Picturing health: the burden of leprosy in eastern Indonesia

Leprosy impacts impoverished communities in low-income and middle-income countries (LMICs), with over 200 000 new cases recorded annually worldwide. This infectious disease is caused by *Mycobacterium leprae* or *Mycobacterium lepromatosis* and primarily affects the skin and peripheral nerves. Effective multidrug therapy is available and, with early detection and treatment, leprosy is curable. Yet disease management can be complicated by immune-mediated reactions, which may cause irreversible nerve damage and lead to lifelong disabilities that are associated with stigmatisation and discrimination. Despite progress in the past few decades, the disease burden has stalled, with some countries not meeting WHO goals of interrupting transmission and reducing incidence.

Indonesia formally reached the status of leprosy elimination in 2000. Yet the country continues to have the third highest number of newly diagnosed patients in the world with pockets of high endemicity spread across the geographically and socioeconomically diverse nation. In 2019, 17 439 newly diagnosed patients with leprosy were reported in Indonesia, of whom 11·5% were children, indicating ongoing community transmission, and 6·4% had a visible disability, signifying diagnostic delays. Since 2000, the leprosy control programme of the Indonesian Government has been scaled back with loss of resources and clinical expertise. Despite the country's remarkable progress in achieving universal health coverage (UHC), health inequalities and within-country differences in access to health services persist. The COVID-19 pandemic has magnified pre-existing health inequities, and further challenges the attainment of the WHO Global Leprosy Strategy 2021–2030 "Towards zero leprosy". In the 2020 WHO global leprosy update, Indonesia reported 36% fewer new cases than in 2019, as a result of disruptions to routine health services. Patients faced barriers in accessing health facilities and treatment, contributing to a surge in new cases and grade two disabilities. Governments need to prioritise UHC and continuity of health-care services to build strong safety nets to support marginalised and vulnerable populations and to mitigate the far-reaching impacts of COVID-19.

In November, 2021, the Eijkman-Oxford Clinical Research Unit in Indonesia and the Sumba Foundation collaborated with photographer Yoppy Pieter to document the impacts of leprosy on people's lives in Sumba, a remote island in eastern Indonesia. The project aimed to visualise the story of leprosy and raise awareness of this debilitating and stigmatised disease. These pictures capture individual stories that illustrate humanity, dignity, resilience, and hope.

Yoppy Pieter, Marlous L Grijsen
Jakarta, Indonesia (YP); Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine, University of Oxford, Oxford, UK (MLG); Eijkman-Oxford Clinical Research Unit, Jakarta, Indonesia (MLG)
https://www.yoppy-pieter.com

This photography project was done in collaboration with the Eijkman-Oxford Clinical Research Unit in Jakarta and the Sumba Foundation in Sumba, East Nusa Tenggara province, Indonesia. All photographs were taken by Yoppy Pieter and the captions that accompany each photograph were written by Yoppy Pieter and Marlous L Grijsen. The project was funded by Wellcome Provision for Public Engagement to Oxford University Clinical Research Unit Vietnam (grant number 106680/Z/14/A).

Anton
Leprosy awareness among health-care professionals is generally low. The disease is often misdiagnosed, leading to unnecessary diagnostic delays and development of irreversible disabilities. Anton developed skin complaints when he was a teenager. He has already developed physical disabilities and has difficulty walking. He was told for many years that he had a fungal skin infection and was repeatedly prescribed antifungal creams, which delayed detection of the disease.

Agustinus

Agustinus developed six hypopigmented skin lesions with loss of sensation in the past 5 years. The lesions started on his chin and slowly extended to his arms and legs. He was diagnosed with multibacillary leprosy a year ago. In endemic settings, leprosy is diagnosed on the basis of the presence of at least one out of three cardinal signs: the presence of skin lesions with definite loss of sensation, a thickened or enlarged peripheral nerve, and a positive slit-skin smear (or skin/nerve biopsy) with the demonstration of mycobacteria.

Agustinus with his parents
After Agustinus was diagnosed with leprosy, all family members were traced and invited to the clinic for further investigations. Consequently, his father, mother, and grandmother were also diagnosed with leprosy. Agustinus explained that his uncle, who passed away several years ago, had many skin lesions and wounds across his body. Poverty-related living conditions, such as household crowding, contribute to the transmission of leprosy, which is primarily transmitted through the respiratory tract during close and frequent contact with untreated patients.

Slit-skin smear

A slit-skin smear from the left earlobe is undertaken to confirm the diagnosis of leprosy. Slit-skin smears can be obtained from a suspected skin lesion or from routine sites that have a high probability of harbouring bacilli, such as the earlobes, elbows, and knees, since the mycobacterium prefers cooler parts of the body. A slit-skin smear is a relatively easy, fast, and inexpensive tool and remains the conventional method to support the diagnosis and follow-up of leprosy. In remote settings, however, laboratory facilities are often not available, and health-care workers need to rely on their clinical skills and recognise the (early) signs of leprosy.

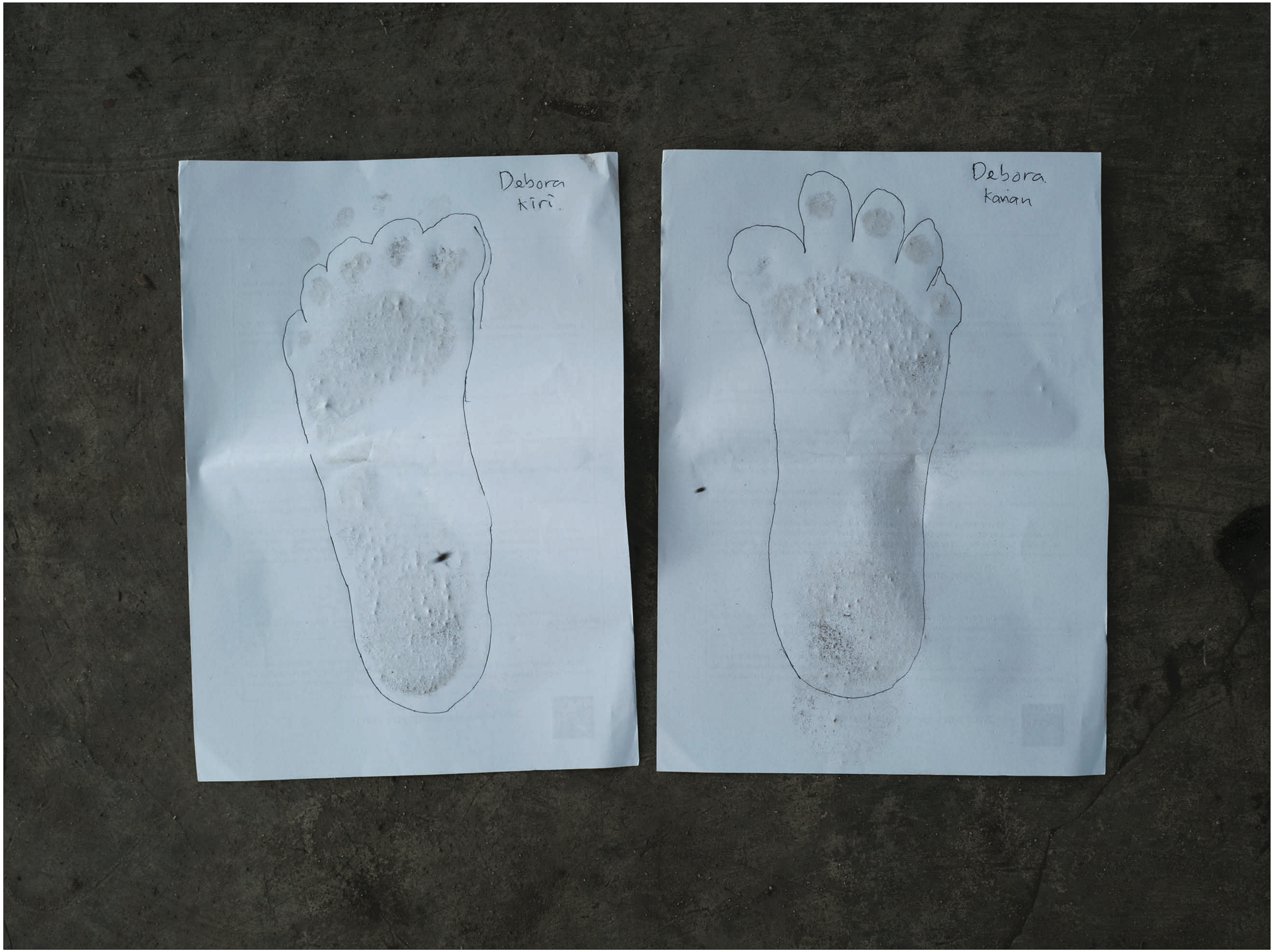
Multidrug therapy

Debora was diagnosed with multibacillary leprosy 5 years ago but never completed treatment. A full treatment course encompasses 6 or 12 months of multidrug therapy depending on the type of leprosy. Patients are no longer infectious after 72 h of multidrug therapy. Debora discontinued her treatment because she did not notice any improvement of her disabilities. Her husband, shown here, had to travel monthly for more than an hour to pick up the drugs. After 6 months he never went back to the clinic. Health education and counselling are important tools to improve understanding of leprosy and treatment adherence, explain expectations, and prevent unnecessary delays and complications.

Debora and her family
Debora's daughter is having similar complaints as her mother and was diagnosed with paucibacillary leprosy. Leprosy often affects more than one individual in a family due to long-term close contact with an untreated infected person and genetic susceptibility.

Debora washes her feet

Debora washes her feet every day with water and soap to prevent secondary infection of existing wounds. Patients affected by leprosy are a neglected group of patients and often suffer in silence. Leprosy affects people who live in remote areas and challenges communities that are already plagued by poverty and inadequate access to health-care services, keeping the next generation anchored in poverty.



Debora's feet
Patients in eastern Indonesia have inadequate access to treatment and specialised care programmes, such as physical rehabilitation, undermining adherence to treatment and increasing the risk of developing severe complications and disabilities that contribute to stigmatisation. These footprints illustrate how for Debora, the delay in diagnosis and treatment contributed to irreversible impairments.

Community members on their way to the rice fields during the planting season

In Sumba, community groups have a crucial role in helping the society survive the harsh living conditions that are encountered on a daily basis, such as low rainfall affecting food security. This picture shows the church community travelling to the rice fields. Despite the economic growth and improvements in overall health of Indonesians in the past three decades, poverty relief remains a big challenge in the country, particularly in remote parts of eastern Indonesia. Leprosy is often overlooked, even more so since COVID-19 disrupted health-care services globally, including in Sumba.

Anton working in the field

Despite his disabilities, Anton is planting rice on the land owned by his family. He has multibacillary leprosy resulting in loss of sensation of both hands and feet. He cannot register any pain. Walking barefoot in the field exposes his hands and feet to injuries that can result in chronic ulcers and secondary skin and bone infections. If poorly managed, such conditions can ultimately lead to deformities or amputation contributing to the existing stigmatisation and discrimination.

Rice feast

Anton and his family are serving lunch to the neighbouring community to thank them for helping plant the rice. In his community, people believe that Anton was cursed when he competed during horse races, a traditional sport on the island. The Sumbanese believe that misfortune strikes when their Indigenous ancestral religion, referred to as Marapu, retracts its protection. In the past and still persisting today, many myths, stereotypes, and misconceptions exist about leprosy in the community and among health-care workers. Stigma results in discrimination and contributes to deferral of health-seeking behaviour which undermines early detection and treatment, thereby prolonging the risk of community transmission.

Yuliana and her friends

Yuliana, shown on the right of this picture holding a flower, has multibacillary leprosy but has no access to treatment. She has developed lagophtalmos, an ophthalmological complication associated with leprosy, and can no longer close her eyes. She has a severe chronic wound complicated by osteomyelitis of her left forefoot that requires amputation. Yuliana's grandmother had similar symptoms. People affected by leprosy can experience challenges in pursuing education or employment. Yuliana is a fourth-year informatics student and lives with her friends in a small student flat. Despite her illness, she is determined to complete her degree. When she finishes university, she wants to build her career and work in an office.