DISABILITY OF PATIENTS WITH LEPROSY IN TEGAL REGENCY (INDONESIA) AND ITS ASSOCIATION WITH HEALTH-SEEKING BEHAVIOR

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Abstract. Tegal Regency in Central Java Province, Indonesia, is a leprosy endemic area. In 2021, the leprosy prevalence was 0.82 per 10,000 population. The total number of new cases was 133, of whom 11% had Grade 2 disability (G2D). The high number with G2D indicates substantial case detection delay (CDD). This delay can be caused by personal, societal and health service-related factors. The aim of this study was to describe the association of disability grade with health-seeking behavior. We employed a cross-sectional research design involving 126 patients with leprosy selected by random sampling among 171 patients with leprosy registered from the 4th quarter of 2020 until the 1st quarter of 2022. Data were collected using a structured questionnaire translated from an international standardized questionnaire (*ie*, CDD questionnaire) through interviews with leprosy patients. Data were analyzed by descriptive and inferential statistics. We found nearly half (46.8%) of the patients aged 35-50 years, and almost two-thirds were male. Of all, 75.4% had completed primary or secondary education. At diagnosis, more than half had no disability at all, and 10.3% had G2D. Nearly half (45.2%) had used 'self-medication' and did not seek appropriate health care services before being diagnosed with leprosy. There was a statistically significant association between health-seeking behavior and the disability grade at diagnosis (p=0.01). In summary, disability caused by leprosy constitutes a significant public health burden in Tegal Regency, which could be lowered through supporting appropriate health seeking behavior.

Keywords: leprosy, disability, health-seeking behavior, Indonesia

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INTRODUCTION

Despite leprosy elimination programs decreasing the prevalence rate successfully and reaching elimination status as a public health problem in many countries, the burden of leprosy disability remains (Vieira *et al*, 2018; WHO, 2015). Disabilities can occur in the hands, feet, and eyes and cause stigma and discrimination against the patients and their families (Sabeena and Bindu, 2020). The World Health Organization (WHO) defines three grades of disability in leprosy. Grade 0 disability (G0D) means normal sensation, no visible impairments; Grade 1 disability (G1D) means impaired sensation, no visible impairments and/or eye problems present but vision not severely affected; and Grade 2 disability (G2D) is when visible impairments/deformities occur in the hands, feet, and/or eyes (Brandsma and Van Brakel, 2003). Currently, approximately 5% of all newly detected leprosy cases worldwide have G2D and the condition is thereby considered an important public health burden (Gnimavo *et al*, 2020; Ogunsumi *et al*, 2021). The number of cases with G2D at the time of diagnosis reflects a delay in early detection, the level of leprosy awareness in the community, and the health system's capacity to detect leprosy cases early. Therefore, the proportion of G2D cases indicates the need for improved leprosy services, especially early detection of leprosy (Dharmawan *et al*, 2021; Dharmawan *et al*, 2022).

After India and Brazil, Indonesia is third highest leprosy endemic country in the world, with a considerable G2D rate in newly diagnosed patients (WHO, 2021). In Indonesia, the G2D rate decreased from 6/1,000,000 in 2000 (when the status of leprosy elimination as public health problem was reached) to 2.47/1,000,000 in 2021 (MOH RI, 2022; WHO, 2010). In 2021, the percentage of G2D in new cases was 6.13 %, with a leprosy prevalence rate being 0.45/10,000 inhabitants (MOH RI, 2022).

One of the leprosy endemic areas in Indonesia is the Tegal regency in Central Java Province. In 2021, the leprosy prevalence was 0.82 per 10,000 population. The total number of new cases was 133, of whom 14 (11%) had G2D (Central Java PHO, 2022). This percentage of new cases with G2D in Tegal Regency is higher than the national figure and possibly reflects delayed detection of leprosy. This delay could be affected by inappropriate health-seeking behavior due to low leprosy awareness in the community (Dharmawan *et al*, 2021). A recent systematic review showed that there is insufficient information about the contribution of health-seeking behavior to leprosy disability in Indonesia, including in Tegal Regency (Dharmawan *et al*, 2021). It is therefore necessary to establish the rate of leprosy disability in the Tegal Regency to determine the burden of the disease. The aim of this study was to describe the association of disability grade with health-seeking behavior in the Tegal Regency. We thus seek to provide recommendations to shorten the detection delay of leprosy and its associated disability.

MATERIALS AND METHODS

The study applied a cross-sectional design. Demographic and health-seeking behavior data were collected by interviewing patients with leprosy, using a structured questionnaire translated from an international standardized questionnaire, the CDD questionnaire (de Bruijne *et al*, 2022). Disability grade data were obtained from the patient chart in the health center. This study included 126 patients with leprosy selected after power calculation through computerized random sampling of all 171 patients with leprosy, aged 18 to 65 years, registered at the District Health Office Report of Tegal Regency from the 4th quarter of 2020 until the 1st quarter of 2022. The inclusion criteria were people affected by leprosy who could communicate well, were willing to be participants, and provide written consent.

Information on health-seeking behavior was obtained through several questions about the activities of the participants to seek cure for their disease. The questions were about the first signs of leprosy, when it occurred, and the action taken after noticing the first signs. Information about this action was categorized into three groups; 1) inaction, 2) 'self-medication' or initially did

not seek appropriate health care services, and 3) visiting appropriate health care services.

Data were analyzed by descriptive statistics using tables and graphics, and inferential statistics for establishing associations employed the Chi-square test with a significance level of 0.05. Statistical Package for the Social Science (SPSS) version 27 (IBM Corp, Armonk, NY) was used for statistical analyses.

Ethical approval was obtained from the Faculty of Public Health, Universitas Diponegoro Semarang in Indonesia, with certificate number 43/EA/KEPK-FKM/2022. All study participants gave written informed consent.

RESULTS

Of the 126 participants, 59 (46.8%) were aged 35-50 years, 36 (28.6%) were younger and 31 (24.6%) older (Table 1). Nearly two-thirds were male (62.7%). Most participants had completed primary or secondary school; 46 (36.5 %) and 49 (38.9%), respectively.

There were many kinds of health-seeking behavior as the first action taken by participants when they first noticed signs or symptoms. These actions were categorized into three groups. A small proportion did nothing (16.7%). Almost half (45.2%) applied 'self-medication' or initially did not seek appropriate health care services. The third group of 48 participants (38.1%) visited appropriate health care services. In the group that applied 'self-medication' or initially did not seek appropriate health care services, 42 (33.3%) applied skin ointment or tinea versicolor medicine, balm, olive oil, coconut oil, or skin care cosmetics, using traditional medicine like "*jamu*" [herb], onion or galangal, and giving a compress; nine people bought medicine from a medicine shop, and six visited non-qualified practitioners such as midwives or nurses without capability in leprosy diagnosis. The third group of participants visited an appropriate health care service, such as a medical doctor (18; 14.2%), hospital (2; 1.5%), health center (21; 16.6%), neurologist (1; 0.8%), or dermatologist (6; 4.8%).

At diagnosis, more than half of the patients (59.5%) had no disability

Table 1
Demographic factors, health-seeking behavior, and disability grade of patients with leprosy

Variable	Frequency *n* (%)
Age group (years)	
18-34	36 (28.6)
35-50	59 (46.8)
51-65	31 (24.6)
Sex	
Male	79 (62.7)
Female	47 (37.3)
Education	
Uncompleted formal education	26 (20.7)
Primary school completed	46 (36.5)
Secondary school completed	49 (38.9)
Higher education completed	5 (4.0)
Disability grade	
0 (No impairments)	75 (59.5)
1 (No visible impairments)	38 (30.2)
2 (Visible impairments)	13 (10.3)
Health-seeking behavior	
No action	21 (16.7)
Self-medication or using inappropriate medicine or health care services	57 (45.2)
Visit appropriate healthcare service	48 (38.1)

(G0D), 30.2% had G1D, and 10.3% had G2D. Disability occurred slightly more often in males (Fig 1), and G2D was more frequent in the age group 35-50 years (Fig 2). Finally, G2D was slightly more frequent in people who had completed either primary or secondary school (Fig 3).

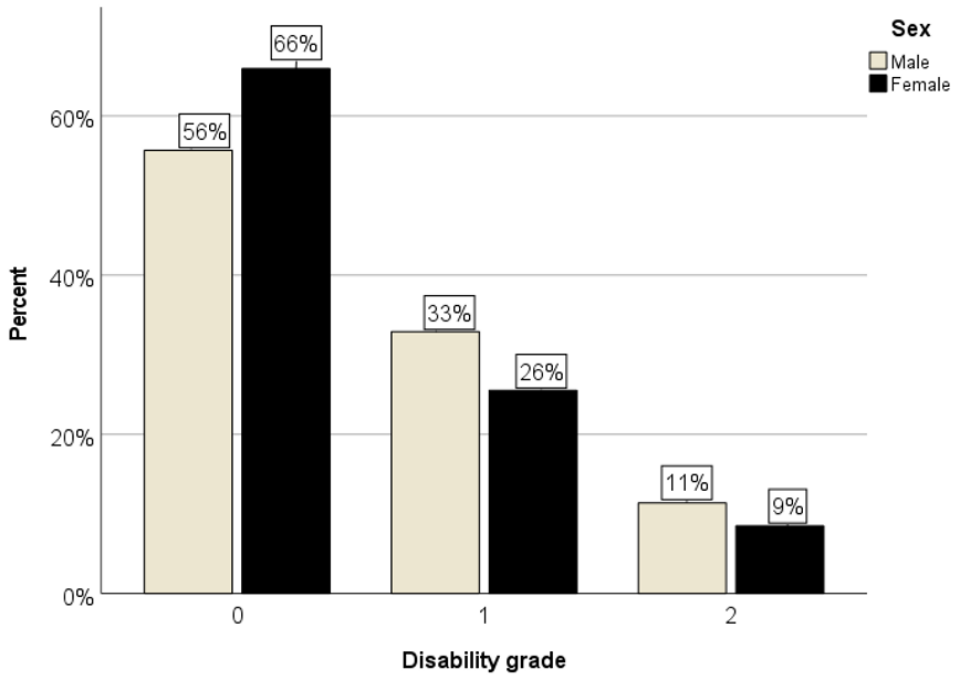

Fig 1 - Distribution of disability grade by sex among the patients with leprosy

The chi-square test described in the cross-tabulation (Table 2) shows a statistically significant association between health-seeking behavior and the disability grade at diagnosis, with a contingency coefficient of 0.308 (p=0.010). This indicates that no initial action or inappropriate initial health-seeking behavior contributed to a higher chance for participants having disabilities.

DISCUSSION

Nearly half of the newly diagnosed patients with leprosy in Tegal Regency had a disability as defined by the World Health Organization (G1D: 30.2%; G2D: 10.3%). Disability was more frequent in males and the age group of 35-50 years. There was also a statistically significant association between inappropriate health-seeking behavior and the chance of having disabilities at diagnosis.

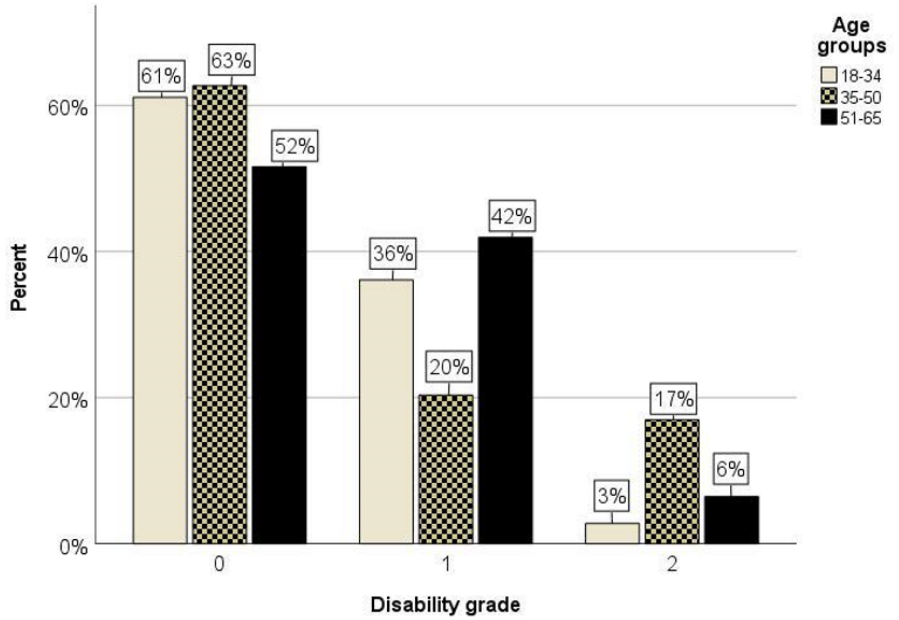

Fig 2 - Distribution of disability grade by age group of patients with leprosy

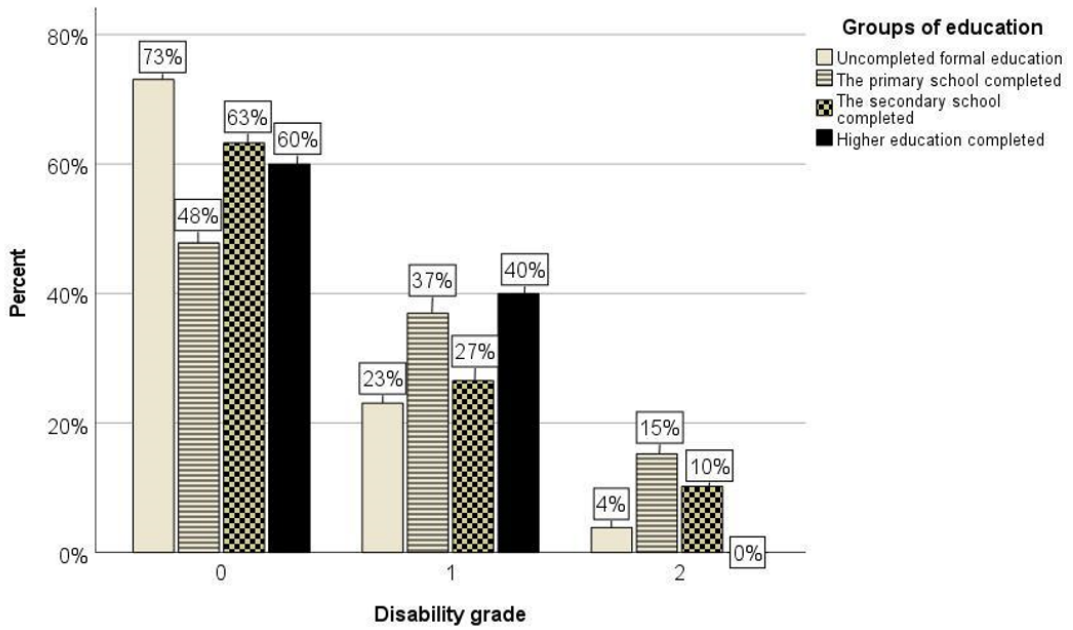

Fig 3 - Distribution of disability grade by educational level of patients with leprosy

Table 2

Demographic factors, health-seeking behavior, and disability grade of patients with leprosy (N = 126)

Health seeking behavior	Disability grade, *n* (%)			Contingency coefficient (*p*-value)
	0 (No impairments)	1 (No visible impairments)	2 (Visible impairments)	
No action	7 (33.3)	11 (52.4)	3 (14.3)	0.308 (0.010)
Self-medication or using inappropriate medicine or health care	37 (64.9)	18 (31.6)	2 (3.5)	
Visit appropriate healthcare service	31 (64.6)	9 (18.8)	8 (16.7)	

The percentage of G2D in patients with leprosy in Tegal Regency (10.3%) was higher than the percentage of G2D among the new cases of leprosy in the world (5.64%) and Indonesia as a whole (6.13%) (MOH RI, 2022; WHO, 2021). The percentage of G2D in the Tegal Regency has been confirmed by other studies, ranging from 5.6% to 43.2% (Dharmawan *et al*, 2021). With a G2D percentage of over 5%, the leprosy burden in Tegal Regency can be considered an important public health problem (Gnimavo *et al*, 2020; Ogunsumi *et al*, 2021). Delayed detection is often due to a lack of awareness in the community of the early signs of leprosy, delay in seeking healthcare services, and the capacity of the health system to detect leprosy cases early (Dharmawan *et al*, 2021; WHO, 2021).

Disability was more common in males, which has been observed regularly (Dharmawan *et al*, 2021). Studies from India and China reported the percentage of males with G2D as 68% and 58%, respectively (Chu *et al*, 2020; Srinivas *et al*, 2019). An explanation is that the delay in case detection is longer in males than in females (Dharmawan *et al*., 2021), which can have several causes, such as difficulties for males to come to health facilities on working days, fear of losing their job because of the stigma of leprosy, and males more often perform strenuous physical activities, increasing the risk of disability (Moschioni *et al*, 2010). Therefore, leprosy programs should give special attention to males in health promotion strategies to avoid disability.

Disability was also more common in the age group 35-65 years. Comparable results were found in China (Chu *et al*, 2020), Brazil (Raposo *et al*, 2018), and India (Sabeena and Bindu, 2020; Srinivas *et al*, 2019). With age the disease can continue to go untreated longer with a higher chance of developing disabilities (Sabeena and Bindu, 2020; Srinivas *et al*, 2019). It indicates that leprosy programs should also give special attention to elderly people to avoid disability.

Disability also showed differences according to educational level. Most participants with G2D had completed primary or secondary education. This can be seen as surprising, but in China a higher percentage of G2D (64%) was also found among literate people (Chu *et al*, 2020). This was also the case in India, were most people with disability (53%) were found among the literate (Srinivas *et al*, 2019). In contrast, a study from Brazil reported that one in

four leprosy patients with G2D had only 0-3 years of education (Raposo *et al*, 2018). Reasons for these differences in educational level with regard to the occurrence of disability in leprosy are unclear and need to be studied further.

This study confirmed that formal healthcare services, such as a medical doctor, health center, dermatologist, or hospital, are often not the first choice in the community to have leprosy diagnosed, as observed previously (Dharmawan *et al*, 2021). Not taking any action or applying self-medication were the most common inappropriate health-seeking behaviors. People with leprosy also visited inappropriate healthcare providers who did not recognize initial signs and symptoms and gave wrong medication (Dharmawan *et al*, 2021). This happens because people do not know the signs or symptoms of leprosy and where to find appropriate healthcare services (Henry *et al*, 2016). Inappropriate health-seeking behavior causes delay in having leprosy diagnosed and receiving multidrug therapy (MDT). Delay can also cause the (further) development of nerve damage and resulting disabilities (Dharmawan *et al*, 2021). Hence, health promotion strategies that focus on increasing community awareness about leprosy and seeking appropriate healthcare services need to be designed and implemented to avoid disability (Govindharaj and John, 2019; Nicholls *et al*, 2006). Health promotion and education should be aimed at both illiterate and literate people. The present study revealed a relatively large proportion of literate people who had disabilities due to leprosy. Clearly, those who can read and write may not have sufficient health literacy (Andrus and Roth, 2002).

The strength of this study is that it for the first time provides insight into the relationship between health-seeking behavior and disability in people with newly diagnosed leprosy in the high leprosy endemic Tegal Regency in Indonesia. The sample size also allows conclusions to support the leprosy program in adjusting its control activities to reduce detection delay. A limitation is that the generalizability of the findings needs to confirm in other areas of Indonesia and other leprosy endemic countries, for that matter.

In summary, disability caused by leprosy constitutes a public health burden in Tegal Regency. The high number of newly diagnosed leprosy patients with a disability is associated with healthcare-seeking behavior. When noticing signs and symptoms suspect for leprosy, many people do not take appropriate action by going to formal health services capable of diagnosing and

treating the disease. Leprosy programs should address community awareness, especially of the initial signs and symptoms of leprosy, and understanding of why and where to find appropriate health care services.

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CONFLICT OF INTEREST DISCLOSURE

The authors have declared that no competing interests exist.

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