Perceived Barriers to Accessing Tuberculosis Care Among Multidrug Resistant Tuberculosis (MDR-TB) Patients: A Qualitative Study in Indonesia

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Abstract--- Indonesia has one of the highest MDR-TB burdens in the world. The success rate of MDR-TB treatment in Indonesia is still low. Indonesia changed the health system policy, which is called the National Health Insurance, in 2013. The purpose of this study is to provide a description from the point of view of MDR-TB patients about barriers during their treatment, although the health system in Indonesia has changed. This study used qualitative semi-structured in-depth questions. Fifteen MDR-TB patients were interviewed concerning the barriers during their treatment. Purposive sampling was used to recruit study participants. Thematic analysis was used to identify and analyse the main topics. Topics generated were financial barriers, poor service, inadequate hospital facilities, ineffective communication of patient-provider, stigma, and lack of social support. Each theme was from verbatim transcripts defined during the coding process. Codes and themes were developed to coincide with data collection. Periodic monitoring of aid disbursements, improvement of hospital services including health workers and facilities, increased social support, increased knowledge and home-based MDR-TB service programs can be implemented to reduce the perceived barriers for MDR-TB patients during treatment.

Keywords--- Barriers; Multidrug-resistant tuberculosis; Patients' perspective; Qualitative study

I. INTRODUCTION

Multidrug-resistant tuberculosis (MDR-TB) is a global health problem with an increasing number of sufferers. Indonesia ranked 8 out of 27 countries and contributes 85% of the burden of global MDR-TB. The World Health Organization (WHO) report estimated that in 2008 MDR-TB cases in Indonesia were as many as 6,427 [1]. Indonesia is one of the countries with the highest TB burden in the world. The number of MDR-TB cases is estimated at around 2.8% among new TB cases. The World Health Organization (WHO) states that the success rate of MDR-TB treatment in Indonesia is still low.

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MDR-TB patients require a long period of treatment of 24 months [2]. That results in various problems faced by patients which are: psychosocial impacts of prolonged isolation, the dislocation of patients from their normal social networks and stigma from providers [3], income loss, financial burden [4], mental distress [5], barriers to treatment adherence including drug side effects, a perceived lack of provider support, patient financial constraints, conflict with the timing of treatment services, alcoholism and social stigma [6]. The fear of transmission of infections within hospital settings, the identification of MDR-TB developing through poor adherence and inadequate treatment regimens [7], extreme social, financial and employment hardship, patients having to move house and leave their job [8].

Indonesia has offered treatment for MDR-TB patients since August 2009 with a Program called Programmatic Management of Drug Resistance TB (PMDT). This Program covers standard diagnosis by using culture and drug sensitivity testing in a national certified laboratory, standardized MDR-TB treatment, services in full outpatient service facilities unless the patients in the clinical condition deteriorates and there is a decision by a team of clinical experts to hospitalize, and direct supervision every day by health workers [9].

There is no cost for implementing MDR-TB treatment because it has been funded by the government. MDR-TB treatment in Indonesia can be accessed at community health centers which have received this training [10]. Although MDR-TB treatment can be accessed at the community health center, in certain cases, patients must be referred to more complete health services. This policy has been implemented in Indonesia since 2013. Formerly, MDR-TB treatment could only be accessed in large hospitals, but with the many new MDR-TB cases, community health centers which have received training can provide services now.

PMDT covers not only MDR-TB patients but also their families. Priorities in the End TB Strategy of 'patient-centred care' and 'patient support' are still delivered in practice in many low-income settings, and in particular consideration of mental distress. China, Pakistan, Bangladesh, Nepal and Swaziland have given us detailed insight into the challenges in facing patients, their families, health professionals and wider health systems. Psychosocial support, and particularly support focused on mental health, is being insufficiently addressed in national MDR-TB programs [5]. In the highest-burden countries of India, China, and Russia there is a commitment to tuberculosis control including improvements in national policies and health systems that remove financial barriers for treatment, encourage rational drug use, and create the infrastructure necessary to manage MDR-TB on a national scale [11].

Hope and high-quality knowledge supported adherence; autonomy and control enabled optimal engagement with treatment-taking; and perceptions of the body, self, treatment, and disease influenced drug tolerance [12]. There has been no study concerning the barriers that MDR-TB patients feel in Indonesia during their treatment. This qualitative study aimed to understand MDR-TB patients and the barriers while undergoing treatment in Indonesia, especially for those who seek treatment at outpatient/ Polis of MDR-TB at Dr. Soetomo Hospital Surabaya.

II. METHODS

This research was conducted at the outpatient ward of MDR-TB Dr. Soetomo Hospital Surabaya. Dr. Soetomo Hospital is a referral hospital in eastern Indonesia. The MDR-TB outpatient ward at Dr. Soetomo Hospital Surabaya is an out-patient service which operates from Monday to Saturday. MDR-TB patients come every day to get injected drugs. The MDR-TB outpatient ward is part of pulmonary outpatient services specifically providing treatment for MDR-TB patients.

Study design and sampling

A qualitative approach was chosen in order to explore the experience of MDR-TB patients with regard to the barriers during the MDR TB treatment process. Patients were selected according to the criteria for patients who were still undergoing an MDR-TB treatment with oral and injected treatment. Patients were selected using purposive sampling to obtain heterogeneity which included gender, age, duration of treatment and their address.

Data collection

MDR-TB patients were approached in the MDR-TB out-patient ward and provided with an overview of the study that would be conducted. Patients who were willing to take part in the study were asked to sign informed consent. Participants were also given the right to step down during the data collection process if they wanted to. The data collection was done in a place that had been agreed upon by researchers and participants. The places used in this data collection varied, from the MDR-TB out-patient ward and the patient's home. The number of participants approached was 20 people and 5 people refused to engage with the study. The reasons for rejection were that they were busy, did not want to join in the study, and had to do other activities. The in-depth interviews were recorded by two study team members who had experience and training in qualitative interviewing and qualitative research. In-depth interviews were conducted in the regional language. The patient interview guide included semi-structured in-depth questions related to knowledge, treatment experiences, factors influencing treatment adherence, barriers faced during treatment, and side effects of the treatment. The interview guide was developed based on the results of various MDR-TB studies.

The researcher began the interview with the opening questions relating to participant demographic data, then continued with the problems faced by MDR-TB patients during treatment. Each interview took around 25-40 minutes. Interviews with each participant were conducted 2-3 times. The researcher then made verbatim transcripts for each participant. After the verbatim transcripts were completed, the researcher returned to the participants to clarify the data presented and asked participants to sign the transcript as a sign of agreement. In-depth interviews were conducted during August-October 2018 among a purposeful sample of 15 MDR-TB patients.

Data analysis

Audio-recorded data from interviews of patients were transcribed verbatim and translated into English. The two authors read and re-read the transcripts 7 and 8 times each to draw out the themes and categories. Each author made a list that formed the analysis. Each theme was defined during the coding process. All transcripts were read by both authors to ensure the themes generated. Codes and themes were developed which coincided with data collection. Direct quotes that illustrated important themes were extracted and presented in this manuscript. One verbatim result was examined by two researchers to analyse whether there were differences in themes to avoid subjectivity in determining themes.

Ethical considerations

The study protocol was approved by the ethics committeee of Dr. Soetomo Hospital Surabaya for ethical clearance. The number for ethical clearance was: 0179/KEPK/IV/2018 and it was granted on 1 April 2018. An explanation of the research and giving informed consent were carried out before starting the interview. After the participant signed the informed consent,

the researcher began the interview process. The results of the interview data were recorded on audio recorders as material for transcripts. The transcripts were also put in a closed folder, which was not transparent and stored in data storage at Poli MDR-TB Dr. Soetomo Hospital Surabaya.

III. RESULTS

The results of the study were obtained from 15 participants, 9 men and 6 women. The level of education of participants was: 7 high school participants, 4 junior high school participants, 1 diploma participant, 1 undergraduate participant, 1 elementary participant, and 1 uneducated participant. The age of participants varied from 29 years to 67 years. The marital status of the participants was: 3 single, 8 married, 4 widowed. Overall, 14 participants were Muslim and 1 participant was a Christian. The work of participants varied, including not working, odd jobs, housewives, entrepreneurs, employees. The duration of treatment also varied from 1 month to 2 years.

Table 1. Demographic Data Of Participants

	Level of Education	Age (years)	Gender	Marriage status	Religion	Jobs	Address	Treatment duration (months)
P1	Senior High School	32	M	Single	Islam	Odd jobs	Surabaya	12
P2	Junior High School	45	M	Widow	Islam	Odd jobs	Surabaya	15
P3	Junior High School	40	F	Married	Islam	Housewife	Surabaya	7
P4	Junior High School	50	M	Married	Islam	Laborer	Surabaya	3
P5	Junior High School	45	F	Married	Islam	Housewife	Surabaya	7
P6	Bachelor's degree	42	F	Married	Islam	Housewife	Sidoarjo	1
P7	Senior High School	44	M	Widow	Islam	Driver	Surabaya	18
P8	Elementary school	57	F	Married	Islam	Unemployed	Surabaya	12
P9	Diploma	29	M	Single	Islam	Employer	Surabaya	24
P10	Uneducated	56	F	Widow	Islam	Unemployed	Surabaya	24
P11	Senior High School	47	M	Married	Islam	Enterpreneur	Surabaya	9
p12	Senior High School	33	F	Married	Islam	Employer	Surabaya	24
p13	Senior High School	51	M	Widow	Christian	Enterpreneur	Surabaya	24
p14	Senior High School	67	M	Married	Islam	Enterpreneur	Mojokerto	1
p15	Senior High School	35	M	Single	Islam	Unemployed	Surabaya	24

M= male; F= female

Most participants could not explain what MDR TB is. They only knew that the disease is dangerous and must be treated for a period of two years. We found that the barriers faced in terms of MDR-TB treatment during in-depth interviews with patients were: financial barriers, poor services, inadequate hospital facilities, stigma, ineffective communication of patient-provider, lack of social support, and distance.

Most participants had a lack knowledge about MDR-TB. Participants did not know about the transmission of MDR-TB, the disease definition of MDR-TB or the impact of not adhering to MDR-TB treatment.

Financial constraints

Financial constraints were reported by participants in this study, especially the transportation costs spent to get treatment at the hospital which were presented as follows:

"I felt that's hard because I had to spend money to buy gasoline (for transportation from home to hospital)" P2, P4, P5, P6, P7, P8, P10, P11, P13, P15

"I have to pay for transportation ... even though we receive assistance from government but need to wait for months to receive it (disbursement)" P1, P4, P7

Some participants expressed difficulties with not being able to work because they had to take treatment at the hospital. As a result, patients and their families experienced economic difficulties and guilt for not being able to care for their children for two years because of the treatment. In the category of patients who could not work because they had to attend treatment that must come every day delivered by participants:

"My husband can't work because he has to take me to hospital every morning, so we only rely on transportation assistance from the government" P5

The participant said that she could not perform her role as a parent who cared for her child well and felt bad as a mother, as stated by participants as follows:

"I cannot provide care for my child for 2 years because of treatment and I am so sad about it" P7

Poor services

Participants conveyed the poor services they had received so far. Poor health services were in the form of unfriendly health workers, who were not really concerned with the patient's condition and the long period of service delivery.

The topic of poor service was found in several categories, such as the category of health workers who were less friendly in providing services as delivered by participants:

"Health workers were not friendly, I thought whether they did it because of my illness, so I felt very bad" P7, P8, P9, P13, P15

Participants stated that health workers did not care about the condition of the patient:

"Health workers don't seem to care, when I experience nausea and vomiting, they do nothing and just leave it" P7, P9

The service speed category was delivered by participants as follows:

"The service provided when I was treated was very long, so I had to spend time from morning to noon just to take medication, so many things became neglected" P14

Inadequate hospital facilities

Participants said that hospital facilities were inadequate such as the use of loudspeakers to call patients, as stated:

" Inadequate facilities, loudspeakers to call patients do not function. Health workers must shout to call the patient's name, and it is so uncomfortable" P14

The more specific care category was identified by participants as follows:

"The number of patients is very large, but the place for treatment is only limited here, so that the place feels very crowded, and becomes less comfortable" P12

The category of unavailability of special space for MDR-TB patients such as places of worship and family companion places was identified:

"there is no place prayer room (musholla) at Poli TB MDR, too far, I am not strong enough to walk" P6

Stigma

Stigma or negative views due to a particular characteristic possessed by a person, on the theme of stigma, was identified in the category of stigma from health workers as stated:

"Once when I came for treatment, the health worker immediately ran away when I arrived, and it made me feel bad"
P12

"At first when the health workers did not know my illness, they were friendly to me, but after knowing my illness, they kept away from me and did not want to be close to me" P12

In the category of local community identified by participants, it was stated that:

Negative treatment from family members of participants with MDR-TB was also conveyed by participants:

" my family stayed away from me, my wife made a distance with me and prohibit me to be close to my children" P1 Participants perceive themselves negatively as a result of the disease as stated in::

"I felt so bad because of this disease that I began to stay away from the people around me" P5, P7, P9, P13

Table 2. Barriers Perceived by Multidrug-Resistant Tuberculosis Patients During Treatment in Surabaya Indonesia

Themes	Categories			
Financial constraints	Transportation costs			
	Difficulty in working			
Poor service	Health workers are not friendly			
	Disregard for health workers			
	Slow service			
Inadequate hospital facilities	The speaker to call the patient does not function well			
	Treatment room is too narrow			
	There is no prayer room			
	Special rooms for patient families are not provided			
Stigma	Health workers			
	Local communities			
	Family			
	Self			
Ineffective communication of patient-provider	Incompleteness and inaccuracy in delivering the results of medical			
	examinations			
Lack of social support	Family support			
	Community support			

Ineffective communication of patient-provider

On the theme of the ineffectiveness of health-patient communication the following issues were discussed by the participants:

[&]quot;There is no special place for patient companions or families" P14

[&]quot; my neighbours starting to stay away from me and my family since they know about my illness" P11, P12

[&]quot;The medical team did not explain to us about the laboratory results to the patient" P9

[&]quot;The doctor just said that I was sick and had to go for treatment for two years without taking a break, he didn't explain the results of my examination" P10

"I did not get the explanation of when to do periodic sputum examinations, so when asked for my phlegm to be examined, I had to come back tomorrow" P4

Lack of social support

In the theme of social support that is lacking, there is a category relating to less family support and community support as expressed by participants:

" my neighbors and friends have never discussed my illness, they tend to avoid me" P11, P12

"I feel my family ignores me and does not help me, they do help me for the money but rarely come near me" P9

IV. DISCUSSION

Almost all participants said that they experienced financial constraints, especially related to transportation costs. The financial constraints presented in this study are consistent with research conducted by Jack and Uys [13]. Almost all respondents came from Surabaya, which means they come to one city with a hospital where they seek treatment. However, the participants must come to the hospital every day for treatment, so the amount of costs incurred for transportation also increases. There was a participant from outside the city who had to stay in a boarding house near the hospital. The participants also stated that they could no longer work due to the need to attend treatment every day so that their income declined. These issues were causing financial difficulties for participants with MDR-TB.

Treatment for MDR-TB in Indonesia is supported by funding from the Global Fund (GF) which is also charged to the state budget and expenditure of central government, state budget and expenditure of local government as well as other funding sources that are valid in accordance with statutory provisions [14]. The government has provided financial assistance to MDR-TB patients but the funds are uncertain in terms of when they are paid which represents a barrier for patients. Other studies [15] states that the government needs to support different finances especially in vulnerable groups such as those from rural areas taking into account indirect costs such as transportation, job loss, language barriers and home care in order to improve health outcomes. Although the cost of MDR-TB treatment is free and participants get help with transportation money from the government or the global fund, the assistance is not worth the transportation costs incurred for treatment.

Some participants reported that health workers were unfriendly, less responsive and slow in providing health services. The attitude of health workers to the patients can affect the continuity of patient treatment. Negative attitudes of health workers, according to patient perceptions, can cause patients to lose confidence and feel unappreciated which can cause patients not to want to continue treatment and the treatment will result in failure [16]. Previous research has shown that patients who feel unappreciated, who feel that health workers are rude to them or are treated by staff who are unhelpful will choose not to continue the treatment [17],[18]. Good service from health workers needs to be improved to prevent treatment failure in MDR-TB patients.

Health care facilities that provide MDR-TB treatment services are still lacking. Participants stated that the speaker to call the patient's name was not functioning so that they did not hear the calling for them in the queue. The space

used was also narrow so participants felt uncomfortable. Facilities for families who needed to deliver necessities were also non-existent, adding to the discomfort of patients and families. Uncomfortable facilities can make patients dissatisfied with the care they receive. Improvement of health facilities needs to be done to build a positive image of the hospital and improve patient satisfaction [19].

Some participants expressed they were getting negative treatment from health workers, the community, family members and themselves. Stigma is one of the social determinants for a person's health that can prevent a person from accessing health care, the ability to manage diseases and prevent a person from completing a period of care that must be received [20], [21]. Stigma in MDR-TB patients must be overcome because social consequences can reduce the effectiveness of compliance with treatments that can cause failure in treating tuberculosis.

Participants stated that health workers did not convey information related to the patient's illness completely or accurately. Patients assess the effectiveness of communication with doctors is related to the completeness of information provided by doctors to patients about their health status [22]. A complete description from the doctor can contribute to patient satisfaction [23] which can improve patient compliance to continue their treatment.

The participants admitted that they received less support from their families and surrounding communities. Previous research shows that a lack of social support can be caused by fear of disease contagion [24], [25]. Increased knowledge among family and community needs to be promoted to avoid social isolation from families and communities related to MDR-TB. The study site was among the first site in Indonesia to research barriers faced by MDR-TB patients during treatment and as the number of patients registered for treatment was limited, the sample used in the study was limited. Although the results of the study cannot be generalized, this study gives the viewpoint of patients and providers with regard to completing MDR-TB treatment successfully. This can help program managers and service providers to understand the motivators, policy and design strategies to improve success rates.

V. CONCLUSION

The study highlights the barriers faced by MDR-TB patients during treatment. These barriers are: financial barriers, poor service, inadequate hospital facilities, stigma, ineffective communication of patient-provider, and lack of social support. Periodic monitoring of aid disbursements, improvement of hospital services including health workers and facilities, increased social support, increased knowledge and home-based MDR-TB service programs can be implemented to reduce barriers for MDR-TB patients while they are undergoing treatment.

CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research and authorship.

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