



Editorial

The end of leprosy is not imminent, but it is on the horizon

Within the leprosy research community, there has been a recent but quite rapid transition away from the old slogan of ‘elimination as a public health problem’ to a new focus on the interruption of transmission. Once transmission has stopped, the disease itself will disappear over a period of time, but this may take some years because of the long incubation period of leprosy; new case numbers will decline quickly, but people living with leprosy will have a normal life expectancy. Their needs, in terms of managing leprosy-related disability and reducing discrimination, will require attention for decades. Many groups engaged in leprosy work subscribe to a three-fold goal of ending transmission, ending disability and ending discrimination.

Ending transmission

Discussions on interventions to end transmission have been going on for some years, with a focus on post-exposure prophylaxis (PEP) and the possibility of a specific vaccine for leprosy. A complimentary discussion has been led by the WHO to look at indicators and definitions relating to transmission; the Task Force on Criteria for the Elimination of Leprosy has produced an interim report this year, and the debate will be taken forward by the Global Leprosy Programme of the WHO¹. Much current research in leprosy looks at improving tools for prevention and designing better tests to diagnose infection and disease (currently, the Achilles heel of leprosy control) so that we can more accurately assess the epidemiological situation.

At present, the main indicator pointing to the interruption of transmission is the absence of autochthonous (locally transmitted) leprosy in children. A country can be said to have reached that stage if there have been no new cases of leprosy in children under the age of 15 yr for the past five years. A significant

number of countries (in particular, in Europe and the Americas) have reached this stage, although many still diagnose cases in older adults or in people coming from abroad. Other countries are on the verge of reaching this milestone, while many others may do so in parts of the country, at sub-national level. Experience over many decades has shown that occasional cases of leprosy in people travelling from an endemic area to a country where transmission has stopped do not in practice lead to any secondary cases.

Ending disability

Ending disability due to leprosy will take decades, although case numbers will decline and severe disability should occur much less frequently. A major effort is being made to investigate and report disability in children so that the appropriate preventive services can be strengthened. If new cases are prevented by PEP or a vaccine, this prevents disability, as does the proper assessment and management of reaction cases. Animal studies suggest that LepVax, a specific subunit vaccine, may provide some protection against nerve damage if used as a therapeutic vaccine alongside multidrug therapy².

While new cases occur, a proportion of them is likely to develop disabilities. There are three supporting pillars in the management of disability (*i*) the primary healthcare services, providing regular nerve function assessment and standardized treatment for reactions; (*ii*) self-care by the affected persons and their families, to prevent further worsening of impairments that are already present; and (*iii*) referral services for specialist care – people with more complex leprosy-related disabilities should have the same access to specialist care as anyone else in the community. These elements are well known and well described in the literature, but lack of access and logistic support have been major issues in the past and require attention.

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As case numbers decline, it is becoming more and more feasible to individualize case management. This will usually mean helping people with leprosy be more aware of their own condition, assess their own status and become partners in their own care³. Support for such schemes through a telephone helpline can be highly beneficial⁴. Research to refine support for self-care practice is ongoing.

Mental well-being is also receiving more attention. The availability of peer counselling within the primary care services is a major advance, providing reassurance and basic care, as well as helping to combat stigma⁵. Referral for specialist care will be needed in some cases.

Ending discrimination

The theme for World Leprosy Day on January 30, 2022 is 'United for Dignity'. We look briefly at the roles of laws, customs and organizations of people affected in promoting dignity.

Laws: According to ILEP there are over 130 laws that discriminate against persons affected by leprosy in 23 countries around the world (<https://ilepfederation.org/updated-list-of-discriminatory-laws/>). These laws normalize humiliation and violence against persons affected by leprosy; these make it harder for them to make a living and participate in society. India has done very well in repealing a number of these laws in the past few years and authorities and lawmakers are working diligently to abolish all such unjust legislation (<https://ilepfederation.org/updated-list-of-discriminatory-laws/>). We need to see an end to all discriminatory laws everywhere.

Customary laws and practices: There are a vast number of discriminatory practices against persons affected by leprosy in many countries. These laws affect their access to work, education, marriage, housing, political and social participation, among other things. Governments need to commit to training their officials in recognizing these practices and avoid tolerating or, even worse, perpetuating them. There needs to be a clear and simple pathway for persons affected and their family members to report such abuse. The relevant institutions must then act swiftly to intervene, investigate, and guarantee the rights and the dignity of persons affected and their family members.

Organizations of persons affected: These organizations play a crucial role in ending discrimination and promoting dignity. These can help government officials to identify and confront discriminatory practices. They empower their members to stand up for their rights. They alone will tell if authorities are really doing enough to guarantee their human rights. Government agencies would do well to support these organizations of persons affected and involve them in planning, executing, monitoring and evaluating the decisions that directly affect them.

The World Leprosy Day coincides with the anniversary of the death of Mahatma Gandhi, who passed away on that day in 1948. Mahatma Gandhi worked tirelessly to help those affected with the disease, seeking above all to treat each individual with dignity.

Conflicts of Interest: None.

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