Family Experience in Implementing Family Task with Tuberculosis Multi Drugs Resistant (MDR-TB) in Bandung

1st R. Nurjanah
 Sekolah Tinggi Ilmu Kesehatan
 'Aisyiyah Bandung
 Indonesia

2nd Y. Hidayat
 Sekolah Tinggi Ilmu Kesehatan
 'Aisyiyah Bandung
 Indonesia
 hy_c74@yahoo.com

3rd P. Yualita
 Sekolah Tinggi Ilmu Kesehatan
 'Aisyiyah Bandung
 Indonesia

Abstract—Background: Tuberculosis Multi Drug Resistant (MDR-TB) is a Tuberculosis disease caused by non-compliance with taking anti-tuberculosis (OAT) drugs. Treatment interrupted or not in accordance with the standard Directly Observed Treatment Short-Course (DOTS) can also result in the emergence of multiple immunity cases against anti-TB drugs. Indirectly family efforts need to be done to support the healing of MDR-TB so that it will help reduce the morbidity of MDR-TB. If family efforts are not made, this will have a wide impact on the spread of MDR-TB. MDR-TB cases in West Java in 2015 reached 764 cases, in Bandung there were 127 cases. Based on the data above, a family effort is needed to heal the process and maximize the prevention of MDR-TB. **Method:** the research method uses a qualitative design with a phenomenological approach. **Results:** The study found 5 themes, namely Perception, supporting factors, reinforcing factors, health services and external factors. **Conclusion:** that companion in MDR-TB patients needs supporting factors, reinforcing factors, affordability of health services, and external factors.

Keywords—Family experience, MDR-TB, implementing family task

I. INTRODUCTION

Multi-drug-resistant tuberculosis (MDR-TB) poses a major threat to public health worldwide, particularly in low-income countries.. MDR-TB incidence is likely to rise between 2015 and 2025. (Clinical drug resistance to anti-TB drugs occurs largely as a result of the selection of resistant mutants caused by poor patient adherence to treatment, inappropriate followups and prescriptions, suboptimal doses of drugs and poor access to health services and treatment. [1] The social impact felt by a person with MDR-TB is isolated from the surrounding environment, daily activities are interrupted and the loss of work because MDR-TB sufferers have to take long treatment for up to one year. This is reinforced by study, about 75% of TB patients occur at the most productive age which results in adult TB sufferers estimated to lose an average of 3 to 4 months of work time resulting in a loss of annual household income of around 20-30 %. MDR-TB has a huge adverse economic

impact on patients due to the long duration and complexity of treatment [2].

Treatment of MDR-TB causes side effects including digestive disorders, liver function, gout, visual disturbances with visual impairment, color blindness, narrowing of the visual field, hearing loss, and decreased balance. Other sources say MDR-TB drugs have side effects of nausea, vomiting, headaches, dizziness, insomnia, joint pain and tendon rupture, liver function, blood clots and hyperthyroidism, then Cycloserine with side effects of difficulty concentrating, weakness, depression, peripheral neuropathies[3]. MDR-TB patients is not only the problem of drug side effects, but the long treatment time, and expensive medical costs are a challenge for patients and families For this reason, MDR TB treatment needs to be treated seriously, focusing MDR diagnostic efforts on previously-treated cases is an efficient first-step approach.[4] Beside that requires assistance that can motivate patients during treatment, because it can provide support and motivation for patients during treatment. Further, it requires HCPs' commitment, communication skill and strong support to the patient to cope with TB [5]. The role of the family is very important in supporting the healing process of MDR-TB patients. The family is a driving factor that reinforces the behavior manifested in attitudes and lifestyles that affect the health status of individuals or society. In line with this statement, experience in maximizing the role of families in the health sector, especially in handling TB transmission is one of the strategic steps that can be prioritized by the government to be made a policy. Functionally support includes five family tasks including, identifying problems, making decisions, caring for family members, modifying the environment and utilizing health facilities [6].

Indirectly the family's efforts in supporting the healing of MDR-TB help reduce the morbidity of MDR-TB. If this is not done it will have a wider impact on the spread of MDR-TB. As the authors found MDR-TB cases in West Java in 2015 reached 764 cases, in Bandung there were 127 cases.

With the hope of a decline in cases both at the district / city, provincial and national levels. Based on the above phenomenon, an effort is needed to explore family experiences in carrying out family tasks with family members suffering from MDR-TB.

II. METHOD

This study uses a qualitative design method with a phenomenological approach. The study was conducted by indepth interview of families of MDR-TB sufferers. This qualitative research is perspective emic, meaning that the data obtained is not as it should be, not based on what is thought by the researcher but based on what is happening in the field, which is experienced, felt and thought by participants or data sources. intuition, analysis, and finally do a description and interpretation.

The focus of the study was to find out the family's experience in carrying out family assignments with MDR-TB family members. Determination of the research subject to this researcher uses a purposive sampling method, that is, the sample chosen is oriented towards the research objectives. Individuals are selected or chosen deliberately because they have experience in accordance with the phenomenon under study with a population of 127 people and a sample of 4 people.

III. RESULT

In this study produced five major themes, 12 sub themes, 20 categories, more clearly described as follows:

A. Themes Family perceptions about MDR-TB are generated based on sub-themes :

(a) ignorance of the disease, obtained from the category: do not know the disease, by coding "*tapi tidak tahu TB*" (R01), "*engga tahu sama sekali*" (R02), "*Belum tahu*" (R03), "*Awalnya tidak tahu*" (R04), "*ya kurang tahu*" (R01 and R02), "*ga tahu*" (tertawa) (R03), "*saya lupa lagi neng*" (R04).

(b) ignorance of the symptoms of the disease felt, the disease is obtained from the categories: Cough and lump as symptoms of the disease, by coding "*disini ada jendilan*" (R01), "*Batuknya parah*" (R03 and R04).

(c) ignorance of complaints; obtained from the Complaints category that was felt by coding "*cuman keluhan pusing*" (R01), "*selama pengobatan itu muntah*" (R02), "*muntah wae*" (R03), "*kendalanya kadang-kadang muntah*" (R04).;

B. The theme of family support factors in dealing with MDR-TB is generated based on two sub-themes including:

(a) family motivation to gain knowledge, obtained from the category of family spirit by coding "*iya itu motivasi berobat*" (R01), "*saya kasih semangat*" (R02). Family advice with coding "*iya saya cuman kasih nasehat saja*" (R03), "*ya kasih kaya semangat*" (R04). Education received by coding "*ada yang dari yayasan*" (R01), "*pernah ada dari puskesmas*" (R02), "*iya ada*" (R03), "*pernah*" (R04)

(b) efforts to supply drugs and costs; obtained from the category: Availability of drugs with coding "*Alhamdulillah selalu ada*" (R01), "*Alhamdulillah ada*

aja" (R02), "*Alhamdulillah Ada*" (R03), "*Ada aja siih*" (R04). Cost Guarantee by coding "*nga bayar ada yang nanggung*" (R01), "*kita pakai BPJS*" (R02), "*Alhamdulillah kan ga bayar*" (R03), "*Pengobatan mah geratis*" (R04);

C. The theme of family empowerment factors in the treatment of MDR-TB was generated based on three sub themes including:

(a) treatment treatment efforts, from the category of treatment beliefs by coding: "*kurang yakin*" (R01), "*Belum pernah*" (R02), "*ga pernah pakai alternative*" (R03), "*ga mau sayanya*" (R04). Treatment with drinking water by coding: "*yang penting banyak minum pakai air kelapa*" (R01), "*minum air kelapa ijo*" (R02), "*air dawegan kelapa ijo*" (R03), "*air kelapa ijo*" (R04). Schedule taking medication by coding: "*kalau jam 8, jam 8 terus*" (R01), "*jam 11 sampai jam 1 itu rutin*" (R02), "*jam 1 ya jam 1*" (R03), "*jam 9 ya terus aja ketemu lagi jam 9 gitu*" (R04);

(b) transmission prevention efforts, obtained from the category of transmission prevention by coding: "*harus pakai ini, (menunjukkan masker)*" (R01), "*ya pakai masker*" (R02), "*pakai masker*" (R03), "*dipake in masker*" (R04), separation of cutlery by coding: "*perabotnya harus dipisah*" (R01), "*sampai sekarang juga perabot saya pisah*" (R02), "*yaitu harus kaya perabotan piring sama gelas dipisah*" (R03), "*cuman perabotan yang dipisah sama alat makan*" (R04).

(c) efforts to increase endurance; from the category of care from sunlight with coding: "*jemur diri gitu*" (R01), "*ada sinar masuk*" (R02), "*jemur badannya*" (R03), "*harus kejemur*" (R04). Self-care by coding: "*bapak tuh tidap hari bersih-bersih*" (R01), "*saling jaga aja kebersihan kesehatan*" (R02), "*ya harus jaga badan yang bersih*" (R03), "*saya suruh jemur-jemur badan*" (R04);

D. The theme of health services serving MDR-TB patients is generated based on two sub-themes including:

(a) decision making brings to health services, category Takes to hospital with coding: "*membawa ke rumah sakit*" (R01), "*berobat rutin saja*" (R02). Bring to the clinic by coding: "*pertama itu ke cibadak terus kambuh, ke dua kali ke klinik An-Nur*" (R03), "*ya saya berobat*" (R04).

(b) health service guarantee; based on the Government guarantee category by coding: "*nga bayar ada yang nanggung*" (R01), "*kita pakai BPJS*" (R02), "*Alhamdulillah kan ga bayar*" (R03), "*Pengobatan mah geratis*" (R04);

E. Themes of external factors are generated based on two sub themes including;

(a) environment, obtained from the category of modifying the environment by coding: "*ada sinar masuk*" (R02), "*harus kejemur*" (R04).

(b) patient's personal hygiene during MDR-TB treatment. Patient's personal hygiene during MDR-TB treatment by coding: "*bapak tuh tidap hari bersih-bersih*" (R01), "*saling jaga aja kebersihan kesehatan*" (R02), "*ya harus jaga badan yang bersih*" (R03), "*saya suruh jemur-jemur badan*" (R04)

IV. DISCUSSION

In this section, the researcher will explain the interpretation of the results of the study

A. Theme 1: Family perceptions about MDR-TB disease

This perception does not arise without a certain reason. The emergence of this perception starts from observations through the process of seeing, hearing, touching, feeling and accepting things which then someone makes a selection, organizes, and interprets the information they receive into a meaningful picture. Family perceptions about MDR-TB, according to two of the four informants in the study, they said the symptoms felt and complaints of patients considered not MDR-TB disease. They assume the symptoms caused is a normal cough. Family ignorance about MDR-TB is partly due to the lack of getting relevant information about MDR-TB disease. Other factors that influence family perceptions include the educational background of the majority of respondents having a junior high school education. The results of this study are in line with Nurkaromah's research there is a relationship between perceptions and the level of education of respondents [7]. In accordance with the theory, the higher the level of one's education, the better the level of knowledge and knowledge is the result of knowing and this happens after people have sensed a particular object.

The results of the study revealed ignorance that there were family members with family members suffering from MDR-TB. According to two of the four informants in the study, they said there was a lack of information about MDR-TB so they expressed their ignorance about MDR-TB. Higher level of education the easier it is to receive the information he gets the better the level of knowledge.

B. Theme 2: supporting factors in dealing with MDR-TB

The results of this study indicate that supporting factors are the main key in dealing with health problems experienced by people with MDR-TB. When companions provide support to MDR-TB sufferers calmly, and discuss solutions to deal with problems with grace. That was stated by four informants in this study. Wai PP (2018) Community -Based BMDR-TB care project improved treatment initiation among patients diagnosed with MDR-TB.[8] Good support from the family will reduce patient noncompliance with treatment, families who understand the management of MDR-TB are one of the good supporting factors in directing and motivating patients to seek treatment to the end.

Family support is very important to pay more attention. Family support is one of the factors that influence adherence to MDR-TB treatment where the nuclear family or extended family functions as a support system for family members. The basic function of the family is the health care function where the care function is to treat family members who experience health problems.

Family support has a very important role for the compliance of pulmonary TB patients. Apart from being a party that always supports for the healing of the family is also responsible as a Drugs Supervisor (PMO) which later will play a role to monitor and improve continuously to patients so that patients can take medication regularly and on time with the dosage set by health workers.

In Devi's study, Cahyo and Shaluhayah (2019) said that there was a relationship between family support and the behavior of MDR-TB patients with 92.9% supporting results and 7.1% of families not supporting, from this study it could be concluded that there was a relationship between families with motivation to cure patients[9].

C. Theme 3: reinforcing factors in MDR-TB treatment efforts

There are several reinforcing factors in the effort to treat MDR-TB disease, including treatment efforts. Medical staff (nurses), a reinforcement in the healing of MDR-TB patients, has an important role in efforts to treat MDR-TB, by giving patients confidence to recover. The results of the study by Fadila (2019) revealed that there was a significant relationship between the role of nurses as educators with curative motivation for Lung Tuberculosis patients and Odd Ratio of 3.991, which means that patients who received the implementation of the nurse's role as educators well had a 3.991 times chance of recovering from tuberculosis lung [10]. Motivation in individuals comes from two sources namely from within the individual and from outside one of them nurse support. Other reinforcing factors in the treatment of MDR-TB by respondents who drink a lot, especially coconut water. According to Fadila Coconut water content is rich in electrolytes and low sugar. So that coconut water is good for refreshing and rehydrating the body. One of the electrolyte content is potassium. Potassium is important for the normal functioning of the heart muscle and nerves. It plays an important role in controlling the activity of smooth muscle and skeletal muscle so that it can increase the normal transmission of the electrical signal throughout the nervous system in the body. The next reinforcing factor is the accuracy of taking the medicine. Comply with treatment programs properly. Getting treatment on the right schedule and control routine is the main key to healing TB. If TB treatment is carried out according to the program, the likelihood of TB resistance to antibiotics decreases. Efforts to prevent disease by the family include using masks and separating cutlery. The use of masks and the separation of cutlery is an attempt by the family to minimize transmission by avoiding the spread of droplets to the surrounding environment. Efforts to increase the body's strength through care from the sun and self-care. Based on Harvard University research Sunlight contains ultraviolet B (UVB). When UV B is exposed to the skin, the skin will form vitamin D3 (Cholecalciferol) in large quantities. Vitamin D3 is an previtamin from vitamin D which will be directly distributed to the liver and kidneys to produce vitamin D needed by the body. The University of Copenhagen has found that vitamin D is very important to activate our immune system. Without adequate intake of vitamin D, killer cells from the immune system (T cells) will not be able to react and fight serious infections in the body.

D. Theme 4: health services that serve MDR-TB patients

Based on the results of late interviews conducted with informants that health workers provide motivation to MDR-TB patients to always seek treatment at a health service place, monitor taking medication, remind to take medication every day. Other roles performed by health workers deliver patients to treatment at designated health centers or MDR-

TB-specific service points. In carrying out their professional duties, nurses remain enthusiastic, be patient as long as patients undergo treatment. During treatment, patients get a free medical guarantee from the government at the specified service facilities. The guarantee is in the form of medical expenses until recovery. The importance of financial support for patients, effective MDR-TB education and the role of the healthcare professional (HCP) patient relationship. These findings add to the existing evidence base and provide insight into care improvements and policy changes that could improve outcomes if prioritised by local and national government [11]

In the opinion of Permana, barriers felt by patients during treatment include social interaction with family and community being very limited, side effects of drugs affect discomfort, especially for disorders of digestion and hearing, psychological disorders feel hopeless with the condition of the perceived illness [12] Emphasise the need for tailored psycho-social support . [13] Even though The extent of family and social support was a key determinant of psychological wellbeing of patient .

E. Theme 5: External factors

Basically, to modify the environment the results of the research show the efforts made by the family to improve a healthy environment, among others by maintaining cleanliness and regulating ventilation. The family believes that by regulating the air vents to be fresh because air can enter and exit.

Environmental health is essentially an optimal environmental condition so that it positively influences the realization of optimal health status as well. Hygiene and environmental sanitation can reduce the risk of transmitting tuberculosis. This can be in the form of maintaining a clean environment and adequate housing. Home ventilation has many functions. The first function is to keep the air flow inside the house fresh. This means that the balance of oxygen needed by the occupants of the house is maintained. Lack of ventilation will cause lack of oxygen in the house which means that the levels of carbon dioxide which is toxic to the inhabitants increases. Besides that the humidity of the air in the room will rise. This moisture will be a good medium for pathogenic bacteria. But in this study, it is still found families who do not maintain environmental cleanliness and pay less attention to the state of ventilation.

Based on research conducted by Maria (2018) on positive pulmonary TB patients that there is a significant or significant relationship between environmental sanitation with pulmonary TB patients is very significant, this shows a strong relationship between environmental sanitation with pulmonary TB patients.

External factors that make MDR-TB patients recover cannot be separated from family factors, government factors and also the support of other parties who are very helpful during the treatment process of MDR-TB sufferers, while undergoing treatment many parties support starting from the support of health workers who always accompany and the most support came from the family.

V. CONCLUSIONS

The conclusions in this study resulted in five themes, that companion in MDR-TB patients needs supporting factors, reinforcing factors, affordability of health services and external factors.

ACKNOWLEDGMENT

We would like to thank all those who have helped in the process of completing this research, especially the College of Health Sciences 'Aisyiyah Bandung, the Government in this case the Government of the City of Bandung through the Health Office and staff who have facilitated this research activity. We do not forget to thank the speakers who were willing to become respondents and all those whom we cannot mention one by one for their support while completing this research. Hopefully the results of this study can be useful to support the prevention of MDR-TB disease.

REFERENCES

- [1] V. J. Gómez-Tangarife, A. J. Gómez-Restrepo, J. Robledo-Restrepo, and J. M. Hernández-Sarmiento, "Resistencia a Medicamentos en *Mycobacterium tuberculosis*: contribución de mecanismos constitutivos y adquiridos," *Rev. Salud Pública*, vol. 20, pp. 491–497, 2018.
- [2] B. E. Thomas *et al.*, "Psycho-socio-economic issues challenging multidrug resistant tuberculosis patients: a systematic review," *PLoS One*, vol. 11, no. 1, p. e0147397, 2016.
- [3] Q. Aini, I. Yovi, and M. Y. Hamidy, "Gambaran Efek Samping Obat Anti Tuberkulosis (Oat) Lini Kedua Pada Pasien Tuberculosis-multidrug Resistance (Tb-mdr) Di Poliklinik Tb-mdr RSUD Arifin Achmad Provinsi Riau," *J. Online Mhs. Fak. Kedokt. Univ. Riau*, vol. 2, no. 1, pp. 1–13, 2015.
- [4] E. A. Kendall, A. S. Azman, F. G. Cobelens, and D. W. Dowdy, "MDR-TB treatment as prevention: The projected population-level impact of expanded treatment for multidrug-resistant tuberculosis," *PLoS One*, vol. 12, no. 3, p. e0172748, 2017.
- [5] B. Getahun and Z. Z. Nkosi, "Is directly observed tuberculosis treatment strategy patient-centered? A mixed method study in Addis Ababa, Ethiopia," *PLoS One*, vol. 12, no. 8, p. e0181205, 2017.
- [6] M. Friedman, *Keperawatan Keluarga Roset, Teori, dan Praktik*. Jakarta, 2014.
- [7] K. NURKAROMAH, "HUBUNGAN TINGKAT PENDIDIKAN DENGAN PERSEPSI ORANG TUA TERHADAP LULUSAN PERGURUAN TINGGI DI DESA GADINGREJO UTARA KECAMATAN GADINGREJO KABUPATEN PRINGSEWU TAHUN 2016," 2017.
- [8] P. P. Wai *et al.*, "Community-based MDR-TB care project improves treatment initiation in patients diagnosed with MDR-TB in Myanmar," *PLoS One*, vol. 13, no. 3, p. e0194087, 2018.
- [9] Z. Devi, Au. Cahyo, K. Shaluhiah, "Faktor-Faktor Yang Berhubungan Dengan Perilaku Pasien Tb Mdr Dalam Pencegahan Penularan TB MDR Di Wilayah Kerja Puskesmas Kota Semarang," *J. Kesehat. Masy.*, vol. 7, 2019.
- [10] R. R. Wati, "HUBUNGAN PERAN PERAWAT SEBAGAI EDUCATOR DENGAN MOTIVASI SEMBUH PASIEN TUBERCULOSIS PARU DI RUANG RAWAT INAP RUMAH SAKIT PARU KABUPATEN JEMBER," 2017.
- [11] T. W. McNally, G. de Wildt, G. Meza, and C. M. D. Wiskin, "Improving outcomes for multi-drug-resistant tuberculosis in the Peruvian Amazon—a qualitative study exploring the experiences and perceptions of patients and healthcare professionals," *BMC Health Serv. Res.*, vol. 19, no. 1, p. 594, 2019.
- [12] S. Permana, "Pengalaman Pasien Post Therapy Tuberculosis Multi Drugs Resistant (TB-MDR) Di Kabupaten Bandung," *STIKes 'Aisyiyah Bandung*, Bandung, 2017.
- [13] S. Khanal, H. Elsey, R. King, S. C. Baral, B. R. Bhatta, and J. N. Newell, "Development of a patient-Centred, psychosocial support intervention for multi-drug-resistant tuberculosis (MDR-TB) Care in Nepal," *PLoS One*, vol. 12, no. 1, p. e0167559, 2017.