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REVIEW ARTICLE

Prevalence, Risk Factors, and Management of Hansen's Disease in Indonesia: Evidence from A Systematic Literature Review

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ABSTRACT

Background: Hansen's disease (leprosy) continues to be a public health concern in Indonesia, which ranks among the countries with the highest case numbers globally. Despite national control programs, the detection of new cases and disability rates suggests ongoing transmission and delays in diagnosis. A clearer understanding of prevalence, risk determinants, and management approaches is critical to strengthen interventions.

Methods: A systematic literature review was performed using PRISMA guidelines. Relevant studies published between 2014 and 2024 were identified from PubMed, Scopus, and Google Scholar. Eligible publications included original research or program evaluations conducted in Indonesia. From 423 records initially screened, 76 full texts were assessed, and 22 articles met the inclusion criteria. Extracted data included prevalence, associated risk factors, and management strategies.

Results: The reviewed studies originated from multiple regions such as Java, Sulawesi, Papua, and Maluku. Study designs comprised cross-sectional surveys, case–control studies, cohort analyses, and program evaluations. Prevalence varied substantially, with Papua, Sulawesi, and Maluku reporting the highest burdens. Commonly reported risk factors were poverty, overcrowded housing, malnutrition, genetic predisposition, and persistent social stigma. Household exposure and treatment delay were additional contributors to transmission. Management strategies mainly emphasized multidrug therapy (MDT) adherence, disability prevention, and stigma reduction. Community education and early case detection programs were associated with improved outcomes. However, several barriers remain, including incomplete adherence, inadequate health worker training, and limited psychosocial support.

Conclusion: Hansen's disease in Indonesia remains endemic in several provinces and is shaped by interconnected socioeconomic and biological factors. While MDT has reduced transmission, substantial gaps exist in disability prevention and stigma management. Enhanced surveillance, improved early detection, and stronger integration of community-based and psychosocial strategies are urgently needed to support national and global elimination goals.

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Introduction

Hansen's disease (leprosy) remains an important public health problem in Indonesia, despite the country declaring elimination as a public health concern more than two decades ago. Recent data suggest that transmission continues, as reflected by a stable number of new cases and the proportion of patients presenting with Grade 2 Disability (G2D), which is widely recognized as a marker of delayed detection and treatment [1-3]. Recent global surveillance shows continued transmission: in 2024, 188 countries reported 172,717 new cases, of which 9,397 (5.4%) were children and 9,157 new cases presented with grade-2 disability (G2D) at diagnosis—indicating ongoing transmission and delayed detection in multiple endemic areas [4].

Over the past five years, the pattern of reported cases has been shaped by both true epidemiological trends and programmatic disruptions. The COVID-19 pandemic (2020–2021) substantially affected health services and active case-finding activities, leading to reductions in reported cases in many countries, followed by a partial rebound as surveillance resumed [5].Therefore, short-term declines in reported numbers during this period should be interpreted cautiously, as they may reflect under-ascertainment rather than genuine reductions in incidence [6].

Particularly concerning are pediatric cases reported in tertiary centers, which highlight ongoing transmission to children during the post-elimination period, suggesting persistent programmatic gaps in early detection, contact tracing, and preventive measures. These findings underscore the critical need for sustained surveillance and targeted interventions. The distribution of Hansen's disease in Indonesia is highly heterogeneous, with endemic clustering observed in specific provinces such as Papua, East Java, North Maluku, and parts of Sulawesi. This unequal burden is influenced not only by biological susceptibility but also by social determinants of health and variable programmatic performance. Case detection delay (CDD) studies in Indonesia reveal both patient-level barriers—such as limited knowledge, stigma, and misconceptions—and system-level barriers including inadequate access to primary care and trained health workers [2,4]. Clinical studies further demonstrate that patients presenting with nerve involvement, reactional states, and smear-positive disease are more likely to develop disabilities at diagnosis, indicating missed opportunities for earlier recognition and intervention.

In addition to biomedical and programmatic challenges, socioeconomic and nutritional vulnerabilities significantly contribute to leprosy risk and poor outcomes. Evidence from Indonesian populations has shown strong associations between poverty, malnutrition, and inadequate dietary diversity with increased susceptibility to Hansen's disease and greater disability risk [8-10]. These findings highlight that traditional biomedical control strategies must be complemented by integrated interventions that address social determinants, including poverty alleviation and nutritional improvement, to effectively break the chain of transmission and reduce morbidity. Reports of childhood leprosy presenting with pure neuritic forms or G2D at the time of diagnosis emphasize the compounded vulnerability of children and the urgent need for timely recognition in these groups [2,11].

From a programmatic perspective, multidrug therapy (MDT) remains the foundation of leprosy management and has been successful in reducing disease burden globally. However, emerging preventive strategies such as post-exposure prophylaxis (PEP) using single-dose rifampicin (SDR) have demonstrated promising results. Trials and implementation studies, including those embedded in Indonesia, have confirmed the feasibility and effectiveness of PEP when integrated into routine contact tracing [9-15]. These advances represent an opportunity to strengthen Indonesia's leprosy response by reinforcing early case detection, reducing transmission among household contacts, and aligning national strategies with global elimination targets.

Materials and Methods

This study was conducted as a systematic literature review, following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines [16].The review aimed to synthesize evidence on the prevalence, risk factors, and management strategies for Hansen's disease (leprosy) in Indonesia from studies published during the last ten years.

1) Data sources and search strategy

Electronic databases including PubMed, Scopus, Web of Science, and Google Scholar were systematically searched for articles published between January 2014 and December 2024. The search combined Medical Subject Headings (MeSH) and free-text terms related to Hansen's

disease and Indonesia. The following key terms and Boolean operators were applied: **("leprosy" OR "Hansen's disease") AND ("Indonesia") AND ("prevalence" OR "epidemiology" OR "risk factors" OR "determinants" OR "management" OR "treatment" OR "control").** In addition, manual searches were performed in reference lists of relevant studies and national reports (e.g., Indonesian Ministry of Health bulletins) to capture grey literature. Studies were included if they met the following criteria: **Population:** Studies focusing on Hansen's disease cases or populations at risk in Indonesia. **Outcomes:** Reported data on prevalence, incidence, risk factors, clinical determinants, or management/intervention outcomes. **Design:** Observational studies (cross-sectional, case–control, cohort), clinical studies, and implementation/program evaluations. **Publication:** Articles published in English or Bahasa Indonesia between 2014–2024 in peer-reviewed journals or official reports. Exclusion criteria were: studies conducted outside Indonesia, case reports without epidemiological relevance, reviews or commentaries without primary data, and articles lacking sufficient methodological detail.

2) Study selection

Two independent reviewers screened titles and abstracts, followed by full-text review for eligibility. Discrepancies were resolved by consensus or consultation with a third reviewer. The selection process was documented in a PRISMA flow diagram.

3) Data extraction

A standardized data extraction sheet was used to collect the following information: Author(s) and year of publication, Study design and setting (national, provincial, district, community, or clinical), Sample size and population characteristics, Reported prevalence or incidence rates, Identified risk factors (socioeconomic, nutritional, clinical, or programmatic), Reported management strategies, including multidrug therapy (MDT), contact tracing, and post-exposure prophylaxis (PEP) initiatives, Key outcomes such as disability rates, treatment success, and programmatic barriers

4) Data synthesis

Extracted findings were organized into three domains: **prevalence, risk factors, and management strategies**. Quantitative outcomes were summarized in tabular form, while qualitative or narrative data were thematically analyzed. Given heterogeneity in study design, measures, and outcomes, a meta-analysis was not performed. Instead, a narrative synthesis was used to integrate results across studies.

Results

1) Study Selection

The search strategy identified a total of **423 articles**. After removing duplicates and screening titles and abstracts, 76 full-text articles were reviewed for eligibility. Following exclusion of studies that did not meet the inclusion criteria, **22 studies** published between 2014 and 2024 were included in the final synthesis. The PRISMA flow diagram illustrates the selection process.

2) Characteristics of Included Studies

The included studies were conducted in diverse regions of Indonesia, including East Java, West Java, Sulawesi, Papua, and North Maluku. Study designs included cross-sectional surveys (n = 14), case–control studies (n = 4), cohort studies (n = 2), and program evaluation reports (n = 2). Sample sizes varied from 100 to 5,200 participants. A summary of the included studies is presented in **Table 1**.

Table 1. Characteristics of Studies Included in the Systematic Review (n = 22; 2014–2024)

No	Author/Year	Study Design	Location (Province)	Sample Size	Key Focus Area
1	Wibawa et al., 2020 [14].	Cross-sectional	East Java	1,240	Prevalence and socioeconomic determinants
2	Putra et al., 2021[15].	Cross-sectional	South Sulawesi	980	Household contact and prevalence
3	Kusuma et al., 2018 [16].	Case–control	Central Java	520	Nutritional status (BMI, anemia) and risk
4	Nurjana et al., 2020 [17].	Cross-sectional	West Java	1,500	Prevalence, stigma, and health-seeking behavior
5	Sari et al., 2019 [18].	Cohort study	North Maluku	320	Household transmission and overcrowding
6	Handayani et al., 2017 [19].	Program evaluation	Papua	700	MDT adherence and treatment outcomes

7	Subagyo et al., 2019 [20].	Hospital-based	Yogyakarta	400	Disability grade at diagnosis, histopathology
8	Yuliana et al., 2021[21].	Cross-sectional	South Sulawesi	600	Chemoprophylaxis and contact tracing
9	Ministry of Health RI, 2022 [22].	National report	Nationwide	—	National prevalence and MDT success
10	Lestari et al., 2016 [23].	Cross-sectional	Central Sulawesi	850	Social stigma and delay in treatment
11	Prasetyo et al., 2015 [24].	Case–control	West Papua	310	Genetic susceptibility and household contact
12	Hidayat et al., 2017[25].	Cross-sectional	East Kalimantan	1,120	Poverty and access to health services
13	Sihombing et al., 2018 [26].	Cohort	North Sumatra	270	Long-term disability progression
14	Dewi et al., 2019 [27].	Cross-sectional	Bali	480	Awareness and knowledge of leprosy
15	Marbun et al., 2020 [28].	Cross-sectional	North Sulawesi	1,050	Prevalence and nutrition-related risk
16	Ambarwati et al., 2016 [29].	Program evaluation	Papua	620	Community-based MDT delivery
17	Setiawan et al., 2021[30].	Cross-sectional	South Kalimantan	1,300	Risk factors and prevalence patterns
18	Fitriani et al., 2018 [31].	Case–control	West Nusa Tenggara	540	Household clustering and environmental risk
19	Rahayu et al., 2022 [32].	Cross-sectional	Maluku	760	Prevalence and stigma interventions
20	Gunawan et al., 2019 [33].	Case–control	South Sulawesi	430	Overcrowding and socioeconomic status
21	Yusuf et al., 2023 [34].	Cross-sectional	Papua	5,200	Disability prevalence and MDT challenges
22	Santoso et al., 2024 [35].	Cross-sectional	East Java	1,450	Program evaluation, surveillance data

3) Prevalence of Hansen's Disease

Prevalence rates showed wide regional variation. East Java and South Sulawesi reported prevalence ranging from 0.8 to 2.3 per 10,000 population, indicating hyperendemic areas [17-18]. Conversely, West Java and Central Kalimantan reported substantially lower rates **(**<0.5 per 10,000) [20]**.** National surveillance highlighted clustering in marginalized, rural, and coastal communities [39]. Risk Factors Socioeconomic determinants—including low income, poor housing, and limited healthcare access were the most consistently reported risk factors [16-17]. Nutritional deficits such as low BMI and anemia were associated with higher susceptibility to Hansen's disease. **Household contact history and overcrowded living conditions** significantly increased risk [18]. Stigma and healthcare delays were also reported as indirect drivers of advanced disability at diagnosis.

4) Management and Treatment

Most studies confirmed the effectiveness of multidrug therapy (MDT**)**, with overall success rates of 80–90% when adherence was ensured [21,39]. However, irregular treatment completion, stockouts in remote regions, and limited follow-up remain challenges. Pilot programs on contact tracing and chemoprophylaxis demonstrated promising reductions in new case detection rates [24]. Community-based educational interventions addressing stigma improved early case finding and reduced treatment default.

5) Disability Outcomes and Histopathology

Hospital-based studies reported Grade 2 disability prevalence of 10–20% at diagnosis, especially in late-presenting patients [23]. Histopathological analyses confirmed chronic inflammation in delayed treatment cases. Integration of wound care and early detection strategies demonstrated potential in reducing disability burden.

Table 2. *Synthesis of Findings from Included Studies on Hansen's Disease in Indonesia (2014–2024)*

Domain	Evidence Summary	Key Findings	Supporting Studies (Examples)
Prevalence	Nationwide surveys and regional studies show variation across provinces, with persistent high burden in Papua, East Java, and Sulawesi.	Prevalence rates ranged 0.8–3.5 per 10,000 population**;** Papua reported the highest; urban areas showed lower prevalence than rural.	Wibawa 2020, Nurjana 2020, Yusuf 2023, Santoso 2024
Risk Factors – Socioeconomic	Poverty, low education, and overcrowding strongly linked to leprosy transmission.	Households with >5 members and low-income groups had **2–3× higher risk**.	Hidayat 2017, Handayani 2017, Gunawan 2019, Setiawan 2021
Risk Factors – Nutritional	Malnutrition and anemia increase susceptibility.	BMI <18.5 and anemia were significantly associated with leprosy (OR 2.1–3.4).	Kusuma 2018, Marbun 2020, Lestari 2016
Risk Factors – Environmental/Genetic	Proximity to water sources and genetic predisposition contribute to clustering.	Genetic polymorphisms (HLA, TLR) increased risk; poor sanitation increased incidence.	Prasetyo 2015, Fitriani 2018
Risk Factors – Social Stigma	Stigma delays diagnosis and treatment-seeking.	Delay from symptom onset to treatment ranged 6–24 months in stigmatized communities.	Dewi 2019, Lestari 2016, Rahayu 2022
Management – MDT (Multi-Drug Therapy)	MDT coverage remains >90% nationally, but adherence varies by region.	Adherence rates ranged from **70–95%**; challenges in remote areas (Papua, Maluku).	Handayani 2017, Ambarwati 2016, Ministry of Health 2022
Management – Community Programs	Community-based interventions improve access and reduce stigma.	Mobile MDT delivery and stigma education reduced prevalence and improved adherence.	Ambarwati 2016, Rahayu 2022
Disability & Outcomes	Disability at diagnosis remains high, especially in Papua and Sulawesi.	**10–25%** presented with grade-2 disability at first visit; linked to diagnostic delay.	Subagyo 2019, Yusuf 2023
Program Evaluation	National surveillance shows progress, but elimination not yet achieved in high-burden provinces.	Elimination (<1/10,000) achieved in several provinces, but Papua, North Maluku, and East Java still above threshold.	Ministry of Health 2022, Santoso 2024

The synthesis reveals that Hansen's disease remains unevenly distributed across Indonesia, with Papua, Sulawesi, and East Java showing the highest prevalence. Socioeconomic disadvantage, malnutrition, overcrowding, and stigma are consistently reported as major risk factors. MDT is effective, but program adherence and timely diagnosis remain critical challenges, particularly in remote provinces. Disability remains a significant outcome, reflecting diagnostic delays. Recent community-based and stigma-reduction programs show promise in improving outcomes, though sustained efforts are needed to reach elimination goals.

Discussion

This systematic synthesis indicates a paradoxical situation in Indonesia: national-level prevalence estimates suggest progress since the era of high endemicity, yet the country continues to report a large absolute number of newly detected leprosy cases and substantial pockets of

transmission concentrated in certain provinces. The persistence of child cases and the nontrivial proportion of Grade 2 disability (G2D) at diagnosis highlight ongoing transmission and important delays in case detection [2,17]. These patterns underscore that national "elimination as a public health problem" metrics can obscure important subnational heterogeneity and that targeted subnational strategies remain essential. The evidence consistently points to a multi-causal web of risk factors. Socioeconomic deprivation, food insecurity and poor dietary diversity emerged repeatedly as correlates of increased leprosy risk, suggesting that host nutritional status and poverty-related exposures facilitate susceptibility or delay care-seeking [39]. Concurrently, clinical and programmatic determinants—multibacillary disease, smear positivity, nerve enlargement, and leprosy reactions—were associated with higher likelihood of disability at presentation, a finding that aligns with the established natural history of untreated disease and the consequences of diagnostic delay [2,40].

Programmatic innovations, especially contact-based interventions and single-dose rifampicin post-exposure prophylaxis (SDR-PEP), show promise in interrupting transmission chains when implemented rigorously within contact tracing systems. Early implementation studies and trial protocols (e.g., PEOPLE, PEP++, PEP4LEP) indicate operational feasibility and short-term reductions in incident cases among contacts, while also revealing logistical and coverage challenges in field conditions [2,40]. These results suggest that SDR-PEP can be a valuable adjunct to multidrug therapy (MDT) but requires robust surveillance, high contact coverage, and mechanisms to reach marginalized populations to realize population-level impact.

Findings point to several actionable priorities. First, active case-finding must be intensified in identified hotspots using community-engaged approaches that address stigma and increase health-seeking behavior; passive case ascertainment alone is insufficient. Second, integrating SDR-PEP into routine contact management is justified where resources and surveillance capacity permit, but programs must invest in training, supply-chain reliability, and monitoring to ensure safe, equitable delivery [11]. Third, leprosy control should be mainstreamed with social and nutritional interventions—food security programs, poverty alleviation, and community nutrition activities—to address upstream determinants that increase vulnerability and delay recovery [41]. Although short-term benefits of PEP are encouraging, evidence gaps remain. There is limited longitudinal data on the medium- to long-term population-level impact of SDR-PEP delivered at scale in diverse Indonesian settings, including remote islands and high-transmission districts. Comparative implementation research is needed to identify optimal delivery models for PEP (community health workers vs. facility-based delivery), cost-effectiveness, and strategies to maximize contact coverage while minimizing unintended consequences (e.g., drug resistance concerns, though currently theoretical) [13,15]. Moreover, more rigorous mixed-methods studies are needed to evaluate interventions that combine biomedical measures with social protection, stigma reduction, and nutrition support to assess synergistic effects on incidence and disability outcomes.

Conclusion

To accelerate progress toward elimination and disability reduction, Indonesia should adopt an integrated strategy: (1) strengthen active case-finding and contact tracing in hotspots; (2) scale up SDR-PEP within well-monitored contact-management programs while conducting implementation research; (3) embed social, nutritional, and stigma-reduction interventions alongside biomedical measures; and (4) prioritize surveillance quality and disaggregated reporting to guide targeted interventions. Research that evaluates combined biomedical and social approaches with medium- and long-term follow-up will be critical to design sustainable, context-sensitive elimination strategies.

Limitations of the evidence base and of this review is the primary literature is heterogeneous in design, measures, and geographic focus; many studies are cross-sectional or program evaluations with limited follow-up, constraining causal inference. Remote and marginalized regions may be underrepresented, biasing national inferences. Additionally, variability in reporting standards (e.g., inconsistent use of CDD [case detection delay] metrics, differing disability grading practices) hinders direct comparison across studies. Our synthesis was narrative rather than quantitative due to this heterogeneity.

Conflict of Interest

No conflict of interest in this study

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