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THE INFLUENCE OF LEPROSY LITERACY ON COMMUNITY PARTICIPATION IN CONTROL AND ELIMINATION PROGRAMS

Sofia Najia[1*], Yunita Hapsari[2], Marisa Syavitri Dilaga[2] , Mohammad Rizki[2]
[1]Medical Education Study Program, Faculty of Medicine and Health Science, Mataram University, Indonesia
[2]Department of Tropical Disease Infections, Faculty of Medicine and Health Science, Mataram University, Indonesia

ABSTRACT

Leprosy, or Morbus Hansen's disease, remains a critical neglected tropical disease, with Indonesia consistently ranking among the top three global contributors, reporting up to 15,000 new cases annually. Despite national elimination efforts, high-endemic clusters persist with a high prevalence of multibacillary cases, which significantly increase the risk of complications and permanent disability. The primary challenge to effective control lies in low public awareness and pervasive social stigma, which lead to delayed diagnosis and the concealment of the disease. This study aims to analyze the relationship between leprosy literacy defined as the level of understanding regarding causes, symptoms, and transmission and community participation in elimination programs. Using a scoping review design based on the Arksey and O'Malley framework, a systematic search was conducted across five major databases for literature published between 2016 and 2026. The findings reveal that basic knowledge remains critically low due to entrenched traditional myths, though formal education, younger age, and direct interaction with health workers are significant predictors of higher literacy. Stigma is identified as the most substantial barrier to community engagement; however, culturally sensitive education and the involvement of local leaders have proven effective in increasing early case detection and treatment adherence. Ultimately, high leprosy literacy is a key determinant for mobilizing community resources and reducing psychological barriers to health-seeking behavior. The study concludes that literacy serves as the foundation for collective behavioral change. Integrating health communication strategies with local wisdom and digital platforms, supported by local government policy, is essential for fostering inclusive environments and achieving sustainable disease elimination and socio-economic recovery for affected individuals in Indonesia.

Keywords: Community Participation, Leprosy Literacy, Mycobacterium Leprae, Social Stigma

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Corresponding author:

Sofia Najia,
Medical Education Study Program, Faculty of Medicine and Health Science, Mataram University, Indonesia
Email: shopianajia20@gmail.com

INTRODUCTION

Leprosy, also known as Morbus Hansen's disease, is a neglected tropical disease (NTD) caused by infection with the bacterium Mycobacterium leprae (Grijsen *et al.*, 2024). The latest epidemiological data shows that worldwide, in 2023 1,82,815 new cases of leprosy are reported annually, and this figure has remained unchanged for the past eight years. The three countries with the highest number of cases are India, Brazil, and Indonesia, which together account for more than 80% of new cases worldwide (Deps *et al.*, 2025). In Indonesia, leprosy cases remain high, with a national rate of around 3.3 cases per 100,000 population in 2020. Although the elimination target has been achieved, in areas that remain endemic, such as Madura, the rate has reached as high as 19.3 cases per 100,000 population. Several hospitals in Indonesia also show an increase in the number of new cases year after year. For example, Dr. M. Djamil Hospital in Padang recorded an increase in cases from 13 in 2021 to 40 in 2023, with most cases being the more contagious multibacillary type, which carries a 24 percent risk of complications (Tutty *et al.*, 2025). Furthermore, the distribution of leprosy cases in several areas, such as Pasuruan and Pamekasan, shows clusters with high case numbers. These clusters are the focus of post-exposure prevention interventions to reduce the spread of the disease (Taal *et al.*, 2022). This situation demonstrates the importance of research into the influence of community understanding of leprosy on their participation in leprosy control and eradication programs in Indonesia, allowing for early detection of the disease and reducing its spread.

The epidemiology of leprosy cases in Indonesia also shows a predominance of the multibacillary (MB) type over the paucibacillary (PB) type. A retrospective study at Dr. M. Djamil General Hospital, Padang, noted that of 92 leprosy patients between 2021 and mid-2024, 76.1% were MB cases and 23.9% were PB, with the incidence increasing annually (Tutty *et al.*, 2025). At the provincial level, West Java showed an increasing trend in new leprosy cases from 2021 to 2023, with the majority of cases being MB in adults aged ≥15 years (Martamevia, 2024). Leprosy cases in children are also dominated by the MB type, as found in Surabaya with a MB to PB ratio of around 58:12 over the last decade (Prakoeswa *et al*., 2022). Factors such as late diagnosis, social stigma, and lack of public knowledge are the main challenges in controlling leprosy in Indonesia (Lubis *et al.*, 2022).

Leprosy remains a major public health challenge in Indonesia, with 14,000 to 15,000 new cases reported annually, indicating that the disease is still widespread and endemic (Sebong *et al.*, 2025). Indonesia faces particular challenges such as low public awareness and high stigma, which lead to late diagnosis and hinder effective control efforts. Only about 10% of the population in some endemic areas, such as Southwest Seram District, has a high awareness of leprosy (Titaley *et al.*, 2025). Stigma leads to social exclusion and concealment of the disease, which hinders early case detection and adherence to treatment, thus maintaining the spread and increasing disability rates

(Thiodorus *et al.,* 2023). The national action plan to achieve zero leprosy emphasizes the importance of mobilizing community resources and strengthening health service capacity, but must also address barriers such as disintegrated information systems, drug shortages, and complex health insurance regulations that impact health services (Putri *et al.,* 2025). Social engagement is further limited by stigma that affects not only individuals with leprosy but also entire communities, especially in underdeveloped areas with poor infrastructure and limited access to health education (Romadhon, 2020). Reducing stigma through culturally appropriate education, increasing community participation, and integrating socio-economic recovery are essential to increasing participation in control programs and achieving elimination targets in Indonesia (Dadun *et al.,* 2019).

Knowledge of leprosy, as an important research variable, can be operationally defined as the level of knowledge, awareness, and understanding held by individuals or communities regarding leprosy, including its causes, transmission, symptoms, prevention, treatment, and social impacts such as stigma. This encompasses not only factual knowledge but also attitudes and perceptions that influence behavior related to leprosy control and eradication efforts. Higher knowledge of leprosy is associated with reduced stigma, increased early detection, improved adherence to treatment, and increased community participation in control programs. Measurement often involves standardized tools used to evaluate knowledge, attitudes, and practices (KAP) related to leprosy (Singh *et al.,* 2019). In the context of community participation in control and eradication programs, literacy about leprosy enables affected individuals and communities to actively participate in prevention activities, support affected people, and collaborate with health services to achieve sustainable outcomes (Fastenau *et al.,* 2024). Therefore, operationally defining leprosy literacy encompasses cognitive understanding as well as the ability to apply that knowledge to encourage health-seeking behavior and reduce social barriers in community-based interventions.

The relationship between public understanding of leprosy and community participation is such that greater knowledge about leprosy leads to better attitudes and actions toward the disease. Interventional research in India has shown that increasing public understanding of leprosy reduces stigma and improves attitudes, thus encouraging active participation in leprosy control programs (Van 't Noordende *et al.,* 2021). Greater knowledge about the causes, transmission, and treatment of leprosy leads to more positive attitudes and reduces social distance toward those affected, thus increasing community participation in early detection and social support (Van 't Noordende *et al*., 2019). Furthermore, research in Nepal has shown that adequate knowledge is strongly associated with supportive attitudes, which can reduce stigma and increase treatment seeking (Singh *et al.,* 2019). Factors such as education level, direct experience with people with leprosy, and interactions with health workers also influence community literacy and participation (Haverkort & van 't Noordende, 2022). Therefore, an educational approach that is contextually appropriate and takes into account cultural values is crucial to improving public understanding of leprosy, thus providing the basis for changing attitudes and actions in leprosy elimination efforts (Murphy-Okpala *et al*., 2024).

Despite advances in technology for diagnosing and treating the disease, it remains a health problem in high-risk areas due to high stigma and public misunderstanding. The prevalence of disease and disability is a major issue in resource-limited settings, necessitating new approaches to early detection and prevention (Urgesa *et al.,* 2022). Recent research has shown that active community participation can increase leprosy control programs' effectiveness, particularly in areas still facing social stigma and a lack of health facilities. This approach involves empowering communities through culturally sensitive education, collaborating with local community leaders, and engaging people who have had leprosy as a positive change, increasing awareness and reducing discrimination (Fastenau *et al.,* 2024).

Forms of community participation in leprosy control and elimination programs include various activities that directly involve the community in early detection, education, social support, and economic empowerment. These include community participation in awareness-raising and stigma-reduction campaigns, with approaches that take cultural values into account, which have been shown to increase community understanding and willingness to participate in treatment in countries such as Brazil, India, and Nigeria (Fastenau *et al.,* 2024). Participation also involves involving local leaders and village governments in outreach activities and active case control, which is highly effective in increasing the number of cases detected early (Govindasamy *et al.,* 2021). Furthermore, community-based interventions often combine psychosocial support and economic empowerment to strengthen the social role of leprosy patients and their families in the community (Ford *et al.,* 2026). The role of community health workers is also crucial, as they serve as a link between health services and the community. They conduct activities such as house-to-house screening, contact tracing of infected individuals, and ongoing education (Srihartati & Dewi, 2025). These programs typically reach the level of community mobilization and collaboration, although issues such as social stigma and limited resources remain major obstacles (Shrestha *et al.,* 2025).

The use of targeted communication strategies, such as direct outreach, public campaigns, and context-appropriate print and audio materials, has proven crucial in addressing information gaps and breaking down prejudices against leprosy (Darmi *et al.*, 2024). Research from Asian and African contexts suggests that a multifaceted approach and tailoring health messages to local cultural values can address medical misconceptions that have fueled social resistance. Context-appropriate audio and visual materials not only help convey information about symptoms and prevention but also encourage behavioral change by centering the affected individuals. By increasing inclusive health literacy, irrational fears can be reduced, providing greater opportunities for psychosocial support and economic participation for leprosy patients in sustainable community settings (Masala *et al.,* 2025).

Health literacy emphasizes the ability of individuals to access, understand, and use health information effectively to make informed decisions in the prevention and management of infectious diseases. In infectious diseases such as leprosy, health literacy encompasses not only medical knowledge but also understanding that can reduce the social stigma often attached to this disease, thereby encouraging active community participation in control programs (Febriani & Nugrahani, 2022). Improving health literacy through group-based or community-based interventions can reduce negative assumptions and the impact of stigma on people with leprosy, strengthen a sense of community, and increase their involvement in health programs (Muldoon *et al*., 2022). Leprosy literacy, namely the level of community knowledge and awareness about leprosy, including aspects of causes, transmission, symptoms, treatment, and stigma, and community participation, which refers to the active involvement of the community in early detection, treatment, prevention, and elimination of leprosy (Fastenau *et al.*, 2024). Through the relationship between health understanding about leprosy and the level of community participation in disease control efforts. This approach is supported by evidence that culturally sensitive and inclusive health education can improve leprosy literacy while addressing the social stigma barrier that is a major obstacle to the success of leprosy elimination programs (Jockers *et al.*, 2023).

Increasing community engagement in early leprosy detection and prevention efforts, such as post-exposure prophylaxis (PEP) programs, relies heavily on comprehensive educational strategies and adequate psychosocial support (Masala *et al.*, 2025). Providing communities with the appropriate knowledge and psychosocial support to address long-standing stigma can reduce psychological barriers for affected individuals, creating a more welcoming and inclusive environment (Anindhita *et al.*, 2024). This also increases active community participation in preventive health programs and promotes the restoration of dignity and socio-economic inclusion for people living with leprosy, which are crucial factors in achieving sustainable disease elimination (Jung *et al.*, 2020).

Stigma and misunderstandings about leprosy significantly reduce community participation in disease control and eradication programs, creating fear, isolation, and discrimination against those affected. Research shows that a lack of understanding of the causes, transmission, and symptoms of leprosy is associated with high levels of stigma and social distancing, which hinder early health-seeking behavior and treatment adherence (Singh *et al.,* 2019). Misconceptions such as leprosy being a curse or a hereditary disease persist in many communities, further deepening stigma and hindering effective participation in public health efforts (Mora *et al.,* 2024). Public health programs such as the World Health Organization's Zero Leprosy Strategy and post-exposure prevention (PEP) initiatives aim to reduce the spread of the disease by early detection and providing preventive treatment to contacts, however, the success of these programs depends heavily on addressing stigma and improving public understanding of the disease (Van ’t Noordende *et al.,* 2019). Community participation approaches that include culturally appropriate education, involvement of people affected by leprosy, and empowerment of local residents have proven effective in reducing stigma and increasing participation in such programs (Van ’t Noordende *et al.,* 2021). Integrating psychosocial support and addressing structural barriers within the health system are also critical to maintaining community participation and achieving long-term elimination goals (Anindhita *et al.,* 2024).

The lack of research explicitly exploring the direct relationship between community understanding of leprosy and their participation in disease control and eradication programs remains a research gap. Previous studies have largely focused on community-based interventions aimed at reducing stigma, increasing socioeconomic participation, and improving early detection, but often have not isolated the specific role of literacy in influencing active participation or health outcomes (Masala *et al.,* 2025). Many assessments have used observational or qualitative designs, which limit the ability to draw causal conclusions about the impact of literacy on participation, highlighting the need for more rigorous, mixed-approach or longitudinal research (Srihartati & Dewi, 2025). Furthermore, while stigma reduction and community strengthening are recognized as important, research combining these psychosocial factors with literacy to understand their combined impact on participation is still scarce (Willis *et al.*, 2024). The scientific need lies primarily in filling this gap to develop targeted, evidence-based interventions that leverage better knowledge about leprosy to effectively enhance community engagement. Practically, this research can help design programs that focus on mastery of reading and writing and are culturally sensitive, thereby empowering communities, reducing stigma, and strengthening sustainable leprosy control efforts at the community level (Muldoon *et al.,* 2022).

The purpose of this study is to clearly see how the level of public understanding about leprosy affects their participation in efforts to control and eliminate leprosy. This study aims to determine the extent to which the community understands leprosy, and how this level of knowledge and understanding can increase their participation in detecting the disease early, preventing its spread, and providing support to leprosy sufferers. In addition, this study also seeks to explore the relationship between the level of public understanding about leprosy and reducing stigma and misunderstandings that have been the main barriers to community participation. Thus, this study also aims to provide a scientific basis that can be used to develop more effective and locally appropriate community-based interventions, thereby increasing community awareness and active participation. This research is very important to help make public health programs more successful, such as the WHO Leprosy strategy and PEP (post-exposure prophylaxis), by improving aspects of community education and empowerment. Finally, the results of the study are expected to provide concrete suggestions for policymakers and program implementers in designing a more inclusive and sustainable approach.

RESEARCH METHODS

This study employed a scoping review design based on the methodological framework created by Arksey and O'Malley and updated by Levac. It involved five main steps, defining the research question, searching for relevant literature, selecting studies, extracting data (charting), and presenting results (Khalil *et al.*, 2016). Presentation of results was conducted in accordance with the PRISMA-ScR guidelines to ensure transparency and quality of reporting (Tricco *et al.*, 2018). A systematic literature search was conducted in five major databases: PubMed, Scopus, SciELO, LILACS, and Web of Knowledge, using structured Boolean AND and OR operators on keywords such as "leprosy" or "Hansen's disease" and "knowledge" or "health literacy" and "community participation" or "community engagement." The publication year was limited to 2016 and 2026, and only articles in English and Indonesian were included. The article selection process was conducted by two independent reviewers who conducted a step-by-step screening process, starting from the title, abstract, and full text. Disagreements between reviewers were resolved through discussion or by involving a third reviewer if necessary. The article selection flowchart is constructed according to the PRISMA standard to show the number of articles at each selection stage.

Data extraction covered key variables such as operational understanding of leprosy literacy (understanding of the causes, signs, and modes of transmission), community engagement (participation in control programs), and leprosy-related stigma. These data were compiled into structured tables to facilitate thematic analysis and narrative description based on key themes. The analysis method employed a thematic qualitative approach and grouped findings from various study types (quantitative observational, controlled trials, qualitative, and mixed-method) to comprehensively integrate the results (Westphaln *et al.,* 2021). This scoping review did not evaluate the quality of the studies according to standard scoping review methodology. Reference management was performed using Mendeley software to systematically identify and remove duplicate articles. Inclusion and exclusion criteria were structured: inclusion included studies measuring or describing leprosy-related health literacy and community participation in endemic areas or global priority countries; exclusion included studies concentrating solely on clinical aspects without a literacy or community participation component. Databases were selected based on their multidisciplinary scope and relevance to the theme of leprosy literacy and community participation in global priority countries such as Indonesia, India, and Brazil (Martos-Casado *et al.*, 2022). A research ethics statement is included to emphasize that this scoping review does not require ethics clearance because it utilizes secondary data from existing publications. Key terminology is consistently explained to prevent confusion during the review process.

RESULT AND DISCUSSION

Basic Knowledge Level

Knowledge about the causes, modes of transmission, and early symptoms of leprosy is very low. This low level of knowledge is likely due to the lack of dissemination of accurate information and the persistence of traditional beliefs deeply embedded in local culture. Misconceptions such as that leprosy is caused by poor hygiene and that it is transmitted through touch remain prevalent, contributing to stigma and discrimination (Willis *et al.*, 2024). This underscores the need for a community education approach that not only conveys factual information but also adapts to the social and cultural context, given that knowledge alone is insufficient to effectively eliminate stigma (Budiawan *et al.*, 2020).

Low Level of Leprosy Awareness as a Major Obstacle to Disease Control

This low level of understanding and awareness is a major barrier to early detection, treatment, and elimination of leprosy. This aligns with a WHO report showing that a lack of public knowledge and stigma remain challenges in leprosy control in a number of endemic areas (Chu *et al.,* 2020).

Formal Education Improves Leprosy Literacy

Formal education has been shown to significantly impact community understanding of leprosy. Those with a university education background demonstrate significantly higher levels of awareness compared to those with less education. Formal education not only broadens knowledge about the clinical aspects of leprosy but also develops critical thinking skills that encourage participation in disease control programs (Titaley *et al.*, 2025).

Marital Status and Age as Social Factors in Leprosy Literacy

Individuals who are not married generally demonstrate higher levels of awareness than those who are married. This may be related to age, as younger, typically unmarried, groups have better access to information, particularly through digital platforms and social media. Therefore, this sociodemographic factor is important to consider when designing educational interventions aimed at various segments of society to ensure their effectiveness (Mohamed *et al.,* 2021).

The Role of Contact with Health Workers in Improving Literacy and Participation

Direct interaction with health workers plays a crucial role in increasing public understanding. Research shows that individuals who have been in contact with health services have greater knowledge about the characteristics, symptoms, and treatment of leprosy, which in turn encourages them to actively participate in disease surveillance and elimination programs (Van 't Noordende *et al.,* 2021). However, many people still obtain information about leprosy through informal channels, necessitating strengthening health education and promotion efforts by health workers, both directly and through other media channels (Aquino *et al.,* 2023).

Stigma as an Inhibitor to Community Participation

Lack of understanding about leprosy also reinforces negative prejudices against individuals with leprosy, leading them to hide their condition and hindering efforts to control the disease (Kinanti & Alinda, 2024). Educational methods that only increase medical knowledge are inadequate if not complemented by measures to reduce stigma and discrimination. Therefore, it is crucial to develop inclusive programs that involve broad community participation (Prakoeswa *et al.,* 2025).

Effective Health Education and Promotion Strategies

The use of various communication channels, including posters, leaflets, counseling, and social media platforms, has proven successful in increasing literacy and community engagement in the study area (Govindasamy *et al.,* 2021). Community-based approaches and the use of local leaders and health professionals as agents of change are highly recommended for reaching groups with low education levels or limited access to health services (Ramasamy *et al.,* 2023).

Forms of Community Participation in the Elimination Program

Programs centered around family education have been shown to effectively lessen the adverse stigma in communities regarding leprosy. This is important as stigma has the potential to obstruct social engagement and undermine efforts for elimination. Health workers and village leaders can execute these initiatives to inform and educate local populations (Lamonge *et al.,* 2024).

Tabel 1. Characteristics of Interventions Related to Community-Based Intervention Programs Among Leprosy Patients (Masala *et al.,* 2025)

Authorship	**Core Intervention**	**Outcome**	**Relationship to the Topic of Discussion**	**Research Description**
(Lusli *et al.,* 2016)	CommunityBased Counseling	Reduction of stigma (internalized,	Reduction of Stigma and Enhancement	This study examines the effectiveness of counseling in

		anticipated, enacted), enhancement of social participation.	of Social Participation	reducing stigma associated with leprosy. The findings indicate that counseling interventions assist individuals with leprosy in enhancing social interactions, seeking employment, and participating in community activities.
(Peters *et al.*, 2015)	Interactive Learning Approach (ILA) Methodology in Leprosy Programs	Identification of Stakeholder Perception Differences Regarding Leprosy and Disability	The Role of Stakeholders in Community-Based Interventions	This study reveals that stakeholders have varying understandings of leprosy interventions. The ILA approach facilitates the alignment of perceptions and enhances the effectiveness of interventions.
(Mwasuka *et al.* 2018)	CommunityBased Awareness and Active Screening	Enhancing Early Detection of New Leprosy Cases	Strategies for the Detection and Prevention of Leprosy in the Community	This study highlights the effectiveness of socialization programs and active screening in detecting new cases of leprosy within communities and schools.
(Dadun *et al.*, 2017)	A Combination of Three Interventions: Counseling, SocioEconomic Programs, and Community Contact	Reduction of Stigma, Enhancement of Social and Economic Interaction	Reduction of Stigma and Enhancement of Social Participation	This study evaluates three different interventions and finds that a combination of approaches is more effective in enhancing the social participation of individuals with leprosy.
(Martos-	A Human	Sustainable	The Role of	This study highlights

Casado *et al.,* 2022)	Rights and Gender-Based Approach in Leprosy Health Services	Improvement of Healthcare Service Access	Stakeholders in Community-Based Interventions	the importance of healthcare worker engagement in community-based programs using a gender-sensitive and human rights-based approach.
(Jay *et al.,* 2021)	Group-Based Support and Social Identity	Strengthening New Identity and Enhancing Psychological Well-being	Reduction of Stigma and Enhancement of Social Participation	This study demonstrates that group-based interventions assist individuals with leprosy in regaining self-confidence and gaining access to broader social networks.

CONCLUSION

A high level of leprosy literacy has been shown to be a key determinant in increasing active community participation in leprosy control and eradication programs, as comprehensive understanding can address negative stigma and psychological barriers to case reporting. This research is scientifically grounded in the belief that literacy is not just about conveying information but also serves as a foundation for collective behavior change. This helps detect cases early and improves adherence to treatment.

The results of this study can be implemented through the development of health communication strategies based on local wisdom and the integration of digital education platforms to reach a wider population. To improve leprosy reduction efforts, further research is recommended to explore the impact of literacy interventions on underserved communities and to analyze the role of policy assistance from local governments in supporting communities with high literacy levels to become more actively involved.

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