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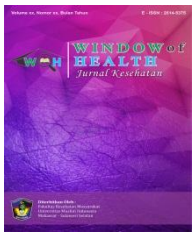

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Data-Based Evidence on the Causality Model of Social Stigma on Medication Compliance in Leprosy Patients in Bone District, Indonesia

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ABSTRACT

Leprosy is an infectious disease and can cause stigma from society. One thing that is important to do to reduce the stigma felt by leprosy sufferers is to obediently take medication. This study aims to determine the relationship between stigma and adherence to taking medication on covariate variables in leprosy patients in Bone Regency. This quantitative study uses an observational analytical approach using a cross-sectional study. The analysis used was multivariate analysis with a causality model. The number of samples in this study was 92 respondents, taken using simple random sampling. The results of this study show that stigma in leprosy patients in Bone Regency is significantly related (ORa = 1.022, 95% CI = 0.306-3.416) to adherence to taking medication, which means 1.022 times more likely to experience non-adherence in taking medication, controlling for gender and side effects of medication. There needs to be preventive efforts through early detection and health education related to leprosy given to patients, the patient's family, and the community, so that it can reduce the stigma experienced by patients and increase compliance with taking medication.

Keywords : Compliance; medication; leprosy; societal stigma

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INTRODUCTION

Leprosy is an infection affecting the nerves and skin caused by Mycobacterium leprae. It is a contagious disease that presents highly complex challenges, not only from a medical perspective but also in social, economic, cultural, security, and national resilience aspects. There are two types of leprosy: multibacillary (MB) and paucibacillary (PB) (1). Leprosy has historically been perceived as a hereditary disease, a divine curse, and an impure condition (2). Leprosy, a chronic infectious disease, has been associated with stigma from ancient times to the present day, often leading to significant challenges in the lives of those affected (3).

The World Health Organization (WHO) reported that in 2023, there were 182,815 new leprosy cases globally, of which 72,845 (39.8%) were among females and 10,322 (5.6%) were among children (4). Indonesia ranked third in leprosy incidence, with approximately 15,000 to 17,000 new cases reported annually in 2022, and children accounting for 9–12% of these cases (5). The prevalence rate of leprosy in Indonesia in 2022 was 0.54 cases per 10,000 population, with a new case detection rate of 4.6 cases per 100,000 population (6). One of the concrete manifestations of the commitment of the Ministry of Health to the elimination of leprosy is the preparation of the National Action Plan (NAP) toward Leprosy Elimination 2023 – 2027 (5).

In 2022, South Sulawesi Province reported 744 new cases of leprosy, comprising 75 new paucibacillary (PB) cases and 669 multibacillary (MB) cases, with a new case detection rate of 8.2 per 100,000 population (6). South Sulawesi recorded a Released from Treatment (RFT) achievement rate of over 95% (5). The highest number of new leprosy cases among districts/cities was recorded in Bone Regency, with 140 cases, followed by Makassar with 72 cases. In Bone Regency, data from the Health Office in 2021 showed a decrease in leprosy cases from 140 to 114, with cases distributed across all community health centers (Puskesmas) in the regency. A collaborative assessment by the Ministry of Health and Netherlands Leprosy Relief (NLR Indonesia) in Bone District, South Sulawesi, revealed that over 30% of individuals affected by leprosy reported feelings of inferiority and shame associated with their condition (5).

Medication adherence is the most critical factor in determining the recovery of leprosy patients (7). It refers to the patient's compliance with the correct use of medication as prescribed by a physician, following prior consultations between the patient (or their family, who plays a key role in the patient's life) and the healthcare provider. Medication adherence is influenced by various internal and external factors. Internal factors include age, gender, occupation, income, education, and knowledge. External factors include the duration of medication use, side effects, family support, and the role of healthcare providers (8). A lack of family support has been associated with a higher incidence of non-adherence to treatment (79.2%) compared to adherence rates. Patients are more likely to discontinue medication if they receive insufficient support from their families. Conversely, greater family involvement in patient care leads to higher adherence to medication regimens. Patients who receive full support from their

families or close friends tend to be more determined to recover and find it easier to visit healthcare providers, particularly in terms of medication adherence (8)

Stigma is a sociological concept that is important in medicine and health because it threatens health as much as the disease itself (9). Social stigma surrounding leprosy patients (LPs) in the community is still related to the adherence of these patients to medication and to their internal motivation for healing (10). Disability among LPs brings stigma in society; even when the disease has been declared cured, LPs still find it difficult to be accepted in the community (11). As a result, social stigma influences a patient's adherence to medication and motivation for healing, resulting in an elevated prevalence of leprosy in the community and helps achieve the WHO's "Toward zero leprosy 2030" goal (12). Based on the aforementioned discussion, this study aims to examine the relationship between social stigma and medication adherence among leprosy patients in Bone Regency.

METHOD

This study employs a quantitative approach with an analytical design, utilizing a cross-sectional study design. The research was conducted in the working areas of nine community health centers (Puskesmas) in Bone Regency, namely Paccing, Ulaweng, Koppe, Lappariaja, Lamuru, Tanabatue, Kajuara, Salomekko, and Bakunge, during March–April. The study population consisted of 114 respondents, selected using a simple random sampling technique. The dependent variable in this study is medication adherence, which refers to a patient's behavior in consuming the prescribed medication and completing the course based on their last visit to the Puskesmas. One of the independent variables is social stigma, which is defined as the perception or judgment of individuals toward leprosy patients when they experience discriminatory treatment, such as social exclusion and avoidance.

The research instruments included questionnaires, interviews, and direct observations. The medication adherence questionnaire consisted of five self-developed questions and was supplemented with direct observation by monitoring patient visits to the Puskesmas, medication collection schedules, the completion of prescribed doses, and remaining medication. The social stigma questionnaire was adapted from the standardized Internalized Stigma of Mental Illness (ISMI) Scale, which originally contained 20 questions. However, in this study, the questionnaire was reduced to seven questions focusing on external stigma—stigma perceived from others rather than self-perceived stigma. Additionally, the knowledge questionnaire comprised 10 written questions answered by respondents, while the family support questionnaire consisted of nine questions.

Data analysis was conducted using SPSS, employing univariate and bivariate statistical analyses, with the chi-square test used for bivariate analysis. Multivariate analysis was performed using logistic regression with a causal model to determine cause-and-effect relationships between variables and to identify the independent variable with the most dominant influence on the dependent variable.

RESULTS

Based on Table 1, which presents the distribution of respondent characteristics, the majority of respondents were aged ≥ 46 years, with 64.1% being female. Most respondents had a low level of education (75.0%) and were unemployed (55.4%). The majority of respondents were diagnosed with multibacillary (MB) leprosy (95.7%) and had been undergoing treatment for ≥ 6 months (80.4%). Additionally, 57.6% of respondents reported experiencing side effects from the medication. The findings indicate that a higher proportion of respondents were non-adherent to medication (54.3%) and experienced stigma (64.1%). However, respondents demonstrated good knowledge regarding medication adherence (76.1%) and received strong family support (71.7%).

Table 1. Distribution of Respondent Characteristics

Variable	n = 92	% = 100
Age		
<46 years	43	46.7
≥46 years	49	53.3
Gender		
Female	59	64.1
Male	33	35.9
Education level		
Low	69	75.0
High	23	25.0
Employment Status		
Employed	41	44.6
Unemployed	51	55.4
Leprosy type		
PB Type (Paucibacillary)	4	4.3
MB Type (Multibacillary)	88	95.7
Treatment duratiom		
≥6 months	74	80.4
<6 months	18	19.6
Medication Side Effects		
Experienced Side Effects	53	57.6
No Side Effects	39	42.4
Medication Adherence		
Non-Adherent	50	54.3
Adherent	42	45.7
Stigma		
Experienced Stigma	59	64.1
No Stigma	33	35.9
Knowledge		
Poor Knowledge	22	23.9
Good Knowledge	70	76.1
Family Support		
Weak Support	26	28.3
Strong Support	66	71.7
Total	92	100.0

Based on Table 2, the chi-square statistical analysis revealed that social stigma (p = 0.046), gender (p value = 0.001), and occupation (p value = 0.009) were significantly associated with medication adherence ($p < 0.05$), indicating that the null hypothesis (H_0) was rejected and the alternative hypothesis (H_a) was accepted.

Conversely, age (p value = 0.731), education (p value = 0.147), type of leprosy (p value = 0.623), treatment duration (p value = 1.000), medication side effects (p value = 0.068), knowledge (p value = 0.082), and family support (p value = 0.542) were not significantly associated with medication adherence ($p > 0.05$), meaning that H_0 was accepted and H_a was rejected.

Table 2. Bivariate Analysis

Variabel	Medication Adherence				OR Crude (95% CI)	P-value	Model candidate
	Non-Adherent n=92	%	Adherent n=92	%			
Stigma							Included
Experienced Stigma	27	29.3	32	34.8	0.367	0.046	
No Stigma	23	25.0	10	10.9	(0.149-0.904)		
Age							Not
<46 years	26	28.3	17	18.5	1.593	0.731	Included
≥46 years	24	26.1	25	27.2	(0.695-3.650)		
Gender							Included
Female	24	26.1	35	38.0	0.185	0.001	
Male	26	28.3	7	7.6	(0.069-0.0493)		
Education level							Included
Low	34	37.0	35	38.0	0.425	0.147	
High	16	17.4	7	7.6	(0.155-1.162)		
Employment Status							Included
Employed	29	31.5	12	13.0	3.452	0.009	
Unemployed	21	22.8	30	32.6	(1.441-8.272)		
Leprosy type							Not
PB Type	3	3.3	1	1.1	2.617	0.623	Included
(Paucibacillary)	47	51.1	41	44.6	(0.262-		
MB Type					26.145)		
(Multibacillary)							
Treatment duratiom							Not
≥6 months	40	43.5	34	37.0	0.941	1.000	Included
<6 months	10	10.9	8	8.7	(0.334-2.652)		
Medication Side Effects							Included
Experienced Side	24	26.1	29	31.5	0.414	0.068	
Effects	26	28.3	13	14.1	(0.175-0.976)		
No Side Effects							
Knowledge							Included
Poor Knowledge	16	17.4	6	6.5	2.824	0.082	
Good Knowledge	34	37.0	36	39.1	(0.989-8.059)		
Family Support							Not
Weak Support	16	17.4	10	10.9	1.506	0.524	Included
Strong Support	34	37.0	32	34.8	(0.597-3.801)		

Based on Table 2, A total of six candidate variables included in the multivariate modeling, social stigma, gender, education, occupation, medication side effects, and knowledge, were included in the subsequent analysis as they met the selection criteria ($p < 0.25$). Meanwhile, four variables—age, type of leprosy, treatment duration, and family support—were excluded as they did not meet the inclusion criteria. The variables included in the multivariate modeling process were social stigma, gender, education, occupation, medication side effects, and knowledge.

Table 3. Multivariate Full Model of the Relationship Between Social Stigma and Medication Adherence Among Leprosy Patients in Bone Regency, 2023

Variable	B	SE	P-*Value*	OR	CI 95%
Stigma	Reference	Reference		1	Reference
Experienced Stigma	0.054	0.630	0.931	1.056	0.307-3.632
Gender					
Female	Reference	Reference		1	Reference
Male	-1.254	0.729	0.085	0.285	0.068-1.190
Education level					
Low	Reference	Reference		1	Reference
High	-0.460	0.573	0.423	0.631	0.205-1.942
Employment Status					
Employed	Reference	Reference		1	Reference
Unemployed	0.352	0.621	0.571	1.422	0.421-4.801
Medication Side Effects					
Experienced Side Effects	Reference	Reference		1	Reference
No Side Effects	-0.340	0.524	0.517	0.712	0.255-1.988
Knowledge					
Poor Knowledge	Reference	Reference		1	Reference
Good Knowledge	0.017	0.158	0.912	1.018	0.747-1.386

The confounding assessment aims to evaluate whether the inclusion or exclusion of certain variables significantly alters the relationship between stigma and medication adherence. The confounding evaluation stage can be seen in Table 4.

Table 4. Confounding Assessment in the Multivariate Analysis of the Relationship Between Social Stigma and Medication Adherence Among Leprosy Patients in Bone Regency, 2023

Model	Variable	OR	95% CI	ΔOR	Description (Confounding)
Model 1	*Gold Standard Model**	1	references		
	Experienced Stigma	1.056			-
Model 2	Gender				
	Female	1	referens		
	Male	0.756	0.244-2.344	28%	*Confounding*
Model 3	Education level				
	Low	1	referens		
	High	1.079	0.316-3.688	2%	-
Model 4	Employment Status				
	Employed	1	referens		-

	Unemployed	0.993	0.296-3.336	5%	
Model 5	Medication Side Effects				
	Experienced Side Effects	1	referens		
		0.926	0.289-2.962	12%	*Confounding*
	No Side Effects				
Model 6	Knowledge				
	Poor Knowledge	1	referens		-
	Good Knowledge	1.059	0.308-3.642	2%	

The above modeling results indicate that, out of the six steps conducted for confounding selection, starting from the variables of knowledge, occupation, medication side effects, education, and gender, the identified confounding variables were **gender and medication side effects**. The final results are as follows:

Table 5. Final Model of Multivariate Analysis on the Relationship Between Social Stigma and Medication Adherence Among Leprosy Patients in Bone Regency, 2023

Variable	OR *Crude*		OR *Adjusted*		P-*Value*
	OR	95% CI	OR	95% CI	
Stigma	0.367	0.149-0.904	1.022	0.306-3.416	0.046
Gender	0.185	0.069-0.493	0.211	0.065-0.684	0.001
Medication Side Effects	0.414	0.175-0.976	0.656	0.240-1.796	0.147

Based on Table 5, among the six variables included in the multivariate analysis—social stigma, gender, education, occupation, medication side effects, and knowledge—the final confounding variables identified were social stigma, gender, and medication side effects. The final multivariate analysis results indicate that the relationship between social stigma and medication adherence among leprosy patients in Bone Regency is statistically significant. The association value (Adjusted OR = 1.022, 95% CI: 0.306–3.416) suggests that patients experiencing social stigma are 1.022 times more likely to be non-adherent to medication when controlling for gender and medication side effects.

DISCUSSION

Stigma is primarily driven by social conflict, insufficient public understanding, distinctive disease characteristics, and its infectious nature. This stigma is perpetuated by various societal actors, including close relations, the general public, institutional representatives, and broader systemic forces. Individuals subjected to such stigma often endure psychological, physical, and social burdens and may adopt concealment as a coping mechanism. However, this behavior can undermine public health efforts and pose a broader risk to society's general health(13). Stigma refers to negative or unfavorable perceptions that can lead to discriminatory treatment of individuals with leprosy. Discrimination may occur in various situations, such as seeking employment, using public transportation, worshiping in religious places, finding a life partner, and other social interactions. This stigma can significantly hinder

both leprosy patients and their families in their social and economic pursuits due to societal rejection or blame-oriented responses (14). Health professionals have always emphasized that the stigma of leprosy has been present since biblical times, and this contributes to poor treatment adherence (15).

This study's findings align with previous research conducted (16), which indicated that individuals who do not perceive stigma tend to demonstrate higher medication adherence. These patients do not experience stigma because they perceive their condition as a common skin disease rather than leprosy. Consequently, they continue their daily activities without significant disruptions. Moreover, most of the patients encountered during the study regarded stigma or differential treatment from others as an ordinary occurrence and responded with indifference (16). The intense stigma in the community associated with leprosy causes LPs to experience stress, ultimately affecting their behaviours during the treatment period (17). It is imperative that LPs are convinced that adherence to medication can help reduce their level of permanent disability (18).

The findings of this study do not indicate a relationship between age and medication adherence among leprosy patients in Bone Regency. This is consistent with the study, which also found no significant association between age and adherence to medication. Elderly patients were more likely to adhere to their treatment regimen due to strong family support, whereas non-adherent patients were predominantly adults who perceived leprosy as a non-severe and non-contagious disease (19).

Female patients tend to have higher awareness and motivation to recover from leprosy, leading to more consistent adherence to medication. However, this study contradicts the findings of research (20), which indicated no significant association between gender and medication adherence. Women are generally more compliant with their medication regimen compared to men, as they are more concerned about their physical appearance. Since any disease that negatively impacts their appearance is something they seek to avoid, they are more likely to adhere to medical recommendations, including regular medication intake (21).

The majority of patients with lower educational attainment adhered to their medication regimen, suggesting that adherence is not necessarily influenced by educational level. This finding is consistent with previous studies indicating no significant association between education level and medication adherence among leprosy patients (19). This may be due to the influence of accessible health information and strong family support in reinforcing adherence. However, other studies suggest that lower education levels contribute to reduced knowledge, which significantly impacts an individual’s attitudes and behaviors (22).

Furthermore, most employed patients demonstrated lower adherence to their medication regimen. This finding contradicts previous research that found no significant relationship between employment status and medication adherence (19) (23). Individuals who are employed often prioritize their work commitments, which may lead to neglecting other crucial aspects of their well-being, including health maintenance.

The type of leprosy refers to the classification of the disease experienced by patients, with the majority of respondents in this study diagnosed with MB-type leprosy. This finding aligns with previous research, which indicates no significant association between the type of leprosy and medication adherence among leprosy patients (20). Both PB- and MB-type leprosy patients understand that irregular medication intake may lead to drug resistance against MDT, potentially resulting in treatment failure and prolonged disease progression (24).

The duration of treatment refers to the length of time a patient undergoes therapy at the community health center based on the type of leprosy. This study aligns with the findings, which indicate no significant association between treatment duration and medication adherence among leprosy patients (23). However, treatment duration can impact patients with lower socioeconomic status in accessing healthcare services. Illiteracy, low monthly per capita income, low social status, poor socioeconomic conditions, and limited knowledge are key factors associated with treatment discontinuation (25).

Side effects are the impacts caused by a particular treatment**.** The side effects experienced by the respondents included skin darkening, joint cramps, peeling, and dry skin. The results of this study showed that there was no association between medication side effects and adherence to treatment among leprosy patients in Bone Regency. These findings are consistent with the study conducted, which stated that medication side effects did not influence non-adherence. The researcher assumed that the side effects experienced by the respondents did not interfere with their daily activities; therefore, they continued their treatment and adhered to the medication provided by healthcare workers (23).

Knowledge refers to the extent to which the community or respondents understand the causes, transmission, and treatment of leprosy. This finding does not align with previous studies that have reported a significant relationship between knowledge and medication adherence obat (26) (27). The lack of knowledge among patients in this study is primarily due to their low educational background, as most have only completed elementary school. Generally, individuals with higher education levels are more receptive to information. Those with good knowledge tend to exhibit better behavior compared to those with limited knowledge, including adherence to medication as part of health-related behavior (28).

Family support encompasses emotional, instrumental, and informational support, including reminders to take medication, logistical fulfillment of leprosy treatment, financial support, and the provision of medication, as well as expressions of care and encouragement to help patients feel more at ease during treatment. In this study, the majority of patients received strong family support, making it difficult to establish its influence on medication adherence. This finding aligns with previous research indicating no significant relationship between family support and adherence among leprosy patients (29). However, it contrasts with other studies suggesting a positive association between family support and treatment adherence, emphasizing that family serves as a natural source of social support for leprosy patients (7) (30).

The limitation of this study is its use of a cross-sectional design, which prevents the establishment of causal relationships as it does not fulfill the temporality aspect of causality. Further

research is related to interventions to reduce social stigma. Stigma reduction interventions should be included in future strategies to combat leprosy within communities. The interventions encourage patients to seek care earlier not only increasing positive treatment outcomes for themselves but also reducing the spread of leprosy in the community

CONCLUSIONS AND RECOMMENDATIONS

There is a relationship between social stigma and medication adherence among leprosy patients in Bone Regency, after controlling for confounders such as gender and medication side effects. However, no significant association was found between age, gender, education, type of leprosy, medication side effects, knowledge, or family support and medication adherence. It is recommended that preventive efforts be strengthened through early detection and health education on leprosy, targeting patients, their families, and the wider community. These initiatives can help reduce stigma experienced by patients and improve medication adherence.

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