

FAMILY SUPPORT AND STIGMATIZATION ON MOTIVATION TO CURE DRUG-RESISTANT TUBERCULOSIS IN WOMEN

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Abstract

Background: The longer duration of Drug-Resistant Tuberculosis (DR-TB) treatment, with stricter protocols and more severe side effects than sensitive TB drugs, is another challenge for patients to be able to complete their treatment completely. The stigma experienced by patients, especially female patients, becomes an obstacle in regulating self-motivation mechanisms to achieve recovery. The role of family support is reported as a supporting aspect of motivation and recovery for DR-TB patients. This study aims to examine the effect of stigmatization and family support towards motivation to recover among female DR-TB patients. **Method:** Cross sectional study of 70 female DR-TB patients in the Special Region of Yogyakarta and Central Java through home visits. Logistic regression was used to determine the exposure variables towards outcomes and determine the most suitable model for predicting patient recovery motivation. **Results:** Stigma was considered as amotivation reducer to recovery motivation among patients ($p=0.002$, $OR=0.1929825$, $\beta=-1.645156$). Family support was able to increase patient motivation ($p=0.012$, $OR=4.804345$, $\beta=1.569521$). **Conclusion:** Women suffering from DR-TB need to receive support from a social environment that is free from stigmatization, and strengthened by ideal family support to have strong motivation in completing treatment and achieving recovery.

Keywords: Drug Resistant Tuberculosis (DR-TB); Stigma; Family Support; Motivation.

A. BACKGROUND

Drug-resistant tuberculosis (DR-TB) is a challenge to global TB control programs. More than 465,000 cases of rifampicin-resistant tuberculosis were reported in 2019, of which only 57% were successfully treated. ¹ In Indonesia, RO-TB patients account for at least 12% of all TB cases treated. ² DR-TB treatment is a longer and more demanding treatment, with stricter protocols and more severe side effects. ³This is certainly another challenge for patients to complete their treatment. Especially with the stigma and discrimination that patients can experience from their social environment. ⁴ This will make patients tend to withdraw, feel hopeless, and have the opportunity to stop treatment, especially in female patients. ⁵especially in female patients. Women face *gaps* in mortality, births, employment, basic facilities, and households. To avoid worsening stigma, women with TB often hide symptoms and diagnosis, do not seek treatment, or discontinue treatment. ⁶ The fatalistic paradigm of a disease has been found to be a barrier to treatment programs and health service utilization, and DR-TB is one of the diseases with a high fatalistic view. ⁷ The high burden of stigma experienced by patients with DR-TB needs to be balanced with positive coping and motivation to pursue a cure.

Families are the closest environment to DR-TB patients in their homes. Families are considered to have a great opportunity to strengthen patients emotionally and materially. ⁸ Family support is divided into four aspects, namely informational support, emotional support, appreciative support, and instrumental support. ⁹ When properly utilized, family support can increase a patient's motivation and chances of recovery.

¹⁰. There have been many studies on stigma in DR-TB, and family support has been found to be a contributing factor.^{11–14} and family support has been found to be a catalyst for the treatment of DR-TB patients.^{8,15–17}. However, there have not been many studies that specifically reveal the forms of stigma that reduce the motivation of women with DR-TB, and the link to family support as a preventive aspect. The hypothesis of this study is that stigma has a negative impact on patient motivation, and family support has a positive impact on patient motivation to recover. This study was conducted to assess stigma and family support on motivation to recover among women with DR-TB in the Special Region of Yogyakarta (DIY) and Central Java, Indonesia.

B. METHODS

Cross-sectional data were collected from 70 women who were clinically diagnosed with DR-TB, registered in the medical records of Moewardi Surakarta Hospital or recorded as DR-TB patients based on data from the DIY Provincial Health Office between January 2016 and December 2020. Patients included in this study were all female patients living in all cities/districts of Yogyakarta Province, Klaten, Surakarta, Boyolali, Karanganyar, Wonogiri, Sragen, and Sukoharjo, whose addresses were found, and who were willing to become respondents during home visits. Willingness to be a respondent was recorded in the signing of *informed consent*. The instrument in this study was a short-form digital questionnaire, which was used to measure the patient's self-reported stigma, family support, and motivation scores. The questionnaire and its scoring had been tested in a previous study¹⁸ and declared valid & reliable. Data were collected directly from the respondents by conducting home visits between July - September 2022.

Data were processed through STATA MP 17 software on the overall univariate, bivariate, and multivariate analysis. Univariate analysis was used as a descriptive analysis of respondents' characteristics and to see the tendency of variable correlation through *scatter plot* by including *fitted line*. Bivariate analysis was conducted to examine the relationship of the independent variables (stigma and family support) and their exposure to the outcome variable (motivation to cure DR-TB patients) along with the Odds Ratio and logistic regression coefficient. Multivariate analysis was conducted by comparing the best-fit models (4 models) in predicting patient recovery motivation, as measured by the significance and *Akaike Information Criterion* (AIC) and *Bayesian Information Criterion* (BIC) values of each model.

C. RESULTS AND DISCUSSION

Of all the data received from the secondary data, most of the respondents' addresses could not be found or had moved, were not willing to be respondents, or closed themselves off from the researcher during data collection. Respondents who did not complete the questionnaire properly and completely were excluded from the analysis. The data we obtained were frequency-distributed to see the proportion of each characteristic.

Table 1: Distribution of Respondent Characteristics

Characteristics	N (%)
Gender	
Women	70 (100%)
Age	
35-39	35 (50%)
40-44	8 (11.4%)
45-49	8 (11.4%)
50-54	6 (8.6%)
55+	13 (18.6%)
Education	
Not in School	4 (5.7%)
Elementary-Middle	21 (30.0%)
Upper Intermediate	34 (48.6%)
Higher Education	11 (15.7%)
Jobs	
Not Working or Housewife	35 (50.0%)
Merchant	11 (15.7%)
Other Private	23 (32.9%)
ASN	1 (1.4%)
Living with Family	
No	21 (30.0%)
Yes	49 (70.0%)
Duration of Treatment	
9-11 Months	21 (30.0%)
18-24 Months	49 (79.0%)

Table 1 shows that most women with DR-TB at the study site were aged 35-39 years (50%), educated to upper secondary level (48.6%), unemployed or housewives (50.0%), living with their families (70.0%), and on long-term treatment regimen (ITR) for 18-24 months (79.0%). Patients completed a digital questionnaire accompanied by the research team, containing questionnaires measuring experienced stigma and motivation to cure using indicator scores. There was a significant trend between feelings of stigmatization and motivation to recover, and there were also many outliers due to the limited sample size due to the scarcity of and access to DR-TB patients, especially women. The red *fitted line* indicates a negative trend between stigma and motivation scores.

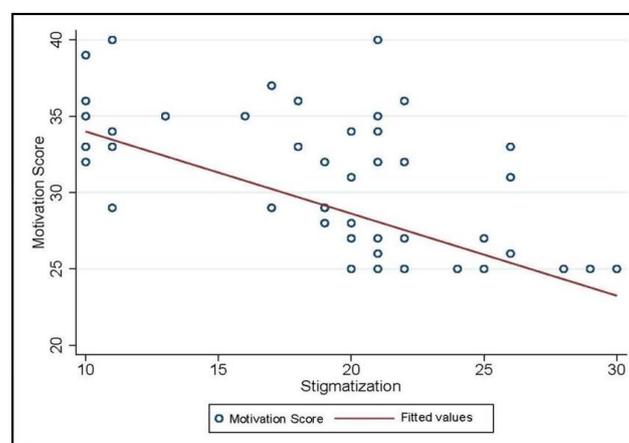


Figure 1: Scatterplot Graph of Perceived Stigma with Self-Reported Recovery Motivation Score

Based on the figure, the greater the stigma score reported by respondents, the lower the motivation score that can be assessed, although there are some respondents with high stigma scores and still have high motivation. Logistic regression was conducted to find the significance of the correlation and influence between the independent variables and the outcome variable. In Table 2, it was found that overall, stigma had a strong effect on recovery motivation with a *p* value of 0.002, and an OR of 0.192825. This means that overall, female patients who perceive themselves to be stigmatized in general, have a potential cure motivation of 0.19 times that of patients who are not stigmatized in general. This means that the motivation for recovery in these respondents is much smaller than patients who are not stigmatized.

Logistic regression of stigma variable components on cure motivation of women with DR-TB

Variable	OR	95% CI	Coef.	95% CI	P> z
Feeling Stigmatized in General	.1929825	.0688059 .5412652	-1.645156	-2.676466 -.613846	0.002
"The neighborhood ostracized me"	.2269508	.0798166 .6453125	-1.483022	-2.528024 -.4380206	0.005
"The Neighborhood Talks About Me Openly"	.3615878	.1265274 1.033339	-1.01725	-2.067296 .0327952	0.058
"The neighborhood showed disdain for me"	.1599198	.0439486 .5819148	-1.833083	-3.124734 -.5414313	0.005
"I was told to go home when I attended a community meeting"	.1734451	.0453076 .6639768	-1.751894	-3.09428 -.4095081	0.011
"The neighborhood avoided me"	.2453623	.0896453 .6715655	-1.405019	-2.411895 -.3981437	0.006
"I feel inferior to my surroundings"	.4311052	.1813521 1.024811	-.841403	-1.707315 .0245087	0.057
Family Support	4.804345	1.411039 16.35797	1.569521	.3443266 2.794715	0.012

Logistic regression tests were also conducted on each component (6) of perceived stigma and general family support. The components of stigma that are significant (at the *p* < 0.05 level) in potentially reducing motivation to recover are respondents feeling often ostracized with OR 0.2269508 (.00798166-0.6453125), feeling the environment shows disgust for respondents with OR 0.3615878 (0.1265274-1.033339), feeling often told to go home when attending community meetings with OR 0.1734451 (0.0453076-0.6639768), and feeling the neighborhood avoided respondents with OR 0.2453623 (0.089645-0.6715655). Although not entirely significant, all components of stigma have negative coefficients on patient recovery motivation, such as feeling ostracized with a coefficient of -1.483022. This means that statistically in this study, stigma decreases patients' motivation to recover. As a test of the hypothesis that family support is a good component for patients to be *coping* in increasing their motivation, a regression test was also conducted on the family support variable and got an OR value of 4.804345 (1.411039-16.35797) and was declared significant. The coefficient of this variable also shows that family support is able to increase patient motivation due to the positive value obtained. Thus, family relationships are stated to be able to be a predictor of increased patient motivation to get their recovery.

To determine the most ideal type of stigma in predicting a decrease in respondents' recovery motivation (Table 3), a multivariate analysis test was conducted using the logistic regression test by comparing 4 models with adjusted variables.

Table 3: Multivariate analysis using logistic regression test by comparing 4 models

Variable	Model 1	Model 2	Model 3	Model 4
Feeling Stigmatized in General	-1.299* (-2.401, -0.197)	-1.242* (-2.385,-0.0979)	-0.943 (-2.172,0.286)	-0.621 (-2.026,0.785)
"The neighborhood ostracized me"	-1.087* (-2.155,-0.0184)	-1.012 (-2.119,0.0959)	-0.755 (-1.957,0.448)	-1.181 (-2.708,0.347)
Family Support		1.355* (0.0454,2.665)	1.402* (0.0571,2.747)	1.642* (0.188,3.096)
"The neighborhood showed disdain for me"			-1.016 (-2.495,0.462)	-1.693 (-4.859,1.473)
"I was told to go home when I attended a community meeting"				-0.667 (-3.082,1.749)
"The neighborhood avoided me"				0.144 (-4.173,4.461)
"The Neighborhood Talks About Me Openly"				1.051 (-0.427,2.529)
_cons	2.506* (0.456,4.557)	1.342 (-1.034,3.719)	2.587 (-0.574,5.748)	3.244 (-0.642,7.131)
N	70	70	70	70
AIC	86.59	84.00	84.02	87.85
BIC	93.34	92.99	95.26	105.8

Of the 4 variable combination models that have been analyzed, "Feeling Stigma in General" is consistently significant in model 1 and model 2 with a negative coefficient value, so this variable is stated to be consistently significant in potentially reducing respondents' recovery motivation in models 1 and 2. In addition, the variable "Family Support" always shows consistent significance in models 2, 3 and 4 with positive coefficient values. So it can be stated that in this study, family support always consistently contributed to the prediction of increasing respondents' recovery motivation. The fittest model in explaining variations in patients' recovery motivation is model 2 with the lowest AIC value of 84.00.

Stigma on Motivation to Heal

In this study, stigma has a significant influence on the low motivation of patients in achieving recovery, which is characterized by negative coefficient values on all components of stigma. Patients who experienced overall stigma even had an OR of recovery motivation of 0.193, or only had 19.3% of the motivation they should have, Patients who felt avoided ($p = 0.006$) and even asked to go home in community meetings ($p = 0.011$) were stated to be related to low motivation to recover. Stigma or overt discrimination is considered one of the most severe forms of stigma.¹⁹ In the case of TB, including DR-TB, this includes disparagement, indifference, avoidance, and apathy. Similarly, Mahbub's research, a photovoice of a bench titled *Mickey Mouse Bench*, tells the story of a female DR-TB patient who experienced overt discrimination.⁶ Other studies have also found that DR-TB patients have a higher prevalence of depression and stigma than drug-sensitive TB patients.²⁰ Feelings of helplessness and depression caused by the stigma attached to patients with DR-TB influence the emotional or motivational burden on patients. This motivational burden is compounded by patients being forced to make substantial behavioral changes, such as not seeing friends and relatives.^{21,22} Stigma is one of the determinants of social

health, which proceeds from the nature and state of being unwanted by certain environments. Individuals with drug-resistant tuberculosis are prone to the effects of social stigmatization around them, and often internalize feelings of shame, disgust, and guilt. This negative stigmatizing attitude results in behaviors that make patients want to withdraw from interpersonal relationships. Tuberculosis stigma contributes to delays in diagnosis and negatively impacts treatment compliance. Negative stigmatization of TB can result in delayed diagnosis and may lead to treatment non-adherence.¹¹ Patients who do not feel discriminated against will avoid psychological disorders such as stress, depression, fear or conditions that can aggravate their illness so that interventions carried out by medical staff can run effectively.²³

Family Support on Motivation to Heal in Women with DR-TB

Family support is a crucial factor in a person's health condition.²⁴ Based on the data obtained, respondents with good family support have a potential recovery motivation 4.8x higher than respondents who lack family support. Family support is said to be ideal if it fulfills 4 aspects, namely informational support, instrumental support, appreciation support, and emotional support.⁹ Informational support is support in the form of providing information, in this case information about Drug Resistant Tuberculosis. The provision of this information can be in the form of assistance to seek education about the DR-TB problem being faced, asking doctors, reading and studying DR-TB, and so on. Family support can be lacking when the family does not actively ask the doctor or do not provide appropriate information for DR-TB patients. Instrumental support is support in providing infrastructure such as an ideal room for patients with DR-TB, which is separate from other family members, has good ventilation or air exchange, and has appropriate humidity. Thus, some respondents may lack support because they are unable to provide appropriate rooms and adequate nutrition, or do not know that they should. Appreciation support is support given in the form of appreciation to DR-TB patients. Appreciation can be given when the patient completes daily treatment, or when the patient successfully manages side effects that become a problem in daily life, or appreciation in other forms that make the patient feel that they have successfully overcome some of the challenges of treatment. Family support for respondents can be lacking when they do not give enough appreciation to respondents. Emotional support is support in the form of providing affection, love, attention, and so on that is closely related to building positive emotions in patients.²⁵ Thus, family support for respondents can be lacking when they do not build the patient's emotional side well, thus making the patient feel more hopeless and psychologically suffer.²⁶

Good family support tends to make patients more confident to recover because they get support that suits their needs. DR-TB treatment is difficult and long-term, so they need more support than when they were healthy.²⁷ In addition, the side effects of DR-TB drugs range from hallucinations, difficulty eating, joint pain, severe headaches, to mental disorders and hopelessness.²⁸ In such cases, what patients need most is support to continue their treatment despite the challenges they face in surviving.¹⁰ When they have good support, their internal strength increases and this can help them complete their treatment²⁹. The results obtained are inseparable from the shortcomings and weaknesses in this study. This study was applied to 70 respondents who received treatment at Moewardi Hospital or were registered in the DIY Provincial Health Office records only, so these results may not be generalizable to all women with DR-TB in Indonesia. In addition, in-depth interviews were not conducted with each

patient, so patients did not have the opportunity to provide detailed explanations of the family support they received and their belief in recovery. Further research should be conducted to examine the stigma and

D. CONCLUSION (10 PT)

Women with DR-TB need to be supported by a social environment that is free from stigmatization, and strengthened by ideal family support in order to have strong motivation to complete treatment and achieve recovery.

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Reference

- 1) Baluku JB, Mukasa D, Bongomin F, et al. Gender differences among patients with drug resistant tuberculosis and HIV co-infection in Uganda: a countrywide retrospective cohort study. *BMC Infect Dis*. 2021;21(1):1-11. doi:10.1186/S12879-021-06801-5/TABLES/4
- 2) Directorate General of PPPL, Ministry of Health. Multi-Drug Resistant Tuberculosis. Ministry of Health of the Republic of Indonesia. Published 2019. Accessed May 18, 2020. <https://www.tbindonesia.or.id/page/view/22/tb-mdr>
- 3) Ministry of Health RI. *Technical Guidelines for Integrated Management of Drug Resistance Control*; 2014.
- 4) Udwardia Z, Furin J. Quality of drug-resistant tuberculosis care: Gaps and solutions. *J Clin Tuberc Other Mycobact Dis*. 2019;16:100101. doi:10.1016/j.jctube.2019.100101
- 5) Gugssa Boru C, Shimels T, Bilal AI. Factors contributing to non-adherence with treatment among TB patients in Sodo Woreda, Gurage Zone, Southern Ethiopia: A qualitative study. *J Infect Public Health*. 2017;10(5):527-533. doi:10.1016/j.jiph.2016.11.018
- 6) Mahbub T, Mathur T, Isaakidis P, Daftary A. "One-by-One, TB Took Everything Away From Me": A Photovoice Exploration of Stigma in Women with Drug-Resistant Tuberculosis in Mumbai. *Affilia - Journal of Women and Social Work*. Published online 2023. doi:10.1177/08861099231162582/FORMAT/EPUB
- 7) Kundu S, Basu R, Sarkar S, Nath S, Biswas D. Psychological profile of multi drug resistant TB patients: A qualitative study from a tertiary care center of Kolkata. *J Family Med Prim Care*. 2021;10(1):392. doi:10.4103/JFMPC.JFMPC_1787_20
- 8) Sukartini T, Minarni I, Asmoro CP. Family Support, Self-efficacy, Motivation, and Treatment Adherence in Multidrug-resistant Tuberculosis Patients. *The International Nursing Conference*. 2019;(Inc):178-182. doi:10.5220/0008322301780182
- 9) Muna L, Soleha U. Motivation and family social support affect treatment adherence in patients with pulmonary TB. *Scientific Journal of Health*. 14AD;7(2):172-179.
- 10) Chen B, Peng Y, Zhou L, et al. Social support received by multidrug-resistant tuberculosis patients and related factors: A cross-sectional study in Zhejiang Province, People's Republic of China. *Patient Prefer Adherence*. 2016;10:1063-1070. doi:10.2147/PPA.S105655
- 11) Courtwright A, Turner AN. Tuberculosis and stigmatization: Pathways and interventions. *Public Health Reports*. 2010;125(SUPPL. 4):34-42. doi:10.1177/00333549101250s407
- 12) 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):16. doi:10.1186/s12960-019-0354-8

- 13) Redwood L, Mitchell EMH, Nguyen TA, Viney K, Nguyen VN, Fox GJ. Psychometric evaluation of a new drug-resistant tuberculosis stigma scale. *J Clin Epidemiol.* 2021;133:101-110. doi:10.1016/j.jclinepi.2021.01.007
- 14) Cremers AL, De Laat MM, Kapata N, Gerrets R, Klipstein-Grobusch K, Grobusch MP. Assessing the consequences of stigma for tuberculosis patients in urban Zambia. *PLoS One.* 2015;10(3):1-16. doi:10.1371/journal.pone.0119861
- 15) Solikhah MM, Nursasi AY, Wiarsih W. The relationship between family's informational support and self-efficacy of pulmonary tuberculosis clients. *Enferm Clin.* 2019;29:424-427. doi:10.1016/j.enfcli.2019.04.062
- 16) 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: Scientific Journal of Medical Students Universitas Airlangga.* 2019;10(2):75. doi:10.20473/juxta.v10i22019.75-78
- 17) Chen X, Du L, Wu R, et al. The effects of family, society and national policy support on treatment adherence among newly diagnosed tuberculosis patients: a cross-sectional study. *BMC Infect Dis.* 2020;20(1):623. doi:10.1186/s12879-020-05354-3
- 18) Rinawati SAW, Reviono S. The Effect of Individual Characteristics and Role of Social Environment on Drug Resistant Tuberculosis Patient's Adherence Treatment during Pandemic COVID-19 Era. *Journal of Advanced Zoology.* 2023;44(S2):2132-2145.
- 19) Daftary A, Mondal S, Zelnick J, et al. Dynamic needs and challenges of people with drug-resistant tuberculosis and HIV in South Africa: a qualitative study. *Lancet Glob Health.* 2021;9(4):e479-e488. doi:10.1016/S2214-109X(20)30548-9
- 20) Redwood L, Mitchell EMH, Viney K, et al. Depression, stigma and quality of life in people with drug-susceptible TB and drug-resistant TB in Vietnam. *International Journal of Tuberculosis and Lung Disease.* 2021;25(6):461-467. doi:10.5588/ijtld.20.0952
- 21) Harnilawati. *Family Nursing Concepts and Processes.* 1st ed. (Amirullah, ed.). As Salam Library; 2013.
- 22) Reis J dos. *Factors Associated with Medication Adherence among Tuberculosis Patients in Timor-Leste.* Queensland University of Technology; 2016.
- 23) Brigaste MBT, Tea LA. The Battle Continues: An Interpretative Phenomenological Analysis of the Experiences of Multidrug-Resistant Tuberculosis (MDR-TB) Patients. *Psychol Stud (Mysore).* 2018;63(1):9-18. doi:10.1007/s12646-017-0436-4
- 24) Bhalavat R. Why Family Support is Crucial for the Recovery Process. Maryland Recovery.
- 25) Peddireddy V. Quality of Life, Psychological Interventions and Treatment Outcome in Tuberculosis Patients: The Indian Scenario Psychological Distress in Tuberculosis. 2016;7(October):1-9. doi:10.3389/fpsyg.2016.01664
- 26) Roba AA, Dasa TT, Weldegebreal F, et al. Tuberculosis patients are physically challenged and socially isolated: A mixed methods case-control study of Health Related Quality of Life in Eastern Ethiopia. *PLoS One.* 2018;13(10):e0204697. doi:10.1371/journal.pone.0204697
- 27) Oladimeji O, Adeyinka DA, Makola L, et al. Clients' Perception of Quality of Multidrug-Resistant Tuberculosis Treatment and Care in Resource-Limited Setting: Experience from Nigeria Olanrewaju. *Mycobacterium- Research and Developmnt.* Published online 2016:13. doi:http://dx.doi.org/10.5772/57353
- 28) Yang TW, Park HO, Jang HN, et al. Side effects associated with the treatment of multidrug-resistant tuberculosis at a tuberculosis referral hospital in South Korea. *Medicine (United States).* 2017;96(28). doi:10.1097/MD.0000000000007482
- 29) Khanal S, Elsey H, King R, Baral SC, Bhatta BR, Newell JN. Development of a Patient-Centred, Psychosocial Support Intervention for Multi-Drug-Resistant Tuberculosis (MDR-TB) Care in Nepal. *PLoS One.* 2017;12(1):e0167559. doi:10.1371/journal.pone.0167559