

Measuring and Comparing Health System Delays in Leprosy Detection Based on the First Healthcare Service Visit in Tegal Regency, Indonesia

Yudhy Dharmawan^{1*}, Atik Mawarni¹, and Dharminto¹

¹ Faculty of Public Health, Universitas Diponegoro, Semarang, Indonesia

Abstract. The prevalence of leprosy patients with disabilities among new cases in Tegal Regency was high in 2021, reaching 10%. This problem is due to the delays in the diagnosis and treatment of leprosy, including health system delays associated with patients' visits to healthcare services. This study aims to measure and compare health system delays based on the types of healthcare service first visited by leprosy patients. This study employed a cross-sectional design involving a sample of 125 leprosy patients recruited in 2022. Data were collected through interviews with leprosy patients using a validated case detection delay questionnaire. Descriptive and inferential statistics were performed using Kruskal-Wallis test. Among the respondents, 67% were male. Patients sought initial care at various types of healthcare services, with community health centers being the most frequently visited (53%). The average health system delay was 3.3 months, with the longest delay observed when the first visit was to a medical doctor (5.4 months). A significant difference in health system delays was found across the types of healthcare services first visited by leprosy patients ($p = 0.001$). Further research is recommended to enhance the leprosy detection capacity of healthcare staff in Tegal Regency.

1 Background

Indonesia ranks third globally in terms of new leprosy cases and cases of grade 2 disabilities (G2D) caused by leprosy [1]. In 2021, 10,976 new leprosy cases were diagnosed, with a prevalence rate of 0.43 per 10,000 population. The rate of G2D was 2.47 per 1,000,000 in the same year [2].

Leprosy and G2D remain a significant burden for leprosy control program in Indonesia. Tegal Regency in Central Java Province is one of the endemic areas for leprosy in Indonesia, with a prevalence rate of 0.82 per 10,000 population in 2021. Additionally, 10% of newly diagnosed cases in Tegal Regency presented with G2D [3].

G2D is often the result of case detection delays (CDD), which in turn delay the initiation of appropriate treatment [4]. Leprosy patients with delays of more than one year have a 2.4 times higher risk of developing G2D compared to those with delays of less than one year [5]. Prolonged delays exacerbate the disease, particularly affecting nerve function, leading to sensory loss and disability [4].

* Corresponding author: yudhydharmawan@lecturer.undip.ac.id

CDD refers to the period the patient's first awareness of leprosy symptoms and the official diagnosis. It can be divided into patient delay and health system delay. Patient delay is the time from the onset of symptoms to the patient's first contact with a healthcare service. Health system delay is the time from the patient's first visit to a healthcare service to the point of diagnosis [6,7].

Longer health system delays indicate a low capacity of healthcare staff to recognize leprosy symptoms and may reflect the quality of the services provided [8]. Such delays signal the need for improvement in leprosy detection services [4].

A significant factor contributing to health system delays is misdiagnosis [9]. Misdiagnosed patients often need multiple visits to healthcare providers, further prolonging the time to diagnosis [10]. Health workers' knowledge and diagnostic skills are critical in avoiding delays [11,12]. Training and capacity building are important to enhance health workers' ability to diagnose leprosy.

Given the variety of healthcare services where patients may first seek care for leprosy, it is necessary to assess the duration of health system delays across different types of healthcare services. Currently, there are limited data on health system delays based on the first point of care for leprosy patients in Indonesia and Tegal Regency. Therefore, this study aims to measure and compare health system delays in leprosy detection based on the first healthcare service visited in Tegal Regency. The results of this study will provide recommendations for planning and managing interventions to improve leprosy diagnostic capacity in healthcare services.

2 Methods

This study employed a cross-sectional design. Demographic data and CDD periods were collected by interviewing leprosy patients using a validated CDD questionnaire specific to Indonesia [13, 14]. The health system delay was measured in months, defined as the period between a patient's first visit to a healthcare service the leprosy diagnosis. This study involved a sample of 125 leprosy patients, who were selected through simple random sampling from the 171 leprosy patients registered in the Regional Health Office Report of Tegal Regency from October 2020 until the March 2022. The sample size was calculated using the formula for cross-sectional studies, with an estimated proportion of 10% G2D among 160 patients (plus an additional 10% to account for nonresponse). Due to various reasons, such as patients being unavailable, refusing to participate, passing away, or relocating, the final sample size was reduced to 125 leprosy patients. The inclusion criteria included leprosy patients who could communicate effectively and provided written consent to participate. Ethical approval was obtained from the Faculty of Public Health, Universitas Diponegoro, Semarang, Indonesia, with certificate number 43/EA/KEPK-FKM/2022. Data were analyzed using descriptive statistics, while inferential statistics were applied to compare the mean health system delays using the Kruskal-Wallis test, with a significance level of 0.05 given the non-normal distribution of the data [15].

3 Results

Among the 125 participants, the majority (46.8%) were aged between 35 and 50 years (Table 1). Males accounted for 62.7% of the sample. Most participants had completed either primary (36.5%) or secondary school (38.9%). Additionally, 68% of the respondents were employed. The most frequently visited healthcare facility for the patients' first visit was the community health center (53%).

Table 1. Characteristics of the sample and types of healthcare services first visited by the patients

Variable		Frequency (n = 125)	%
Age	18-34 years	36	28.8
	35-50 years	59	47.2
	51-65 years	30	24.0
Sex	Male	79	63.2
	Female	46	36.8
Education	Not attending formal education	26	20.8
	Primary school	45	36.0
	Secondary school	49	39.2
	Higher education	5	4.0
Occupation	Non-employed	40	32.0
	Employed	85	68.0
First healthcare visited	Medical doctor	36	28.8
	Hospital	6	4.8
	Community health center	67	53.6
	Dermatologist	16	12.8

The mean health system delay was 3.3 months, with a standard deviation of 7.1 months and a median of 0 months. As illustrated in Figure 1, the data distribution was not normal.

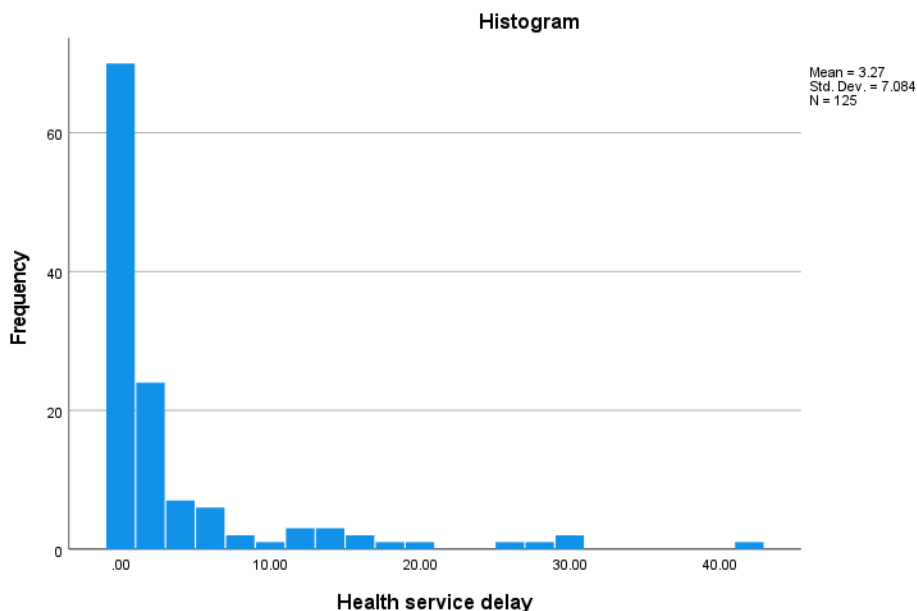


Figure 1. Histogram of the health system delay

Table 2 provides an overview of health system delays according to the types of healthcare services first visited by leprosy patients.

Table 2. Health system delays according to the types of healthcare services first visited

First healthcare visited	Mean (months)	Median (months)	Minimum (months)	Maximum (months)	Standard deviation
Medical doctor	5.5	1.0	0	30.0	8.3
Hospital	1.7	1.0	0	5.0	2.1
Community health center	1.7	0	0	42.0	6.0
Dermatologist	5.4	3.0	0	29.0	8.2

According to Table 2, the longest delay was observed when the first visit was to a medical doctor (5.5 months), while the shortest delay was observed for first visits to hospitals and community health centers (1.7 months). However, the minimum health system delay observed was 0 months across all types of healthcare services first visited by the patients. This indicated that leprosy could be diagnosed during the first visit, although not in all cases.

To compare health system delays across healthcare services, the Kruskal-Wallis test was employed, given the non-normal distribution of the data. The test revealed a significant difference in health system delays among the various healthcare services first visited by the patients ($p = 0.001$). This indicated that the type of healthcare service initially visited determines the duration of health system delay.

4 Discussion

Health system delays occur when leprosy patients visit healthcare services, but are not diagnosed with leprosy during their initial consultation. This study revealed that, on average, more than three months passed between a patient’s first visit to a healthcare service and their eventual diagnosis of leprosy. This health system delay was shorter than what has been reported in China, where Zhang and Chu documented health system delays of 25.7 and 34.3 months, respectively [16, 17]. Prolonged health system delays contribute to case detection delays, which in turn increase the likelihood of disabilities (G2D) among leprosy patients [18].

Health system delays reflect the ability of health workers to recognize leprosy symptoms [8]. The competence of health professionals in diagnosing leprosy is crucial for early detection [11, 12]. Diagnosing leprosy requires a combination of clinical, microbiological, and histopathological assessments, making it challenging for general healthcare professionals to identify the disease [19]. The diverse and subtle presentation of leprosy symptoms further complicates its diagnosis [20]. As a result, patients often require multiple visits to healthcare providers before receiving a correct diagnosis. Misdiagnoses can further extend the detection delay [10]. These negative experiences may lead patients to distrust the healthcare system, perceiving leprosy services as a waste of time and money [6].

Training and capacity building should be implemented to enhance the ability of health workers to diagnose leprosy early [6, 21]. However, frequent mobility and turnover of health workers can disrupt leprosy programs, especially in terms of diagnostic capacity. Therefore, it is necessary to provide regular training to all healthcare staff to maintain and improve their skills in leprosy detection [22]. Training content should be tailored to the specific skills of the health workers and integrated into routine health programs [23,24]. Additionally, training should target professionals at various levels, from general practitioners to specialists such as dermatologists and neurologists, to maintain a high level of awareness and competence in leprosy diagnosis [16].

The findings of this study indicated that the type of healthcare service initially visited determined the duration of health system delay. It is recommended that the leprosy programmer in Tegal Regency focus on improving the diagnostic capacity of all healthcare providers to reduce delays in case detection [9]. Special attention should be given to training medical doctors, as the longest delays were observed when patients first visited them.

5 Conclusion

Health system delays in leprosy case detection occur across all types of healthcare providers. To prevent disabilities in new leprosy cases, the leprosy program in Tegal Regency should address these delays. Further research is recommended to enhance the diagnostic capacity of healthcare staff, especially medical doctors, in identifying and diagnosing leprosy.

References

1. WHO. Global leprosy (Hansen disease) update, 2019: time to step-up prevention initiatives. *Wkly Epidemiol Rec* **95**, 417–440 (2020).
2. Ministry of Health Republic of Indonesia. *Indonesia Health Profile in 2021* (2022).
3. Provincial Health Office of Central Java. *Central Java Province's Health Profile in 2021* (2022).
4. M. T. Raposo, et al. Grade 2 disabilities in leprosy patients from Brazil: need for follow-up after completion of multidrug therapy. *PLoS Negl Trop Dis* **12**, e0006645 (2018).
5. J. Sabeena, R. S. Bindu. Grade 2 disability in leprosy and its predictors: a 10-year retrospective study from Kerala, India. *Indian J Lepr* **92**, 199–209 (2020).
6. T. Muthuvel, et al. “I wasted 3 years, thinking it’s not a problem”: patient and health system delays in diagnosis of leprosy in India: a mixed-methods study. *PLoS Negl Trop Dis* **11**, e0005192 (2017).
7. M. Henry, et al. Factors contributing to the delay in diagnosis and continued transmission of leprosy in Brazil: an explorative, quantitative, questionnaire-based study. *PLoS Negl Trop Dis* **10**, e0004542 (2016).
8. WHO. Global leprosy update, 2018: moving towards a leprosy-free world. *Wkly Epidemiol Rec* **94**, 389–411 (2019).
9. Y. Dharmawan, et al. Delayed detection of leprosy cases: a systematic review of healthcare-related factors. *PLoS Negl Trop Dis* **16**, e0010756 (2022).
10. M. Subedi, U. B. Engelbrektsson. Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives from a community study in Dang district. *Dhaulagiri J Sociol Anthropol* **12**, 11–17 (2018).
11. D. Turner, S. McGuinness, K. Leder. Leprosy: diagnosis and management in a developed setting. *Intern Med J* **45**, 109–112 (2015).
12. S. R. Atre, et al. Perceptions, health-seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India. *Lepr Rev* **82**, 222 (2011).
13. Y. Dharmawan, et al. The leprosy case detection delay questionnaire: Indonesian translation, cross-cultural adaptation, and evaluation. *Lepr Rev* **94**, 148–161 (2023).

14. N. D. de Bruijne, et al. Development of a questionnaire to determine the case detection delay of leprosy: a mixed-methods cultural validation study. *PLoS Negl Trop Dis* **16**, e0010038 (2022).
15. T. Hambridge, et al. Establishing a standard method for analysing case detection delay in leprosy using a Bayesian modelling approach. *Infect Dis Poverty* **12**, 71–81 (2023).
16. F. Zhang, et al. Healthcare seeking behaviour and delay in diagnosis of leprosy in a low endemic area of China. *Lepr Rev* **80**, 416–423 (2009).
17. T. Chu, et al. Comprehensive measures succeeded in improving early detection of leprosy cases in post-elimination era: experience from Shandong province, China. *PLoS Negl Trop Dis* **14**, e0007891 (2020).
18. Y. Dharmawan, et al. Individual and community factors determining delayed leprosy case detection: a systematic review. *PLoS Negl Trop Dis* **15**, e0009651 (2021).
19. B. A. Forbes, et al. Practical guidance for clinical microbiology laboratories: mycobacteria. *Clin Microbiol Rev* **31**, e00038-17 (2018).
20. M. S. Duthie, et al. Comparative evaluation of antibody detection tests to facilitate the diagnosis of multibacillary leprosy. *Appl Microbiol Biotechnol* **100**, 3267–3275 (2016).
21. P. V. Rao, et al. Knowledge, attitude and practices about leprosy among medical officers of Hyderabad urban district of Andhra Pradesh. *Indian J Lepr* **79**, 27–43 (2007).
22. G. Srinivas, et al. Risk of disability among adult leprosy cases and determinants of delay in diagnosis in five states of India: a case-control study. *PLoS Negl Trop Dis* **13**, e0007495 (2019).
23. W. C. Smith. Sustaining anti-leprosy activities requires radical changes. *Lepr Rev* **81**, 281–283 (2010).
24. O. Faye, et al. A public health approach for leprosy detection based on a very short term-training of primary health care workers in basic dermatology. *Lepr Rev* **78**, 11–16 (2007).