Prevalence and health-seeking behavior of leprosy patients at Universitas Mataram Hospital

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Abstract

Purpose: This study aims to acknowledge leprosy patients' prevalence and health-seeking behavior at the outpatient clinic of UNRAM Hospital. **Methods:** This study used a retrospective cohort design of leprosy patients from January 2021 to April 2023. Results: There were 40 leprosy patients, including 35 patients (87.5%) with multibacillary type, and five patients (12.5%) were identified as paucibacillary type. This study included 21 men (52.5%) and 19 women (47.5%). Based on age, the most frequent group came from people aged around 26-45 years old (45%). There were 16 unemployed patients (40%) and 14 (35%) senior high school graduates. Mataram had the most leprosy cases (52.2%) in UNRAM hospital. There were 20 cases (50%) of Type 1 reaction and 32 patients (80%) who received multidrug therapy. There were 21 patients (52.5%) who developed a disability. Most patients (45%) came to the clinic several times yearly. They were mostly female (56%), while men went to the clinic at least once yearly (67%). Patients under 45 (67%) and those with lower educational levels (78%) came more frequently than other groups. Conclusion: The prevalence of the study is important for realizing the burden of the disease and establishing a preventive approach towards leprosy. The role of health providers is important in engaging the awareness of leprosy patients' self-care because it is important to prevent serious disabilities.

Keywords: disability; infectious disease; leprosy; leprosy reactions

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INTRODUCTION

According to the World Health Organization (WHO), Leprosy is one of the neglected tropical diseases [1]. It is an infectious disease caused by acid-fast bacteria, Mycobacterium leprae. This disease is a chronic granulomatous disease and is transmitted through droplets [1,2]. Globally, the prevalence of the disease has been declining for the past couple of years. Nevertheless, WHO states more than 200.000 new cases every year, and more than 120 countries are still in battle with the burden of this disease. In Southeast Asia, over 140.000 cases were reported in 2019 [1]. Indonesia is one of the countries with an increasing number of leprosy cases. Along with other countries, Brazil and India, Indonesia accounted for 79% of leprosy cases in 2019 [3]. In West Nusa Tenggara, the cases of leprosy fluctuated in the past 5 years and significantly increased in 2022. The prevalence of Leprosy in 2022 in West Nusa Tenggara was 1.7 over 10.000 people. Over 40 % of cases have come from the Bima region in the past 5 years [4].

Leprosy causes mucocutaneous symptoms and peripheral nerve dysfunction. The bacteria are more likely to reside in the Schwann cell and have an affinity towards keratinocytes and the skin's innate immune system [5], thus creating those typical symptoms of leprosy [6]. This disease is curable; however, if left untreated, this disease could cause great morbidity, including deformity and disability. According to WHO, the disease is divided into paucibacillary (PB) and multibacillary (MB) types. Leprosy causes 2 kinds of reactions: type 1 reactions (T1Rs), also known as reversal reactions, and type 2 reactions (T2Rs), known as erythema nodosum leprosum (ENL). There are 3 degrees of disability caused by leprosy depending on its severity (0-degree, 1st-degree, and 2nd-degree). The risk factors for leprosy include age, gender, socioeconomic factors, hygiene, and close contact history [7,8]. The antibiotic of choice for leprosy includes multidrug therapy. The most common medication is a combination of Rifampicin, clofazimine, and Dapsone (standard MDT). Another well-known regimen is a combination of rifampicin, ofloxacin, and minocycline (ROM), which have been widely applied as an alternative treatment of leprosy globally.

Since the stigma of leprosy disease is still prevalent, it will affect the behavior of leprosy patients and people in society [9]. Factors that influence the behavior toward leprosy include knowledge, gender, marital status, and occupation [10]. India and Indonesia, as the endemic region of leprosy, had poor knowledge and a high stigma towards leprosy [11]. A community-based cross-sectional study from India showed that 45.3% of participants had inadequate knowledge of leprosy, yet 76.7% of people expressed unfavorable attitudes toward leprosy patients [10]. Another study from Nepal stated around 57.9% of respondents had poor knowledge and 59.1% of the participants did not necessarily have a positive attitude toward leprosy. Moreover, around 38.8% of participants reported that they would not go to the hospital if they developed signs and symptoms of leprosy [9].

An analytical study in Sumedang, Indonesia, used a questionnaire related to leprosy, and the result showed low scores (42.6 ± 4.04) before counseling [12]. Poor knowledge, especially of the signs and symptoms, and an unfavorable environment toward leprosy could cause delays in diagnosis and affect health-seeking treatment. Knowledge will also influence the compliance of treatment [11]. Besides, occupation also affects behavior because unemployed or unskilled people tend to have trouble seeking medical treatment due to out-of-pocket expenditures [10]. Furthermore, gender also influences health-seeking behavior. Despite men being the most prevalent group among leprosy cases, women are more likely to delay treatment compared to men. In addition,

the mortality rate among female patients is more likely higher than among male patients [13]. This condition relates to the accessibility of women to adequate knowledge about leprosy and a higher percentage of experienced stigma in women [13,14]

Epidemiologically, Indonesia has greatly worked on the leprosy elimination program and reached the target in 2020 with the number of cases less than 1 per 10.000 per population. In 2017, the leprosy prevalence reached 0.7 per 10.000 population. Even though the elimination report continued to increase in the past 20 years, the target was not achieved in 2019. By the end of 2022, there were still 7 provinces and 113 districts/cities of leprosy-endemic regions [15]. This predicament is associated with a higher level of stigma in Indonesia. This stigma is a result of poor knowledge and misconceptions about leprosy, which affects the attitude toward leprosy patients and their health-seeking behavior. Although leprosy is a curable disease, the stigma of this disease is responsible for serious impacts and disabilities. It also leads to avoidance of contact with leprosy patients, such as refusal to sit next to patients. This milieu creates the tendency of leprosy patients to cover up the symptoms of leprosy and lead to more serious complications if left untreated. Moreover, around 12-59% of leprosy patients were delaying treatment and neglecting self-care, which contributed to more disease burden [10]. Thus, in this study, we would like to assess the prevalence and health-seeking behavior of leprosy patients at Universitas Mataram Hospital to help mitigate further morbidities of this disease.

METHODS

This study used a retrospective cohort design describing leprosy patients' prevalence and health-seeking behavior in Universitas Mataram Hospital, Mataram City, Lombok, West Nusa Tenggara. The target population of this study was collected by a total sampling method. This method requires all leprosy patients entering the dermatology and venerology outpatient clinic from January 2021 until April 2023. The participants were adults, which consisted of 40 patients. Medical records, as the secondary data, were utilized in this study to gather information on leprosy patients about sociodemographic distribution (gender, age, occupational status, educational level, and region), leprosy types, the occurrence of leprosy reaction, choice of treatment, and degree of disabilities.

The exclusion criteria in this study were incomplete data on the medical records and patients who had been released from treatment before the study started. The age group of this study consisted of 5 subgroups (<17 years old, 17-25 years old, 26-45 years old, 46-65 years old, and > 65 years old). The occupations of patients varied from being unemployed, students, employees, housewives, civil servants, daily workers, and police. The patient's level of education consisted of no school, elementary, junior, or high school, 3rd and 4th diploma degree, undergraduates, and postgraduates. Lastly, the region is based on the patient's living address, including Mataram, North, East, West and Central Lombok, Sumbawa, West Sumbawa, Bima, and East Nusa Tenggara. Leprosy types were divided based on WHO classification: paucibacillary (PB) and multibacillary (MB) types. The paucibacillary type is leprosy with less than 5 skin lesions without the presence of the bacteria in slit skin smear results. Meanwhile, the multibacillary type has more than 5 lesions with positive skin smear results and is accompanied by peripheral nerve symptoms [7]. Leprosy reactions, acute or subacute inflammation that occurs during the clinical course of the disease, are divided into type 1 and 2 reactions, reversal and Erythema Nodosum Leprosum (ENL) reactions, respectively [2]. Leprosy disability includes grade 0, grade 1, and grade 2. Grade 0 means the absence of disability, no apparent deformities; grade 1 is loss of sensory function in the eyes, hands, or feet without visible deformities; grade 2 is the presence of deformities and visible damage on the hands, eyes, or feet [16]. The patients in UNRAM hospital received either two choices of therapy: the combination of Rifampicin, clofazimine, and Dapsone, known as standard multidrug therapy (MDT), and Rifampicin-Ofloxacin-Minocyclin (ROM) regimen.

Univariate analysis was performed to describe the distribution of each category. The health-seeking behavior is determined by the frequency of medical checkups and the patient's self-care, which is reflected in the prevalence of disability. Then, the data were analyzed using Microsoft Excel 2022 and attached as tables in the study. This study has received ethical approval from the ethics committee of the Medical Faculty of Mataram University No: 239/UN18.F8/ETIK/2023.

RESULTS

The total number of selected cases of leprosy patients in UNRAM Hospital was 40 patients from January 2021 until April 2023. The multibacillary type was the most frequent case found at UNRAM Hospital. There were 35 patients (87.5%) with Multibacillary type, while 5 other patients (12.5%) were identified as paucibacillary type, as shown in **Table 1**.

Table	1.	Distribu	tion o	f lej	prosy	type	at	outpatient
clinic	Un	iversitas	Matara	am H	Iospit	al		

Leprosy types	Total leprosy patients
	n (%)
MH-PB	5 (12.5)
MH-MB	35 (87.5)

MH = Morbus Hansen; PB = Paucibacillary; MB = Multibacillary

Table 2. Sociodemographic distribution of leprosy patients at outpatient clinic Universitas Mataram Hospital

Dationto charactoristic	Total leprosy patients			
Patients characteristic	n (%)			
Gender				
Male	21 (52.5)			
Female	19 (47.5)			
Age				
<17	0 (0)			
17-25	10 (25)			
26-45	18 (45)			
46-65	10 (25)			
>65	2 (5)			
Occupation				
Unemployed	16 (40)			
Students	3 (7.5)			
Employees	7 (17.5)			
Self-employed	7 (17.5)			
Housewives	1 (2.5)			
Civil Servants	3 (7.5)			
Daily Workers	2 (5)			
Police	1 (2.5)			
Education				
No education	12 (30)			
Elementary School	5 (12.5)			
Junior High School	2 (5)			
Senior High School	14 (35)			
3 rd Diploma Degree	1 (2.5)			
4 th Diploma Degree	1 (2.5)			
Undergraduates	4 (10)			
Postgraduates	1 (2.5)			
Region				
North Lombok	3 (5)			
West Lombok	7 (17.5)			
Middle Lombok	1 (2.5)			
East Lombok	0 (0)			
Mataram	21 (52.5)			
Sumbawa	2 (5)			
West Sumbawa	2 (5)			
Bima	3 (7.5)			
East Nusa Tenggara	1 (2.5)			

Among those patients, men were more prevalent in cases of leprosy compared to women. There were 21 men and 19 women in this study. Based on age, the most frequent group came from people aged around 26-45 years old (45%), followed by people around 17-25 years old (25%) and 46-64 years old (25%). Most leprosy patients in UNRAM Hospital were unemployed, which accounted for 16 patients (40%). Moreover, according to educational background, patients with leprosy were more common in people with senior high school backgrounds, and there were 14 patients (35%). Besides, Mataram had the most leprosy cases in UNRAM hospital, accounting for 52.5% of cases, as shown in **Table 2**.

The most common leprosy reaction that occurred in UNRAM hospital was Type 1 Reaction. There were 20 cases (50%) of Type 1 reaction (Table 3). Two patients (5%) suffered both reactions in different disease episodes. Thirty-two patients received standardized MDT as the therapy, accounting for 80% of cases. There were 6 (15%) patients that received both therapies in different timelines because of several instances such as MDT shortage and suspected drug resistance. The majority of the patients did suffer from disabilities.

There were a total of 21 patients (52.5%) who developed disabilities during the disease, with 1st-degree disability being the most common (32.5%). In contrast, the rest of the patients (20%) suffered from 2^{nd} degree disability, as shown in **Table 3**. The frequency and regularity of health-seeking behavior of leprosy patients were determined based on gender, age, and educational

level (**Table 4**). Most patients (45%) came to the clinic several times yearly. They were mostly female (56%), while men went to the clinic mostly at least once per year (67%). Patients under 45 years old (67%) and those with lower educational levels (below bachelor's degree) (78%) came more frequently compared to other groups.

Table 3. Distribution of leprosy reaction, treatment,
and disability degree of leprosy patients at outpatient
clinic UNRAM Hospital

	Total leprosy		
Categories	patients		
_	n (%)		
Leprosy reactions			
None	15 (37.5)		
Type 1 Reaction	20 (50)		
Type 2 Reaction	3 (7.5)		
Type 1 & 2 Reactions	2 (5)		
Treatment choice			
MDT	32 (80)		
Rifampicin Ofloxacin Minocycline (ROM)	2 (5)		
Both	6 (15)		
Disability degree			
None	19 (47.5)		
1 st -Degree	13 (32.5)		
2 nd -Degree	8 (20)		

Table 4	4. Frequency	and regularity	of health-seeking	behavior ar	nd patients'	self-care	based o	n disabili	ty
prevale	ence among le	eprosy patients a	at UNRAM Hospital						

	Total		Gender		Age	Education level	
Categories	Frequency	Male	Female	< 45	>=45	Low	High
	(n, %)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Check-ups frequency							
Several times per year (18;45%)	18 (45)	8 (44)	10 (56)	12 (67)	6 (33)	14 (78)	4 (22)
Once per year (12;30%)	12 (30)	8 (67)	4 (33)	8 (67)	4 (33)	9 (75)	3 (25)
Less regular than once per year (10;25%)	10 (25)	5 (50)	5 (50)	6 (60)	4 (40)	10 (100)	0 (0)
Self-care (based on disability occurrence)							
No disability (19;47.5%)	19 (47.5)	10 (52.6)	9 (47.4)	13 (68.4)	6 (31.6)	13 (68.4)	6 (31.6)
Disability (21;52.5%)	21 (52.5)	11 (52.4)	10 (47.6)	13 (61.9)	8 (38.1)	20 (95.2)	1 (4.8)

DISCUSSION

Leprosy type in this study showed more cases of multibacillary leprosy. Several studies showed multibacillary (MB) leprosy was more prevalent than paucibacillary leprosy. According to an epidemiological study in Brazil, more than half the new leprosy cases yearly were multibacillary cases [17]. Another study also reported almost 72.5% of cases are MB cases [6]. The most common type of leprosy in Indonesia is multibacillary leprosy, which accounts for 86.2% compared to the paucibacillary case (11.1%) and is followed by other types of leprosy such as indeterminate, lucio, and histoid leprosy [18]. Multibacillary leprosy is associated with male gender, low educational level, and number of skin lesions [14]. That also correlates with men being the most prevalent in leprosy cases in general. In Sichuan, China, leprosy case was most common among the male gender. The male-to-female ratio admitted in the study was 2.5 [13]. Moreover, a retrospective study from Indonesia reported that 66.8% of leprosy cases came from men. Surakarta, a city in Central Java, had more male leprosy cases in Indonesia, while Jakarta had more female leprosy cases [18]. Furthermore, men suffer more frequently from grade 2 disability and are physically affected compared to women [13].

In our study, women sought treatment more frequently compared to men in a year. Studies have found that women were more concerned about their physical appearance than men [19]. Based on the male perspective, they tended to ignore the first signs of leprosy more frequently [14]. On the contrary, several studies showed women with leprosy were more likely to delay treatment [20,21]. Women took two times longer to establish the diagnosis of leprosy (P < 0.0001), while men had a shorter duration of treatment due to early diagnosis [20]. The delay in seeking medication was higher in women (10 months) than in men (6 months) [13]. Despite men being the most prevalent group in disease detection, Kumar et al. stated that men were more likely to have a higher proportion of treatment completion than women (79.2% vs 65.6%) because they had more access to MDT compared to women. Even though women have a lower proportion among leprosy cases, Kumar et al. also showed that women were more likely to become defaulters compared to men (34% vs 21%) [22]. There were assumptions that men could gain more health-related information because they mostly worked outside while women mainly were at home as

housewives. Thus, men were reported higher in self-reporting cases. Women faced more social problems due to social stigma because they experienced more rejection and isolation from their family or society, thus causing more delayed detection [13]. Around 8.3% of unmarried women also admitted that leprosy might affect their prospects of marriage. Therefore, they would delay the detection and medical treatment [21].

Age is one of the risk factors for acquiring leprosy infection. In this study, most patients were in the 26-45-year-old group. Among the younger people group (<45 years old), less than half of the patients visited the hospital more than once a year. The age-related risk of leprosy increases in a bimodal pattern; the elevated risk increases between 5 to 15 years old and continues after 30 years old [7]. This study is similar to another study that showed the median age of patients with leprosy was 40 years old, with an interguartile range (IQR) between 25-55 years old [23]. Patients under 15 years old were reported only 3.2%. Based on gender, women acquired leprosy infection at a younger age compared to men. The median age of women with leprosy infection was 36 (IQR 24-50), while men were 44 (IOR 28-57) [23]. Moreover, age was also associated with a higher risk of delayed treatment of leprosy, which could increase the risk of disability [24]. The disability-non-disability ratio among older people was 1.3:1, while the ratio was 1:1 in younger people in our study, respectively. One study stated that the mean age of delayed treatment mainly occurred in the 45-54 and 55-64-year-old groups [25]. This was supported by another study in which the risk factor of delayed detection was highest among the 45-59-year-old groups (OR 3.44) [26]. The awareness of patients in this study to do frequent check-ups was similarly low among both groups since more than half of each group had only once or fewer check-ups in a year.

This study showed that most patients had low educational levels (below a bachelor's degree). Only 14 patients in that group had frequent visits, while the rest did not visit the clinic regularly. Higher education is associated with better knowledge of leprosy [27]. There was also an association between the role of education and delayed detection of leprosy cases, thus increasing disability [28]. People with low educational backgrounds are more prone to getting leprosy infection compared to highly educated people because they have poor knowledge of leprosy and inadequate decisions for health-seeking treatment [8,26]. Similar findings from a study in Indonesia reported that around 59.7% of patients with leprosy come from low-educational backgrounds (p-value 0.001). The risk of infection was over two times higher in patients with lower educational backgrounds because they tend to be unaware of the signs, symptoms, risks, and transmission of leprosy [8]. Poor knowledge of leprosy also increases misconceptions and stigma in society. The existence of stigma makes patients afraid if their disease becomes known to their family and community because it will lead to further discrimination, stigmatization, and delayed detection [26]. Additionally, leprosy detection was also associated with health-seeking behavior. A study showed that 70.2% of leprosy patients took no action after realizing the signs and symptoms of leprosy, and around 12-59% of leprosy patients visited traditional healers or bought over-the-counter medicines [26,29]. Moreover, good self-care in leprosy patients was also related to a good educational background compared to poor knowledge (p-value 0.038) [30].

Furthermore, most of the participants were unemployed in this study. People with stable occupations will have better incomes and socioeconomic status. Poor socioeconomic status will increase the risk of leprosy because they are more likely to have poor living conditions [8]. Low-income patients (per capita income less than 0.25 times the minimum wage) or no-income people had an increased risk of leprosy infection by 40% compared to people with minimum wage. In the same study, the result showed that unemployment reduced leprosy risk. However, this protective effect was only available in a subgroup of 18-30-year-old patients [31]. Moreover, unemployment, as one of the socioeconomic factors, was also associated with delayed leprosy detection accompanied by living in rural areas and working daily wage labor. Usually, infected people who come from poor socioeconomic households will take self-medication first or visit conventional treatment. Since the disease does not cause pain, they will not consider this disease as a physical health problem, thus delaying disease detection [26]. In addition, a study from Brazil stated that low-risk occupation correlated with a higher risk of activity limitation from leprosy. Low-risk occupations such as housewives or retired people are more prone to have limitations due to leprosy compared to high-risk occupations (p-value <0.05) [32].

During the clinical course of the disease, an individual could suffer from reactions. Leprosy reactions are episodes of inflammation during leprosy disease. This study showed most patients in UNRAM Hospital suffered from reversal reactions (50%). T1Rs might occur in patients within the borderline spectrum due to instability of immune response towards the pathogen. This includes borderline-tuberculoid (BT) leprosy, borderline-borderline (BB) leprosy, and borderline-lepromatous (BL) leprosy. Meanwhile, T2Rs occur in lepromatous leprosy (LL) patients and, in a few cases, borderline-lepromatous (BL) leprosy patients [7]. Patients with higher bacterial index (BI) increase the risk of developing T2Rs. The odds of patients with $BI \ge 4$ is 5.2 times greater risk of developing T2Rs compared to individuals with lower bacterial index [33]. An epidemiological study from Brazil reported the prevalence of leprosy reactions from 2010-2015. This study showed that most patients (53.7%) developed T1Rs [34]. However, an epidemiological study from Indonesia reported otherwise. Type 2 reactions were more common among leprosy patients in Indonesia, which accounted for 20.3% of cases, followed by 13.3% cases of reversal reactions and 0.7% cases of the Lucio phenomenon [18].

In this study, disabled patients (52.5%) outnumbered nondisabled patients (47.5%). Based on the disability grade, grade 1 disability was more common among the patients (32.5%). A study performed in India reported grade 1 disability was more prevalent (21.25%) than grade 2 disability (6.31%). The deformities were commonly noticed at the moment of diagnosis (66.14%), and hand deformities are the most common complication (44.8%) [16]. It was similar in Indonesia, which showed patients with grade 1 disability were the most prevalent case; hand deformities as the most common defect [35]. The major risk factor for the development of disability is patient delay [24,26,28]. Factors that increase patient delay include male gender, older age, lack of knowledge, having MB leprosy, and having low perceptions of leprosy symptoms [26]. These factors are relevant to the findings in our study which contribute to a higher amount of disability. Moreover, several behavioral factors could influence patient delay, such as visiting traditional or alternative healers, medicine shopping, and ignoring the first appearance of signs and symptoms of leprosy [26]. The patients in our study could do these behaviors since they mostly had low educational backgrounds and poor socioeconomic status. Thus, more disability could occur.

There are several limitations to this study. Firstly, the sample size in this study was very small. The population was limited because the hospital recently cooperated with social health insurance (BPJS Kesehatan) in 2020, and the COVID-19 pandemic struck. Thus, the number of leprosy patients before January 2021 was null. Therefore, the data on leprosy were only available from January 2021 to April 2023 before the study started. Besides, many incomplete medical records were excluded from the study, which affected the sample size. Secondly, this study was held only at one hospital in Mataram City, thus, the result of this study could not generalize apparent situations in the whole region. Lastly, a prevalence study of leprosy in Mataram, especially data from other hospitals or healthcare facilities, is still limited. Thus, comparison data on leprosy prevalence is hardly done. Therefore, more sources of data, especially bigger data from primary health care centers, should be obtained to get a better picture of leprosy in Mataram.

CONCLUSION

Leprosy cases are still causing health problems because of the stigma that occurs in society due to complications of the disease. Especially, leprosy prevalence in West Nusa Tenggara was 1.7 per 10.000 people in 2022. The prevalence study on leprosy in Mataram itself, however, is still limited. It is important to know the depth of the disease burden for establishing a preventive approach towards leprosv through prevalence data. Most of the leprosy cases at UNRAM Hospital were multibacillary types, male gender, around productive age, mostly unemployed, and had a low educational background. Type 1 reaction was more prevalent. Most of them had disabilities and received standardized multidrug therapy. The health-seeking behavior among leprosy patients at UNRAM Hospital was still concerning. Thus, the number of disability cases was still higher. Since most patients come from lower educational levels, more efforts must be made to educate more about symptoms, risks, disease transmission, disability prevention, and self-care promotion. The role of health providers is important in engaging the awareness of patients' self-care and medical-seeking behaviors because it is important to prevent serious disabilities. Primary health care in Mataram should arrange more integrated programs to decrease leprosy incidence. Not only for the patients, but also health promotion, education, and counseling should be done regularly for society. Thus, they will raise awareness of the disease and improve the attitude toward leprosy.

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