

## REVIEW ARTICLE

# Prevention of Disability in Leprosy

## Pencegahan Disabilitas pada Kusta

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 <https://doi.org/10.56186/jbk.216-223>

### ABSTRACT

Leprosy, a chronic granulomatous infectious disease caused by *Mycobacterium Leprae*, presents a complex challenge with profound social, physical, and economic implications. The burden of leprosy is a persistent concern in many developing countries, despite substantial control efforts. The World Health Organization (WHO) initiated the "Global Leprosy Strategy 2016-2020" to combat this issue, focusing on reducing children diagnosed with leprosy, eliminating visible deformities, and enacting anti-discrimination laws. Disability in leprosy is multifaceted and preventing disability in leprosy is a critical endeavor, such as prophylaxis, early diagnosis, and comprehensive care strategies. Vaccination with the BCG vaccine provides moderate protection, and combining it with single-dose rifampicin (SDR) can enhance its effectiveness, particularly for lepromatous cases with delayed diagnoses. Improved training for healthcare providers can facilitate early detection, reducing the risk of disability. After effective leprosy treatment, long-term morbidity remains a concern. Continued education of healthcare workers and communities is pivotal in preventing damage to hands, feet, and eyes, especially in cases of peripheral neuropathy. Disability progression is a substantial risk, highlighting the need for ongoing medical assessments, even post-MDT treatment. Restructuring primary care services to ensure quality post-treatment care is essential. Stigma remains a significant obstacle in leprosy prevention. Community awareness and stigma reduction can motivate individuals to seek treatment. Epidemiological patterns transmission within households, play a crucial role in identifying new cases. Routine examinations of household contacts of leprosy patients can expedite early diagnosis. Nutrition also plays a role in leprosy prevention. Ensuring access to nutritious food is critical to reducing the risk of developing the disease. In conclusion, the prevention of disability in leprosy is a multifaceted endeavor that demands comprehensive strategies, early intervention, awareness, and community engagement. Addressing this issue is vital for improving the quality of life for individuals affected by leprosy and for achieving a leprosy-free world.

**Keywords:** *Disability, Leprosy, Prevention.*

## ABSTRAK

Penyakit kusta merupakan penyakit menular granulomatosa kronis yang disebabkan oleh *Mycobacterium Leprae* dan merupakan tantangan yang kompleks dengan dampak sosial, fisik, dan ekonomi yang mendalam. Beban penyakit kusta merupakan masalah yang terus ada di negara berkembang walaupun ada upaya pengendalian yang besar. Organisasi Kesehatan Dunia (WHO) memulai "Strategi Kusta Global 2016-2020" untuk mengatasi masalah ini, dengan fokus pada pengurangan kasus kusta pada anak, eliminasi disabilitas yang dapat dilihat dan menerapkan hukum anti-diskriminasi. Disabilitas dalam kusta sangat beragam dan upaya pencegahan adalah merupakan faktor yang penting, seperti profilaksis, diagnosis dini, dan strategi perawatan komprehensif. Vaksinasi dengan vaksin BCG memberikan perlindungan yang moderat, dan menggabungkannya dengan Rifampisin Dosis Tunggal (SDR) dapat meningkatkan efektivitasnya, terutama untuk kasus kusta lepromatik dengan diagnosis yang tertunda. Peningkatan pelatihan bagi penyedia layanan kesehatan dapat memberi kemampuan bagi untuk mendeteksi secara dini, sehingga mengurangi risiko disabilitas. Morbiditas jangka panjang tetap menjadi suatu perhatian pada pasca pengobatan kusta. Pencegahan kerusakan tangan, kaki, dan mata, terutama pada kasus neuropati perifer dapat dilakukan dengan memberikan pendidikan berkelanjutan pada tenaga kesehatan dan komunitas. Progresivitas disabilitas merupakan risiko yang signifikan, sehingga diperlukannya penilaian medis berkala, bahkan setelah pengobatan MDT. Penataan ulang layanan perawatan primer merupakan sesuatu yang penting untuk memastikan perawatan berkualitas pasca-pengobatan. Stigma tetap menjadi masalah signifikan dalam pencegahan kusta. Kesadaran masyarakat dan pengurangan stigmatisasi dapat memotivasi individu untuk mencari pengobatan. Pola epidemiologi penularan dalam rumah tangga, memainkan peran penting dalam mengidentifikasi kasus baru. Pemeriksaan rutin terhadap kontak rumah tangga pasien kusta dapat mempercepat diagnosis dini. Nutrisi juga memainkan peran dalam pencegahan kusta. Memastikan akses makanan bergizi sangat penting untuk mengurangi risiko terkena penyakit ini. Pencegahan disabilitas dalam kusta adalah upaya yang membutuhkan strategi komprehensif, intervensi dini, kesadaran, dan keterlibatan masyarakat. Mengatasi masalah ini sangat penting untuk meningkatkan kualitas hidup individu yang terkena kusta dan untuk mencapai dunia bebas kusta.

**Kata kunci:** Disabilitas, Kusta, pencegahan

## INTRODUCTION

Leprosy is a persistent granulomatous infectious condition caused by an intracellular parasite, *Mycobacterium leprae* (*M. leprae*), which targets macrophages and Schwann cells. The clinical manifestation of the disease varies depending on the host's immune status, ranging from localized to widespread and self-limiting to progressive. Nerve damage in leprosy doesn't solely occur due to the infection of peripheral nerves by the bacilli but also results from the immune and inflammatory response to *M. leprae*. Although sensory function is the most severely affected, all three functions of peripheral nerves—autonomic, sensory, and motor—suffer impairment. Peripheral nerve damage is strongly linked to physical disability and is considered the most severe complication of leprosy.<sup>1</sup>

Leprosy may lead to facial deformities, neuropathic pain, and physical disability. These changes can significantly impact psychosocial aspects, including altered body image, diminished self-esteem, and social avoidance. These consequences can ultimately result in impaired social interactions and a negative self-perception. The damage caused by leprosy extends beyond the

physical discomfort, leading to experiences of social stigma, discrimination, and a reduced quality of life.<sup>2</sup>

## METHODS

The keywords disability, prevention, and leprosy were used to search the literature in PubMed, Medline, and Science Direct databases. Articles with pertinent titles and abstracts were included. All papers that looked at disability prevention in leprosy were included.

## BURDEN OF LEPROSY

Despite extensive control efforts, which have included the widespread use of Multi-Drug Therapy (MDT) and stabilization of reported new case detection rates in recent years, leprosy remains prevalent in many developing countries. It is crucial to prevent the transmission of *M. leprae* through the provision of an effective vaccine, early diagnosis, and timely treatment of the disease. The primary goal of these measures is to reduce the risk of physical disability and deformity, lessening the overall physical, psychosocial, and economic burden imposed by leprosy. To address these challenges, the World Health Organization (WHO) introduced a new global strategy titled "Global Leprosy Strategy 2016-2020: Accelerating toward a Leprosy-free world." This strategy primarily focuses on reducing the number of children diagnosed with leprosy and displaying visible physical deformities to zero, enacting specific anti-discrimination legislation in all countries, and decreasing the incidence of new leprosy cases with Grade 2 disability to fewer than one case per million.<sup>3</sup>

According to the International Classification of Functioning, Disability, and Health (ICF) domains, disability encompasses impairment, limitations in activity, or restrictions in participation. Sensory function loss leads to repeated injuries, ulcerations, and limb shortening. Corneal sensation loss can result in unnoticed corneal injuries and significant visual impairment. The loss of motor function is associated with finger and toe deformities, the inability to close the eyes (lagophthalmos), and foot and wrist drops.<sup>4</sup> WHO's disability grading for hands and feet includes:<sup>5</sup>

Grade 0: No anesthesia, no visible deformity, or damage.

Grade 1: Anesthesia is present, but no visible deformity or damage.

Grade 2: Visible deformity or damage is present.

Leprosy also places a significant socioeconomic burden on the lives of patients. Stigmatization of leprosy patients has persisted for decades, not only from the broader community but also due to self-stigmatization by the patients themselves. The limitations imposed by physical disability often restrict their employment opportunities, forcing them to seek occupations that do not demand intense strength and repetitive tasks to avoid exacerbating their condition. This leads to marital difficulties, challenges in social interactions, and a loss of respect within society, which can interfere with treatment adherence.<sup>6</sup>

The Sustainable Development Goals (SDGs) emphasize the promotion of mental health and well-being for all, irrespective of age, by 2030. This is particularly relevant for individuals living with leprosy and its consequences, as they face both stigma and discrimination in addition to physical disability, making them more susceptible to mental health problems. They are frequently marginalized, with their fundamental rights violated, creating a significant struggle to overcome the challenges posed by leprosy.<sup>7</sup>

## RISK FACTORS OF DISABILITY IN LEPROSY

Several risk factors can contribute to the development of disabilities in leprosy. The WHO Global Leprosy Strategy 2010-2020 aims to expedite efforts toward a world free of leprosy, with a primary focus on early case detection to prevent disabilities and conducting active case-finding campaigns in highly endemic areas or communities.<sup>8</sup>

Patients with disabilities, regardless of whether they have a grade 1 disability (G1D) or grade 2 disability (G2D), share a common risk, which is a delayed diagnosis leading to an increased risk of disability. Patients diagnosed after more than two years face a higher risk compared to those diagnosed within two years. The extent of nerve damage is also a contributing factor, with patients having damaged nerves facing a higher risk compared to those without nerve damage.<sup>9,10</sup> Patients with MB Leprosy also have a heightened risk of developing a grade 2 disability.<sup>9,11</sup> They often experience prolonged pain, resulting in a reduced functional capacity that impacts daily activities, motivation, and self-esteem in performing work.

Delayed diagnoses also play a role in the occurrence of disabilities in leprosy.<sup>(12)</sup> Many patients tend to ignore their illness or wait for symptoms to disappear on their own. This is often due to the stigma associated with leprosy, as doctors sometimes refer patients to higher centers for diagnosis, avoiding mentioning leprosy and its consequences. This lack of consistency in follow-up care leads patients to seek multiple doctors for alternative diagnoses, particularly affecting male patients, who are twice as likely as females to experience physical disabilities due to social behaviors and difficulties in accessing healthcare services.

Leprosy reactions are another risk factor for disabilities. Since these reactions can occur during or after completing multidrug therapy, there is a risk of disability progression even after treatment. This underscores the importance of long-term follow-up and neurologic examinations for early identification and management of leprosy reactions to prevent neuropathies and disabilities.<sup>8</sup> The level of education has also been linked to the occurrence of disabilities. Higher levels of education are considered a determining factor for disease improvement. In comparison, lower levels of education, coupled with low socioeconomic status and income, are associated with a higher prevalence of leprosy.<sup>13</sup>

## PREVENTION OF DISABILITY

There is an increasing demand to invest in effective preventive measures and early detection, as well as to implement comprehensive care strategies during treatment, including post-discharge follow-up to maintain functional capacity. Currently, the most commonly administered vaccine is the BCG vaccine, offering protection ranging from 20% to 80%.<sup>1</sup> The use of single-dose rifampicin (SDR) in combination with the BCG vaccine can boost protective effects to as high as 80%. This approach is particularly beneficial for lepromatous patients who may experience delayed diagnoses due to the absence of early symptoms. Enhancing the training of primary healthcare providers can facilitate earlier diagnoses, especially for lepromatous leprosy patients.<sup>5,11</sup>

Even after successful leprosy treatment, long-term morbidity and disability continue to pose challenges. It is crucial to continually educate healthcare professionals and the community to prevent damage to the hands, feet, and eyes in individuals with peripheral neuropathy. Timely and appropriate referrals are essential for addressing acute complications, and improved rehabilitation services are needed for those with disabilities to enhance their quality of life.<sup>14</sup> Research indicates that the cumulative probability of physical disability worsening in individuals treated and bacteriologically cured of leprosy increases with time. After 10 years, this probability stands at 30%, rising to 35% after 15 years in a cohort study of patients from Mato Grosso, Brazil. Hence, disability prevention efforts should encompass regular medical assessments for those who have completed MDT treatment. Primary care systems would need to be restructured to provide standardized and high-quality services post-treatment.<sup>15</sup>

Addressing the stigma associated with leprosy is another key aspect of disability prevention. Stigma remains prevalent in many communities, necessitating increased community awareness to motivate affected individuals to seek treatment. Although Hansen's disease is primarily treated on an outpatient basis today, there are still many individuals who have been cured but continue to live in communities, villages, or settlements mainly comprised of others affected by the disease and their families. Stigmatization can also occur in healthcare encounters when medical professionals hold stigmatizing beliefs about the disease. Therefore, a dual focus on rehabilitation and stigma reduction is crucial to help individuals develop sustainable livelihoods, ultimately achieving the goal of disability prevention. It is imperative for programs to foster partnerships with people affected by leprosy, as increased community participation can facilitate the formulation and implementation of policies that enhance case finding, treatment adherence, and disability prevention.<sup>16,17</sup>

Giving special attention to the epidemiological patterns of leprosy can aid in the identification of new cases. Household contact is a primary source of leprosy transmission, and it remains a prominent factor, particularly in cases involving children. A routine comprehensive examination of household contacts of leprosy patients can contribute to early leprosy diagnosis.<sup>18,19</sup>

Leprosy is a disease that takes a significant amount of time to develop, and nutritional balance may play a role in reducing the risk of acquiring the disease. Decreased levels of

antioxidants and essential nutrients can lead to increased oxidative stress and skin and neurological issues during *M. leprae* infection. Ensuring the provision of nutritious food to all members of a leprosy patient's household is paramount. Poverty alone can result in reduced consumption of protein-rich foods, fruits, and vegetables, leading to nutritional deficiencies. Prolonged nutritional deficiencies can impair the immune response and contribute to clinical leprosy.<sup>20</sup>

## CONCLUSIONS

The after-effects of leprosy can impact a patient's life significantly. There should be more awareness in increasing the ability to do earlier diagnoses, post-medication monitoring, reducing stigma, a detailed of close contact cases, and ensuring nutritional balance as a preventative action.

## ACKNOWLEDGEMENT

None

## CONFLICT OF INTEREST

The authors declared no conflict of interest related to this article.

## FUNDING

None

## AUTHOR CONTRIBUTIONS

All authors contributed to this article.

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