4	MR	31	Cured	ITR
P5	MB	27	Cured	ITR

This study involved 5 cured DR TB patients during 2022 treatment period in the Special Region of Yogyakarta. Each participant was interviewed once and two times data validation. Language used for the interview are Indonesian and Javanese. The participants ages ranged between 27 – 54 years and all of them were using Individualized Therapy Regimen (ITR) treatment.

Theme 1 Socioeconomic Status

Socioeconomic factors including psychological management, spiritual strength, and economic ability. The incidence of social stigmatization to DR TB patients is still often experienced by participants. According to the results of interviews with participants, stigma exists when people find out about their illness for the first time, then they will isolate or stay away from the patient. Indirectly, the existence of stigma has an impact on limited social relations, especially in their neighborhood. This is evidenced in the following interview excerpt:

"When receiving treatment, they were given information that this disease would be contagious, so it made my family felt anxious and afraid. That is why my wife and my children stayed away from me" [P1]

"… if only talking about financial my children can help me. But at least don't ostracized me that's all. Don't differentiate me with others, we just want to get protected that's all I don't need anything else" [P5]

The source of income or socioeconomic also affects medication adherence, related to the health facilities and infrastructure completeness, as an example to fulfill basic needs, transportation cost to health services for treatment.

"…that's why I can't go there, what do I have to do to get there? My physical condition make me can't ride the motorbike. Maybe I can go there by car, but it would cost three hundred thousand rupiah. There's so many thing I can bought with three hundred thousand rupiah instead of just rent a car" [P3].

Social discrimination in DR TB patients causes emotional changes in early stages. According to Udwadia and Furin (2019) the existence of social discrimination such as losing a job, losing the comfort from the living place, and if it still burdened with a lack of family support will increase the

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shame and feeling down who make the patient become inadequately to do the treatment. This will also affect the outcome of the treatment. The DR TB patient with good strong mental health has a greater chance of healing rather than those who do not [11].

Social support can increase defense against stress, change affective states, increase self-efficacy, and influence changes in negative behavior patterns [23]. The affective management of DR TB patients also becomes more stable when followed with the environment who support their treatment [24].

Financial problems are also affect the adherence of the treatment in DR TB patients. Patients with higher income levels increase the opportunity to get stronger family support which family support is very influential on treatment adherence [25]. Patient with higher income level can well covered the cost burden of DR TB treatment without need to do any extra efforts from the family in seeking additional income [26, 27, 28 , 29]. Hence, the family has sufficient time and energy to meet other support needs for the patient, such as affective support and informational support [30, 31]. Patients with low incomes will make the family spend extra effort in meeting material needs and make another support needs can be neglected.

Theme 2 Diagnosis Acceptance Process

Changes in DR TB patients have an impact on emotional changes in participants. When a patient is tested positive TB for the first time, the patient tend to experience fear, anxiety, and worry they will shortly die like their recent family history. 3 out of 5 participants had a family record of TB.

“I vomited blood then I got checked and the result was positive TB. I was so scared and worried” [P1]

“There’s one person in my family died (positive TB). Every night I pray to get well (*while crying)* I want to see my grandson. My son is still young. I want to take care of my child” [P3].

Participants who tend to get motivation and support from their families, healthcare workers, and surrounding communities tend to get their enthusiasm back for doing the treatment. Therefore, this also affect the outcome of DR TB treatment.

“There are 3 – 4 times in a week a healthcare workers came to survey in here, they were asking and forcing me to do the treatment again and sometimes the health care staffs also give masks, immune protection packages, and vitamin to me” [P4].

“Even though I’m sick but I feel better because of the support from my friends who always cheer me up telling me to this and that and always support me” [P3]. 3 out of 5 participants had a family history of TB. This can be the TB port de entry to participants.

Exacerbations and comorbidities also influence the severity of the disease-causing patients begin to feel the loss of functional roles in social, mobility, independence, and as an individual. This can trigger the patients grieving process which according to Kulber-Ross [32] will experience denial, anger, offer, sadness, and acceptance [33].

Patient’s emotional changes will affect the motivation during the treatment process. Motivation and support from surrounding people is a form of support system that can foster enthusiasm in participant to re-build their life goals until they are finally able to accept the situation. Salehitali et al., (2019) in their research stated that TB treatment therapy had an impact on the social, mental, and emotional aspects of the patient’s quality of life. Therefore, special attention and monitoring the patient’s quality of life is needed because it can determine the continuity of the treatment [34].

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Theme 3 Side Effects and Alternative Medicine.

Participants in this study were taking the Individualizes Therapy Regimen (ITR) type of treatment that required a long duration of treatment. The results of the interview concluded that the duration of treatment, side effects of treatment and the lack of knowledge about the process and type of treatment made participants decided to switch into the alternative medicine, consider it was cheaper, practical, and harmless because it did not show any side effects.

"I received 20 pills for the treatment and the effect from the drug I became anxious and my body turned black, my ears were ringing and I was afraid it also affecting my kidneys because I had to take a lot of medicine ma'am" [P1].

"People said herbs are safer than the treatment ma'am. So whenever someone came to offer me I would definitely take it (the herbal medicine). I also drank spices and jamu ma'am" [P3].

"I got traumatized in the health care facilities ma'am, especially in Solo (Moewardi Hospital) *ya Allah* (mention the God) how come I have wires installed in my body every time I got the treatment it's so scary!" [P4].

The knowledge about TB and the type of its treatment affect the treatment adherence of TB patients [35]. The lower knowledge about TB and anti-TB therapy makes a person less likely to comply the treatment which will affect the outcome of the treatment in the future. Especially in patients with increased severity of the disease, they will easier to give up on the treatment. Patients with less knowledge are 4x more likely to discontinue the treatment [10].

Knowledge of treatment include providing information related to the type of chosen treatment. The long duration of the treatment and aggravating side effects will determine the quality of life of DR TB patients. Therefore, controlling side effects is also important [36]. In this study, all of the participants taken the ITR type of treatment. The results showed that the majority of the patients complained of mild to moderate side effects. Side effects have a negative effect on medication adherence, meaning that the more side effects occurred, the lower the level of patient medication adherence [15].

The result showed the more the side effects happened supported by the inadequacy of infrastructure to go to the health facilities center made the participants tend to use herbal medicines and spices as another alternative medications because they were easier to obtain, practical and did not have many side effects.

Theme 4 Self-Awareness

The results of the interviews concluded that patient awareness in doing the treatment was influenced by motivation and support from people around them, a good motivation and support can formed a coping mechanism for participant to start adapting into new habits in order to break the transmission chain, improve the treatment adherence and to improve the quality of their life.

"It's impossible ma'am. Whether we like it or not you have to do the treatment because it can't heal on its own. Sometimes to support it I also take herbal medication to make it heal faster and always pray to God to get well…" [P3].

"At home, I also anticipate the transmission by eating and drinking individually. I also don't go out to see *Wayang Kulit* (traditional puppet-shadow show in Java) if people were there" [P1]. Another influencing factor is the role of the government as a health facilitator. By providing free treatment through BPJS (Social Security Agency of Health) it can be the main reasons for DR TB

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patient to continue the treatment. “If we use BPJS we don’t have to pay for the treatment because it’s free. Wherever I stayed at hospital such as in Moewardi Hospital I don’t have to pay for anything. But still the transportation costs are too expensive to get there” [P3].

Living with TB patients will changes the daily activities in order to break the chain of transmission [37]. In this case, patients who have accepted their own condition including their illness are more likely to be able to take the preventive steps and motivate themselves to continue their treatment well rather than someone who still deny their illness. The ability to motivate themselves are also influenced by a lack of empowerment and low income. Hence, it is necessary to encourage people to choose the path of disease prevention over disease denial [38].

The government role as a treatment facilitator also influences the treatment adherence in DR TB patients. The results of the study stated the existence of a government program named BPJD (Social Security Agency of Health) which covering the treatment of DR TB patients has an impact on the cure DR TB cases. Especially for patients with low income. Even though the prescribed regimen is free of charge [39] the cost for DR TB patients still quite high [25] because the burden on the patient is high enough to be able to covered the transportation needs, nutrition needs, and other expenses [40].

4. CONCLUSION

The experience of DR TB patients in their treatment period resulted in 4 themes, they are socioeconomic status, diagnosis acceptance process, side effects and alternative medications, and self-awareness. These factors are interrelated with each other to improve the treatment adherence of DR TB patients which also influenced by emotional aspect, financial, infrastructure, sociodemographic support, and the role of the government as the treatment facilitator.

Conflict of interest

Not any conflict of interest in this research.

Authorship

All researchers in this study contribute the same role, including as follows:

1. Substantial contribution for concept or protocol design, acquisition, analysis, and interpretation of data in this research.
2. Draft critical improvements for important intellectual content.
3. Final approval of the published version.
4. Agreement to be responsible for all aspects of work in ensuring every questions related to accuracy or integrity in this study are investigated and properly resolved.

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