Editorial



Zero leprosy: A united effort using existing & new tools but new perspectives

Zero leprosy

The WHO Global Leprosy Strategy 2021-2030 'Towards zero leprosy' was published in 2021¹. 'Zero leprosy' is an often-used term to express the global vision of what partners in the leprosy field are striving to achieve. It is commonly differentiated into 'zero transmission' (or 'no disease'), 'zero (no) disability' and 'zero (no) discrimination'². It is good to reflect on what these goals mean since their horizons and the tools needed to achieve them are very different.

Zero transmission and zero leprosy disease

This area is a priority in the WHO Global Leprosy Strategy since three of the four global targets for 2030 are related to interruption of transmission and reducing the incidence of new leprosy cases. The WHO Global Leprosy Programme (GLP)¹ has added a new pillar to its global strategy dedicated to the prevention of leprosy using post-exposure (chemo) prophylaxis (PEP). The current regimen uses single-dose rifampicin (SDR), but it is hoped that even more effective regimens will become available in the foreseeable future. Adding this new preventive tool to existing successful approaches, like active case detection and contact screening, it is appropriate to set our sights on interrupting transmission of Mycobacterium leprae and on achieving zero incidence of new cases of leprosy in endemic countries.

The global goal is 'elimination of leprosy', defined as interruption of transmission and absence of disease $(i.e. \text{ new cases})^3$. One of the global targets is zero new autochthonous cases of leprosy in 120 countries. For WHO to ascertain whether countries have indeed reached this milestone, a verification process is needed. In other neglected tropical disease programmes, this comprises verifying that the elimination target has been reached and ascertaining that the country (i) has an adequate surveillance system in place, (*ii*) has met the criteria for elimination, (*iii*) has ongoing services for detection, treatment and management of infection and/or cases that may occur even after elimination has been achieved, and (*iv*) has continued services for care and inclusion of persons with disabilities in place. Such evidence is collected in a so-called 'dossier'. To develop concepts, criteria, indicators and milestones for a leprosy elimination dossier, the WHO GLP set up a Task Force on Criteria for Elimination of Leprosy (TFCEL) in March 2020⁴.

When considering the elimination of leprosy, it is important to distinguish 'interruption (=cessation) of transmission' and achieving 'elimination of leprosy disease' as separate concepts. With COVID-19 disease, the timing of stopping the transmission of the virus and ending the occurrence of new cases of COVID-19 are very close. Depending on the severity of disease, COVID-19 patients remain infectious no longer that 10-20 days after the onset of symptoms⁵. With leprosy, this is very different. The time between infection and appearance of signs and symptoms can be very long (average five years but up to 20 yr or longer has been documented). Consequently, after the transmission of leprosy bacilli has been stopped in an area or country, we can still expect new autochthonous cases to emerge for a number of years. 'Zero leprosy' refers to both 'interruption of transmission' and 'zero leprosy disease', but each needs its milestone. If SDR-PEP or enhanced PEP regimens are used widely in the future, one can hope to shorten the time between these two milestones since PEP will prevent leprosy in those who are already infected. Based on the work of the TFCEL, the WHO GLP is developing technical guidance on the interruption of transmission and elimination of leprosy, which is to be published sometime in 2022.

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Zero disability

Zero disability comprises both prevention of disabilities (POD) and the management of disability⁶. POD refers to the prevention of primary and secondary impairments and to preventing impairments from causing disability in terms of limitations in functioning^{7,8}. Primary impairments often occur in the form of damage to peripheral nerves9. The most effective strategy is early detection and prompt treatment with multidrug therapy (MDT), before any clinically detectable nerve damage is present. Research has shown that patients detected at this stage have a much-reduced risk of developing nerve damage during or after treatment¹⁰. However, POD remains relevant throughout the treatment period and indeed also afterwards⁸. Services and procedures are needed for prompt detection, diagnosis and treatment of leprosy reaction and nerve damage. The WHO has published technical guidance on this in 2020⁶. Due to the shortening of MDT, many reaction episodes, especially in multibacillary (MB) patients, occur or continue to occur after release from MDT. Patients with MB leprosy, those who already have nerve damage and patients who have had at least one episode of reaction during MDT, are at increased risk of developing new additional impairments after release from MDT¹⁰. Establishing post-MDT surveillance of former patients at increased risk of new impairments should therefore be a priority. Since there are millions of people living with leprosy-related disabilities, services to prevent such disabilities from worsening remain necessary, also after the zero leprosy milestones have been reached. These would include training in self-care, wound care, provision of protective devices, such as protective footwear, and vocational training to enable people to earn their livelihood in a way that does not put their damaged limb at risk.

Often, the impairments of eyes, hands or feet would lead to functional limitations, *e.g.* in activities of daily living. In that case, physical rehabilitation, such as the provision of assistive devices, physiotherapy or reconstructive surgery may help optimize functioning. Interaction of impairments with environmental factors, such as stigma, often leads to restrictions in social and work participation. Interventions to reduce stigma and socio-economic rehabilitation may help to normalize social functioning¹¹. Mental well-being deserves special attention since it has been neglected for so long and is affected by disability and stigma, as well as general factors, such as poverty^{12,13}. The first step would be to create awareness of the mental health problems common among persons affected during health worker training, supervision and to incorporate this in programme policy and guidelines. Preventive counselling at diagnosis, interventions, such as peer support, and referral to primary care level mental health services can make crucial contributions to improving the mental well-being of those affected¹⁴.

The horizon for disability services relates to the life expectancy of persons living with leprosy-related disabilities. Since many are still young, relevant services will be needed for many years to come. Since these disabilities are not unique to leprosy, programmes should work towards accommodating these needs in integrated POD, wound care and rehabilitation services.

Zero stigma and discrimination

Leprosy-related stigma and discrimination are almost universal in endemic and even non-endemic countries¹⁵. It is fuelled by historic discriminatory regulations and practices, such as forced isolation and exile to leprosaria. Sadly, such regulations and practices, and even legislation, still exist in many countries. This includes immigration regulations that require leprosy patients to declare their status upon entry into certain countries, as well as deportation of newly detected patients who are migrant workers. Employees may lose their job if their leprosy status is discovered. Similarly, children may still be excluded from education for the same reason. Besides these obvious human rights violations, stigma manifests in a myriad of more subtle but no less damaging ways such as avoidance, gossip, name-calling or loss of status, dignity and respect¹⁶.

This situation should not be allowed to continue. 'Zero stigma and discrimination' refers to a situation where persons affected by leprosy and their family members are accepted as they are, with full respect and dignity and with opportunities and rights equal to everyone else. Tools are available to measure stigma and thus visualize priority areas for stigma reduction interventions¹⁷. Several interventions have been shown to be effective in reducing stigma and discrimination in communities and among healthcare personnel. Assessment tools and interventions usually work across conditions and can therefore be used also for people affected by other stigmatized conditions, such as HIV, tuberculosis or mental health conditions^{18,19}. This facilitates a 'health-related stigma approach' that is easier for health or other services that need to implement interventions to reduce stigma. Raising awareness of human rights among persons affected and among people who stigmatize has been shown to be effective²⁰. It also helps to connect people affected by leprosy to people discriminated for other reasons, thus increasing their potential for a joint voice against discrimination and exclusion.

Leprosy and COVID-19

The COVID-19 pandemic has affected many aspects of leprosy services. The number of new cases detected in 2020 was down by almost 40 per cent compared to 2019²¹. MDT services were also interrupted temporarily in some countries. The screening of contacts and distribution of SDR-PEP was severely hindered by lockdowns and reassignment of health personnel to COVID-related duties. This also affected services and activities related to disability prevention, such as self-care group meeting²². In the meantime, guidelines for the management of leprosy in the context of the pandemic have been issued by the International Federation of Anti-Leprosy Associations (ILEP)²³, the Global Partnership for Zero Leprosy²⁴, the Brazilian Society of Hansenology²⁵ and the Indian Association of Dermatologists, Venereologists and Leprologists²⁶. Reports indicate that leprosy services are continuing, sometimes using modified approaches to ensure the safety of staff and personnel.

Conclusions

Knowledge, tools and interventions are available to work towards the triple goals of Zero leprosy, Zero disability and Zero stigma and discrimination. New tools have become available, such as preventive using SDR-PEP, offering chemotherapy new perspectives to work towards the interruption of transmission and elimination of leprosy disease. While important gaps remain in knowledge, tools and interventions to achieve goals, research is underway to fill these. The COVID-19 pandemic has added serious operational challenges. However, if we renew our resolve to achieve these goals in a united manner, we will be able to put an end to leprosy and its consequences.

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