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The Association between Disability and Psychosocial Issues in Individuals with Leprosy

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ABSTRACT

Introduction: Leprosy is a disease that can cause physical disabilities, which in turn contribute to the emergence of psychosocial problems in affected individuals.
Objective: This study aims to analyze the relationship between the level of disability and psychosocial problems among leprosy patients in the working areas of Jrengoan Health Center and Karang Penang Health Center.
Method: This study employs an analytical observational design with a cross-sectional approach. The study population consists of all leprosy patients in the working areas of the two health centers, totaling 47 individuals. The sampling technique used is non-probability sampling with a purposive sampling method, resulting in 42 respondents who meet the inclusion criteria. Disability levels were measured using an observation sheet, while psychosocial problems were assessed through a questionnaire. Data analysis was conducted using the Spearman Rho statistical test.
Result: The results of the crosstabulation analysis revealed that among patients with level 2 disabilities, 12 individuals (28.6%) experienced severe psychosocial problems, while 2 individuals (4.8%) had mild psychosocial issues. The Spearman Rho test indicated a relationship between disability occurrence and psychosocial problems, with a p-value of 0.043 > 0.05. These findings suggest that the higher the level of disability, the more severe the psychosocial problems experienced by leprosy patients.
Conclusion: In conclusion, the majority of leprosy patients in this study had level 1 disabilities, but those with level 2 disabilities tended to experience more severe psychosocial issues. This reinforces the notion that as the degree of disability increases, the psychosocial impact on leprosy patients also becomes more significant.

Keywords: disability, leprosy, psychosocial

Introduction

Leprosy, also known as Hansen's disease (*Lepra Morbus Hansen*), is a chronic infectious disease caused by the obligate intracellular bacterium *Mycobacterium leprae*. This bacterium thrives only within specific human and animal cells (Siswanto et al., 2020). Historically, leprosy was feared as a highly contagious disease with severe consequences (Kementerian Kesehatan RI, 2022). Individuals with leprosy often face a range of physical, psychological, social, and economic challenges. Physically, the disease can cause disabilities affecting the eyes, hands, and feet, classified into three levels (0-2) (Susanto et al., 2013). Psychologically, leprosy-related disabilities can lead to depression, as patients develop negative self-perceptions due to societal stigma (Susanto et al., 2013). Emotional struggles such as disappointment, fear, shame, low self-esteem, and feelings of worthlessness, along with concerns about social rejection (self-stigma), are common among leprosy patients. Additionally, public stigma results in ostracization not only for patients but also for their families (Kementerian Kesehatan RI, 2018). Leprosy patients also experience psychological difficulties stemming from within themselves, such as withdrawal behaviors and self-concept disturbances, which hinder social interactions (Jatimi et al., 2020; Hidayat et al., 2020). Depression among leprosy patients exacerbates social and economic hardships. Social issues include fear of public interaction and reduced participation in community activities. Economically, the negative perception of leprosy patients often leads to exclusion from employment opportunities, preventing them from achieving financial independence (Mahanani & Idris, 2020).

Globally, leprosy remains a significant public health concern. In 2021, the World Health Organization (WHO) reported a registered prevalence of 133,781 cases, with 140,546 new cases detected. Indonesia ranked third worldwide in new leprosy cases, with 10,976 cases, following India and Brazil (WHO, 2021). The prevalence of leprosy in Indonesia in 2021 was 0.45 cases per 10,000 people, with an incidence rate of 4.03 cases per 100,000 people. Additionally, 10,976 new cases included both Paucibacillary (PB) and Multibacillary (MB) leprosy types, with a grade 2 disability rate of 2.47 per million people (Kementerian Kesehatan RI, 2021). In East Java, the provincial health department recorded 1,725 registered cases in 2020, with a prevalence rate of 0.4 per 10,000 people and 1,670 newly identified cases, equating to an incidence rate of 4.2 per 100,000 people (Dinas Kesehatan Provinsi Jawa Timur, 2021). Sampang Regency, one of the regions in East Java, has a significant number of leprosy cases. In 2021, 188 cases were recorded, with a prevalence of 1.8 per 10,000 people and 174 new cases detected. Among the 21 community health centers (Puskesmas) in Sampang, Jrengoan Health Center ranked second in new leprosy cases, with 17 patients, following Karang Penang Health Center, which reported 30 new cases in 2022 (Dinas Kesehatan Kabupaten Sampang, 2022).

Leprosy patients often struggle with feelings of inferiority, psychological distress, fear of disease progression, disability, and paralysis. Additionally, they experience anxiety about acceptance from their families and communities. Many hesitate to seek treatment due to shame, apathy, or the burden of their disability, which may render them dependent on others (Siswanto et al., 2020). The physical disabilities caused by leprosy contribute to societal stigma and discrimination against both newly diagnosed and recovered patients (Anwar & Syahrul, 2019). Misconceptions about leprosy persist, leading to the belief that individuals with visible disabilities remain contagious, fostering fear and avoidance within communities (Jufrizal & Nurhasanah, 2019). A scoping review by Bennis et al. (2018) found that diseases causing permanent scarring or disabilities can result in significant psychological distress. Psychological challenges are influenced by internal factors, such as self-stigma and withdrawal behaviors, as well as external factors, including negative societal perceptions (Jatimi et al., 2020). These factors contribute to the emergence of psychosocial issues among leprosy patients (Putra & Tahlil, 2018). Based on these findings, it is evident that leprosy patients face various physical, psychological, social, and economic difficulties. Consequently, this study aims to explore the relationship between disability and psychosocial problems among leprosy patients in the working areas of Jrengoan and Karang Penang Health Centers. Notably, no previous research has been conducted on this topic in these specific locations, highlighting the need for this study.

Objective

This study aims to explore the relationship between disability and psychosocial problems among leprosy patients in the working areas of Jrengoan and Karang Penang Health Centers.

Method

The research design used was analytical observational with a cross sectional research design. This research was conducted in the working area of Jrengoan Community Health Center and Karang Penang Community Health Center from June to July 2023. The population of this study was all leprosy sufferers in the working area of the Jerengoan Community Health Center and the Karang Penang Community Health Center, totaling 47 people. The sampling technique in this research uses a nonprobability sampling method using purposive sampling. A total of 42 respondents were selected using the inclusion criteria, namely 1. Patients who are cooperative and willing to become respondents 2. All leprosy sufferers, whether still undergoing treatment or those who have RFT (Release from Treatment) 3. Leprosy sufferers who experience level 1 and 2 disabilities 4. Sufferers Multy bacillary (MB) type leprosy 5. Leprosy sufferers who can communicate well which is then measured using an observation sheet for the level of disability and a psychosocial problem questionnaire. The validity and reliability tests were conducted on 10 leprosy patients in the working area of Kamoning Community Health Center, Sampang Regency, who were not included in the research sample, showing valid results. The data obtained was then analyzed using the Spearman Rho test.

Result

Table 1. Distribution of Respondents' Data Characteristics

Variable	***N***	***%***
Age		
10-30 Years	*10*	*23.8*
31-50 Years	*22*	*52.4*
51-70 Years	*10*	*23.8*
Sex		
Male	*23*	*54.8*
Female	*19*	*54.2*
Insurance Ownership		
Yes	*42*	*100.0*
No	*0*	*0.0*
Leprosy Type		
PB	*0*	*0.0*
MB	*42*	*100.0*
Undergoing routine treatment		
Yes	*29*	*69.0*
No	*13*	*31.0*

Based on Table 1, the characteristics of the respondents indicated that the majority were 31-50 years old (52.4 %), and most were male, totaling 23 individuals (54.8 %). All respondents have health insurance with a classification of multibacillary leprosy, showing a 100% presentation. 29 respondents regularly undergo leprosy treatment (69 %).

Table 2. Level of Disability

Level of Disability	***N***	***%***
0	*0*	*0*
1	*24*	*57.1*
2	*18*	*42.9*

The respondents involved in this study experienced disability due to leprosy at level 1, with a total of 24 individuals (57.1%), while those with level 2 disability totaled 18 individuals (42.9%).

Table 3. Psychosocial Problem

Psychosocial Problem	***N***	***%***
Mild	*9*	*21.4*
Moderate	*10*	*23.8*
Severe	*23*	*54.8*

A total of 9 individuals with leprosy (21.4%) experienced mild psychosocial problems, 10 individuals (23.8%) experienced moderate psychosocial problems, and 23 individuals (54.8%) experienced severe psychosocial problems.

Table 4. The Relationship Between the Level of Disability and Psychosocial Problems

Level of Disability	*Psychosocial Problem*			*N*
	Mild	*Moderate*	*Severe*	
0	*0* *0%*	*0* *0%*	*0* *0%*	*0* *0%*
1	*7* *16.7%*	*6* *14.3%*	*11* *26.2%*	*24* *57.1%*
2	*2* *4.8%*	*4* *9.5%*	*12* *28.6%*	*18* *42.9%*
N	*9* *21.4%*	*10* *23.8%*	*23* *54.8%*	*42* *100%*

Spearman's rho test 0,043 (a=0,05)
Correlation coefficient 0.314

Table 4 shows that out of 42 respondents, nearly half of the leprosy patients with level 2 disabilities who experienced severe psychosocial problems amounted to 12 individuals (28.6%). Additionally, none of the leprosy patients with level 0 disabilities experienced mild, moderate, or severe psychosocial problems. The Spearman Rho test results for the relationship between the level of disability and psychosocial problems among leprosy patients in the working area of Karang Penang Public Health Center showed a result of 0.043, with a significance value of 0.05 as a comparison. Statistically, since 0.043 < 0.05, it indicates that there is a relationship between the level of disability and psychosocial problems among leprosy patients in the working area of Karang Penang Public Health Center.

Discussion

The study results indicate a relationship between the occurrence of disability and psychosocial problems in leprosy patients. Based on the Spearman correlation test, a value of 0.043 was obtained with a significance level of 0.05, indicating a significant relationship between the two variables. The higher the level of disability experienced by patients, the more severe the psychosocial problems they face. The study also found that patients with level 2 disabilities experience more severe psychosocial issues compared to those with moderate psychosocial problems. During observations conducted in the study, many leprosy patients lost their jobs and their self-confidence to return to work as they did before experiencing disability. Additionally, their disabilities led to social stigma, including being ostracized by society, even by their families and closest relatives (Jufriyanto et al., 2020). Society often perceives leprosy as a cursed or incurable disease, causing many patients to lose hope and discontinue their treatment (Jatimi, Yusuf, et al., 2020). The social impact of disability is not only felt by the patients themselves but also by their families and the surrounding community (Jatimi & Hidayat, 2022). In level 1 disability, the impairment is more sensory and not physically visible, such as reduced visual acuity. However, in level 2 disability, body deformities become more apparent, exacerbating the psychosocial impact on patients. The psychosocial issues faced by leprosy patients arise from society's negative perception that leprosy is highly contagious, leading to frequent social exclusion (Govindharaj et al., 2018).

This study applies Sister Callista Roy's adaptation theory, which focuses on the concept of human adaptation to environmental and physical changes. The majority of leprosy patients in the working areas of Jrengoan and Karang Penang Community Health Centers struggle to adapt to their physical condition after experiencing disability. The physical changes they undergo make it difficult for them to adjust to their social environment, leading them to withdraw and only interact with fellow patients or close family members (Jatimi, Nenobais, et al., 2020). Additionally, the psychosocial problems faced by leprosy patients are influenced by several factors, including physical health, psychological conditions, social relationships, and the surrounding environment (Correia et al., 2019). Psychosocial problems not only indicate how well individuals function in daily life but also reflect how they perceive their health status and how that perception affects their quality of life (Zamparoni, 2017).

Based on the findings of this study, many leprosy patients still experience severe psychosocial problems due to the high level of disability they endure. This condition is exacerbated by society's stigma, which considers leprosy an incurable and highly contagious disease (Yudanagara, 2020). Such negative perceptions cause patients to lose hope, ultimately affecting their psychosocial well-being (Armaijn, 2019). Therefore, broader public education is needed to change societal perceptions of leprosy, ensuring that patients are no longer subjected to social discrimination (Muhammad Najmuddin, 2021). Furthermore, the study found that more men suffer from leprosy than women. This impacts their roles in their families, particularly as breadwinners. Many of them are abandoned by their wives because they are perceived as incapable of fulfilling their family's needs. This situation adds further psychosocial pressure on patients, ultimately worsening their mental well-being (Mahanani & Idris, 2020). Therefore, a more holistic approach is needed in handling leprosy patients, addressing not only medical aspects but also social and psychological dimensions.

Conclusion

There is a relationship between the occurrence of disability and psychosocial problems because the higher the incidence of disability, the more severe the psychosocial problems experienced by leprosy patients in the working areas of Jrengoan Community Health Center and Karang Penang Community Health Center.

Conflict of interest

The researchers stated that there is no conflict of interest related to the implementation and publication of the results of this research. The entire research process, from planning, data collection, analysis, to report preparation, was carried out independently without any influence or pressure from any third party. A commitment to research ethics is upheld throughout the research process, ensuring transparency, accuracy and honesty in reporting results. Respondents' participation was voluntary with informed consent, and their confidentiality and privacy were maintained in accordance with applicable research ethics standards. With this statement, researchers hope that the research results can be trusted and used as a valid reference for the development of science and health practices related to ethnomedicine and reproductive health.

Authors' contribution

Each author makes an equal contribution to all parts of the research. All authors have reviewed and approved the final draft critically and are responsible for the index and similarity of the manuscript.

Ethical consideration

This study has passed the ethical feasibility review with the number 17/KEP/UNT/DEA/VII/2023 from the Research Ethics Committee of Universitas Nazhatut Thullab Al-Muafa Sampang.

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