ORIGINAL ARTICLE

Patients' Perceptions of Multi Drug Resistant Tuberculosis Outpatient in Healthcare Services: A Qualitative Study

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ABSTRACT

Introduction: Assuring the quality of Multidrug Resistant Tuberculosis (MDR-TB) care is important for a better treatment outcome. Indonesia is one of the countries with the highest MDR-TB cases in the world, thus it becomes an unresolved issue in Indonesia. This study aimed to gain insight of the MDR-TB patients perceptions about the out-patient healthcare services in a public healthcare facility in Surabaya. **Methods:** This study used qualitative phenomenological approach. This study was conducted in a hospital in Surabaya. Fifteen MDR-TB patients were recruited by purposive sampling and were interviewed semi-structurally and audiotaped. The research data were further analyzed using thematic analysis. Research data from the participants were conveyed word by word, collected, defined, coded, and arranged into each theme. The process of collecting the research data was done by developing codes and themes. **Results:** Topics generated were Interaction of Provider-Patient, Lack of Human resources, and Inadequate Hospital Facilities. **Conclusion:** Patients' satisfaction of healthcare services also an important factor in long-term care of MDR-TB patients. Healthcare services can be improved by involving both healthcare worker resource and facilities. In addition, the role of health workers in understanding the problems experienced by MDR-TB patients is also needed in order to increase their satisfaction while providing the services.

Keywords: Communicable disease; Healthcare; Multidrug resistant tuberculosis; Patients perspective; Tuberculosis

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INTRODUCTION

The global epidemic of Multidrug Resistant Tuberculosis (MDR-TB) is a major challenge for tuberculosis (TB) control efforts worldwide. MDR-TB is a disease caused by Mycobacterium tuberculosis which is immune to antimicrobial drugs (1). The treatment duration for most of MDR-TB patients with the regimen is 18 to 20 months. This duration can be changed according to the patient's response to therapy(2). The health care system recommended by the World Health Organization for MDR-TB patients are isoniazid tuberculosis regimen, drug composition, treatment duration, standardized drugs, patient response monitoring, antiretroviral in patients with MDR-TB and Health Immunodeficiency Virus, surgery when necessary, care and support (2). There is limited information about the quality of MDR-TB care service delivery in Indonesia, particularly related to the perspective of patients.

Indonesia is one of the 30 countries that have high MDR-TB cases in the world, in which 23.000 patients were estimated to suffer from this disease in Indonesia (3). There was about 2.8% of new MDR-TB cases in Indonesia. Furthermore, the World Health Organization (WHO) in 2018 stated that Indonesia has not been successful in implementing MDR-TB treatment (3). In East Java during 2014 to 2017 the treatment success MDR-TB treatment rate was low and the number of defaults was high (4).

The impact of MDR-TB treatment can be classified into 3 parts: costs related to medical costs (such as medicine costs, examinations, doctor's services, and nurses), direct non-medical costs (such as transportation to hospital, eating, and drinking), as well as indirect

costs (such as loss of income)(5). The side effects of drugs experienced by MDR-TB patients are nausea, vomiting, hyperuricemia, allergies, heat and many other effects (6).

MDR-TB patients' treatment is high risk of treatment failure. Various factors of treatment failure or non-adherence to treatment in MDR-TB patients are expectations, good knowledge, autonomy, patient involvement, self-body perception, and drug tolerance. Research in Europe explained that the health care system is the key to successful treatment for MDR-TB patients. The health system includes timely diagnosis, financial system for accessing the treatment, patient-centered approach with cross-border collaboration, emotional, social needs, health workers, and adequate health facilities (7).

Study in Portugal showed the problems experienced by MDR-TB patients were depression, social discrimination, and drug side effects. Good interactions between patients and health workers, as well as careful treatment are associated with factors of adherence and successful treatment. The health system problems faced by MDR-TB patients based on research in Mozambique are delays in diagnosis, stigma associated with diagnosis and treatment, long stay at the hospital, lack of nutritional support, no comprehensive psychosocial support, and lack of knowledge (8).

Study in Indonesia concluded that patients' behavior, self-efficacy, and social support were factors associated with MDR-TB treatment adherence. Meanwhile, according to the research findings in primary health care, less than optimal infection control and feelings of insecurity due to stigma from health workers are related to MDR-TB treatment (9). In addition, knowledge and motivation of health workers in complying with the MDR-TB treatment protocol (9),(10), patients education, patients knowledge, type of drugs, transportation, family support (10),(1),(11) and social organizations also support the adherence of MDR-TB patients (12).

The results of research in Indonesia on MDR-TB treatment have not explained in depth regarding the perceptions of MDR-TB patients to the health care system. The MDR-TB patients' perception about the health care system during the long treatment duration is a consideration for improving health services in the future. This study aimed to gain insight of the MDR-TB patients perceptions about the out-patient healthcare services in a MDR-TB Poly in Indonesia, specially Surabaya.

MATERIALS AND METHODS

Study Design

The qualitative approach was chosen by the researcher to conduct this research through a phenomenological approach. The approach allowed researchers to explore patients' perceptions of MDR-TB outpatient healthcare services in public health facilities, particularly the personal perspectives of MDR-TB patients. This perspective helped to strengthen memory and reveal the experiences of MDR-TB patients in obtaining healthcare services at the MDR-TB Poly.

Sampling and participants

Patients were selected based on criteria of undergoing a MDR-TB treatment for oral and injection treatment. The number of patients who were approached by the researcher was 21 people and 6 people refused to be research participants. Inclusion criteria in this study were diagnosed with MDR-TB disease, aged more than 17 years, able to communicate, currently undergoing treatment for MDR-TB. Exclusion criteria were MDR-TB patients with complications of other diseases such as diabetes mellitus, HIV-AIDS, etc Patients were further selected using purposive sampling to obtain heterogeneity which include gender, age, duration of treatment, receiving MDR-TB poly services for at least a month, and their address. Audio recordings between PI and participants were transcribed in words and translated into Indonesian and English. Codes were then given for each theme. All words were then read by both authors to be compared and confirmed the themes obtained. The code and themes developed were carried out during the data collection process. Direct quotations describing important themes were summarized and written in the manuscript. One verbatim was examined by two researchers to analyze whether there were differences in theme determination to avoid subjectivity.

This research was conducted at a hospital in Surabaya in 2019. MDR-TB Poly is an out-patient service which operates every day except Sunday. MDR-TB patient came every day. The services provided at MDR-TB Poly are examinations in other rooms, treatment consultation, oral drugs, and injection drugs. MDR-TB poly is separated from other poly. Furthermore, the interview process was conducted in March-April 2019 with 15 MDR-TB patients as research sample.

Data collection

MDR-TB patients were invited to talk, while waiting

in line at the MDR-TB Poly. In this case, the researcher first explained the procedure, the research objectives, the benefits of the research result, the possible risks that arise, and how to overcome them in the study process. Furthermore, the MDR-TB patients also signed an informed consent after declaring themselves as participants in the study. Patients were given the right to withdraw from the research process if they did not want to continue their participation in the study. The process of collecting the research data from the participants was carried out at a place and time agreed by both parties. The location of data collection used in this study was varied, including the waiting room of MDR-TB Poly and the patient's house.

MDR-TB patients refused to be participants with the following reasons: busy, afraid, having to do the other activities, side effects of drugs, and the medical examination process. Furthermore, in terms of the interview conducted, two Principal Investigator (PI) were involved, carrying out in-depth interviews with participants that were further recorded. PI already had experience and training in qualitative interviews and qualitative research. The languages used in-depth interviews were Indonesian language, Javanese language, and Madurese language. PI has a semi in-depth interview guide that contains: knowledge, treatment experience, factors that affect treatment, barrier faced, social impacts, treatment of health workers, health facilities, procedures for getting services, and side effects of treatment. The interview guide was developed from the results of various MDR-TB studies.

The interview started with the opening, concerning the demographic data or general data of participants, followed by participants' perceptions of the health care system, and experience of health care procedures, specifically MDR-TB during treatment. Each interview took around 40-60 minutes. Each interview was conducted 2-3 times. The recorded interview results were then written to be used as verbatim for each participant.

Data analysis

Credibility was done by means of peer debriding and member-checking by three people as a research team. The peer debriefing activity is where the PI explained the summary of the results of the interviews and discussed the findings with the research team and two lecturers from the Faculty of Nursing, Universitas Airlangga who are experts in qualitative methodologies to get feedback on data collection and analysis. These activities aimed to reduce bias.

All interviews were recorded and written in the field notes. Dependability was achieved if all auditors consisting of three co-authors agreed on the conclusions and written notes made during the process of data collection and data analysis. Meanwhile, transferability was achieved by providing a specially marked description.

Ethical consideration:

This research protocol approval permit number is 0179/KEPK/IV/2018 on 10 April 2018. The ethical test was carried out at the research hospital. After the ethics certificate was issued by the hospital ethics committee, the researchers made leaflets containing information about the research to be conducted and distributed to patients at the MDR-TB Poly.

Rigor and trustworthiness

Every three participants were member-checked by returning to interview summaries from the participants to clarify the verbatim reports. At the end of the session, the PI examined and presented the participant's point of view and if it was appropriate, the participant signed the verbatim. Confirmability was done by auditing the research process including: data collection, checking the accuracy of coding in the analysis process, and confirming the consistency of the researcher's conclusions.

Translation

The translation process was carried out by: 1) identifying topics related to the research, word by word translated into English including the existing field notes. If there is a difference, then a discussion is held. This study used two translator, English and Indonesian translator.

RESULTS

The study was conducted on 15 participants with demographic characteristics of 9 males and 6 females. The age of the oldest participant was 67 years old, while the youngest was 29 years old. Most of the participants were senior high school graduate, married (8 participants), and unemployed. The longest duration of treatment was 24 months, while the shortest was 1 month.

Most of the MDR-TB patients had unpleasant experiences related to the communication with the health personnel. When seeking treatment at the health service, the patient had the experience of being yelled at, scolded, and not being open. In addition, they also met unfriendly health workers and had inadequate consultation time. Health information regarding the procedure of action and incomplete examination results were conveyed to MDR-TB patients. Participants also felt that health workers cared less about them. The number of health workers on duty was also insufficient even though the number of MDR-TB patients continued to grow. In addition, the facilities and infrastructure in health

services were also inadequate. This is in accordance with the statement of the participants:

Theme 1. Interaction between the provider and patient
Interaction between the provider and patient include: interactions between patients and doctors, nurses, administrative officers, and others. This interaction occurs in the hospital, namely in the MDR-TB Poly while receiving treatment. Most of the participants thought that the provider attitude, respect, and compassion was not good enough. This includes unfriendly behavior, less patience, and less caring. This explanation is further quoted in table II.

Theme 2. Lack of human resources
MDR-TB patients who underwent treatment felt that the number of health workers serving them was insufficient. These health workers include doctors, nurses, administrative officers, and drug taking supervisors. In addition, the ratio of the number of patients and health workers were not balanced. This explanation is further quoted in Table II.

Theme 3. Inadequate hospital facilities
During MDR-TB treatment, the patient received oral and injectable drugs. The facilities needed are patient waiting room, families' waiting room, examination room, drug administration room, and injection drug room. Participants said that the hospital facilities were inadequate. In this case, the shortcomings include hot temperatures, less space, a narrow place for treatment, inadequate equipment at the MDR-TB Poly, posts provided according to the lack of therapy time, no loudspeakers, and a place of worship that is far away. This explanation is quoted in Table II.

DISCUSSION

The research participants claimed that the services and facilities at the research site had both advantages and disadvantages. It is expected that the deficiencies delivered can improve the quality of services provided by the hospital. We identified the structural barrier related to healthcare services facility for MDR-TB patients namely interaction between the provider and patient, lack of human resources, and inadequate hospital facilities.

Provider and patients' interaction is an important factor that affect treatment adherence. In addition, participants also experienced poor interaction between the provider-patient such as unfriendly

Table I : Demographic Data of Participants (n=15)

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

M= male; F= Female

Table II : Themes identified through interviews with Multi Drug Resistant Patient

Theme	Subtheme	Quotations
I. Interaction between the provider and patient	i. Unfriendly behavior	"Were shouted at (by the health workers)." "I've been yelled at by the health workers here." "They are not friendly"
	ii. Less patience	"I hope that they will be more patient" "Maybe too many pastients. Please be more patient"
	iii. Less caring	"For nursing staff, the majority of them are caring, but not all of them, some are lacking." "The nurse near me doesn't do anyting"
II. Lack of human resources	i. Insufficient human resources	"The number of personnel was insufficient and in the end, the assistance was lacking." "There was no nurse who guided the patients and standby." "Since there were many patients, so the nurses did not have the chance to manage patients according to the length of treatment group." "The doctor was not here yet."
III. Inadequate hospital facilities	i. Hot	"This place sometimes it is hot." "The place is very hot."
	ii. Less space	"The place is not wide enough, because there are many patients. "The injection site is narrow" "Families room it is still not spacious" "The poly was too crowded."
	iii. Inadequate equipment at the MDR-TB Poly	"In the Poly MDR-TB, the equipment was incomplete." "I had to be referred because the equipment wa incomplete,."
	iv. Posts provided according to the lack of therapy time	" many places for body examination, why not make it close together." "The queue was very long eventhough I had to eat lunch."
	v. No loudspeakers	"It should be equipped with a microphone so that when you call the patients you will not scream." "The nurse called us in a loud voice because there was no mic"
	vi. A place of worship is far away	"The prayer room is far" "I want to pray but the place is far away."

behaviour, less patience, and less caring. The health workers behaviour affects the patient's treatment continuity. The poor provider-patient interaction such as negative behavior of health workers according to patient perceptions can cause patients to lose confidence and feel unappreciated which could lead to MDR-TB non-adherence and the treatment will be incomplete (13,14). The results of previous studies showed that patients had experiences of being unappreciated as well as encountered rude and uncaring health workers. Therefore, the patients would choose not to continue the treatment (15), (16). Nurse caring behaviour improve patient satisfaction during treatment (17).

Many participants stated their desire for psychological supports during treatment, one of them is derived from healthcare provider. Prior study, it was found that patient–provider relationships are characterized by trust, mutual respect, and shared decision-making which facilitate adherence to chronic disease treatment (18). Complete information about disease, treatment, examination, and disease progression can be an effective communication to increase interaction between patients and health workers (19). Furthermore, providers should also show more supportive attitudes which might improve patient willingness to remain in care. The quality of service from health workers needs to be improved to prevent treatment failure of MDR-TB patient.

Participants stated that health information related to disease was not conveyed completely and accurately by health workers. Doctors are less effective in communicating about the completeness of information regarding health status and examination procedures that must be carried out and treatment progress (20). Whereas, complete health information explanation from doctors can increase patient satisfaction so that it affects the patient’s compliance and motivation to undergo the treatment.

Furthermore, health care facilities for MDR-TB patients services are still lacking. Participants stated that the speaker to call the queue did not work and the room for injection drugs was also narrow so patients felt uncomfortable. The distance of worship room was also far from the treatment room so that the patient was not comfortable. In addition, the facilities for the accompanying family were inadequate. The number of special seats for families was less than the number of families who accompanied them. Therefore, improvements and additions to health facilities need to be done to improve hospital image and increase patient satisfaction (21,22). Good family support reduces the risk treatment failure (1).

In this research, the sample size involved is small and the results of the study cannot be generalized, yet the results of this study can provide information for relevant providers to increase the success of the MDR-TB treatment program. The results of this study can provide information to program managers and service providers to increase patient satisfaction with health facilities and design MDR-TB treatment strategies. The limitation of this study is collected data carried out while participants were undergoing treatment because not all participants were willing to be visited at home. The results of the interview can different when the interview is conducted outside the treatment period. This is accordance with research that MDR-TB patients can experience hearing loss, coclear dysfunction due to drug side effects that can affect participant communication (23).

CONCLUSION

The study highlight is the MDR-TB patients’ perceptions about health care facility during treatment. During the treatment, MDR-TB patients’ state that there is still poor interaction between Provider and Patient, Lack of Human resources, and inadequate hospital facilities. The negative perception of patients leads to dissatisfaction and uncomfortable feeling during their treatment. Therefore, the hospital services need to be improved by improving the healthcare workers and facilities quality, so that MDR-TB patients’ satisfaction during treatment increases and further affects their adherence in long term treatment.

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REFERENCES

1. Ainiyah SN, Soedarsono S, Umiastuti P. The Relationship between Family’s Assessment Support and MDR TB Patient’s Adherence on Treatment in RSUD Dr. Soetomo Surabaya. JUXTA J Ilm Mhs Kedokt Univ Airlangga. 2019;10(2):75.
2. WHO. Consolidated Guidelines on Tuberculosis Treatment. 2016.
3. World Health Organization. Global tuberculosis report 2018. World Health Organization. http://www.who.int/iris/handle/10665/274453. 2018. 265 p.
4. Fitriya L, Artanti KD. Treatment Outcomes of Multidrug Resistant Tuberculosis Patients in East Java From 2014 To 2017. J Berk Epidemiol. 2020;8(2):141.
5. Tanimura T, Jaramillo E, Weil D. Financial burden for tuberculosis patients in low- and middle-income countries: a systematic review. Eur Respir J. 2014;43:1763–75.
6. Fatmawati U, Kusmiati T. Characteristics and the Side Effects of New MDR-TB Treatment. J Respirasi. 2017;3(3):67–73.
7. De Vries G, Tsolova S, Anderson LF, Gebhard AC, Heldal E, Hollo V, et al. Health system factors influencing management of multidrug-resistant tuberculosis in four European Union countries - learning from country experiences. BMC Public Health. 2017;17(1):1–12.
8. Bhering M, Sarubbi Junior V, Kritski A, Souza FBA, Duarte R. Multidrug-Resistant Tuberculosis in Portugal: Patients’ Perception of the Challenges Faced during Treatment. Port J Public Heal. 2021;38(2):62–70.
9. Probandari A, Sanjoto H, Mahanani MR, Azizatunnisa L, Widayati S. Being safe, feeling safe, and stigmatizing attitude among primary

health care staff in providing multidrug-resistant tuberculosis care in Bantul District, Yogyakarta Province, Indonesia. Hum Resour Health. 2019;17(1):1–10.
10. Utomo GC, Joebagyo H, Murti B. Case Study on Multi-Drug Resistance Tuberculosis in Grobogan, Central Java. 2017;2:83.
11. Rato D, Nursalam, Makhfudli. PENGOBATAN TUBERCULOSIS PARU DI MASYARAKAT (The Role of Direct Observed Treatment in Tuberculosis Treatment Successful at Community). J Ners. 2008;
12. Kusmiati T, Agustiyanto C, Rampengan VR, Soedarsono. The sustainability approach to treatment of DR-tB patients through community social organization (aisyiyah). J Pure Appl Microbiol. 2020;14(4):2477–81.
13. Ibrahim LM, Hadjia IS, Nguku P, Waziri NE, Akhimien MO, Patrobas P, et al. Health care workers' knowledge and attitude towards TB patients under Direct Observation of Treatment in Plateau state Nigeria, 2011. Pan Afr Med J. 2014;18(8).
14. Tristiana RD, Yusuf A, Fitryasari R, Wahyuni SD, Nihayati HE. Perceived barriers on mental health services by the family of patients with mental illness. Int J Nurs Sci. 2018;5(1):63–7.
15. Jaiswal A, Singh V, Ogden JA PJ. Adherence to tuberculosis treatment: lesson from the urban setting of Delhi, India. Trop Med Int Heal. 2003;8(7):625–633.
16. Kurniawati ND, Bakar A, MHas E, Ulfiana E, Hidayati L, Endang H, et al. Knowledge-Management-Based-Nursing Care Model Improves Patient Adherence to Tuberculosis Treatment. J NERS. 2016;11(1):99.
17. Yuni Sufyanti Arief*, Ertawati** DL. PERILAKU CARING PERAWAT MENINGKATKAN KEPUASAN IBU PASIEN (Nurse ' Caring Behaviour Improve the Satisfaction of Patient ' s Mother) Yuni Sufyanti Arief *, Ertawati **, Durrotul Laili * Perilaku Caring Perawat (Yuni Sufyanti Arief). 2014;144–8.
18. Horter S, Stringer B, Greig J, Amangeldiev A, Tillashaikhov MN, Parpieva N, et al. Where there is hope: A qualitative study examining patients' adherence to multi-drug resistant tuberculosis treatment in Karakalpakstan, Uzbekistan. BMC Infect Dis. 2016;16(1):1–15.
19. Purwaningsih, Nihayati HE, Mu'jizah K. PERSEPSI PENDERITA Tb BTA (+) TENTANG PENGOBATAN DENGAN STATUS KESEMBUHAN (Perception of Tb BTA (+) Patients About Treatment With Healing Status) Purwaningsih *, Hanik Endang Nihayati *, Khikmatul M u ' jizah *. 2009;
20. Cubaka VK, Schriver M, Kayitare JB, Cotton P, Maindal HT, Nyirazinyoye L, et al. 'He should feel your pain': Patient insights on patient–provider communication in Rwanda. African J Prim Heal Care Fam Med. 2018;10(1).
21. Nandkeshav A, Kalpana K, Mangesh R, Akanksha J, Balaji B. Patients' Waiting Time and Their Satisfaction of Health Care Services Provided at Outpatient Department of Government Medical College, Nanded (Maharashtra, India). IJHSR. 2014;4(4):21–7.
22. Sulistyono RE, Susanto T, Tristiana RD. Barriers in Tuberculosis Treatment in Rural Areas (Tengger, Osing and Pandalungan) in Indonesia Based on Public Health Center Professional Workers Perspectives: a Qualitative Research. J Ners. 2019;14(1):62.
23. Brahmono A, Purnami N, Surarso B. Cochlear Dysfunction after Kanamycin Injection in Multidrug Resistant Tuberculosis Patients. Folia Medica Indones. 2021;56(3):216.