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*Zugang zu Medikamenten*

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***Consigning leprosy to history***

**The challenges with improving access to leprosy treatment**

Von Penny Grewal

*Leprosy is one of the few diseases that can be eliminated. It typically affects young adults, particularly among the poorest of the poor. Early treatment protects them from developing disabilities and going down a downward spiral towards social exclusion and destitution. Achieving the goal of elimination will accomplish much more than simply resolving a public health problem. It will enhance the credibility and confidence of local health services and put in place systems that can be used to tackle other diseases.*

To eliminate leprosy, we need to find everyone suffering from the disease and cure them using multidrug therapy. While this is not an insurmountable challenge, important hurdles remain which hinge around improving patients' access to treatment. Experience in leprosy clearly indicates that access to treatment is complex and goes beyond the issue of price alone. Although leprosy treatment has been available free of charge through WHO since 1995 a significant hidden case load persists.

**Significant progress to date  
... important challenges remain**

Multidrug therapy - usually referred to as MDT - has literally changed the face of leprosy. Its effectiveness in curing leprosy, its impact on transmission, ease of use under field conditions and good tolerability has made the elimination of leprosy feasible. The clinical signs of early leprosy are easily visible, and the cardinal diagnostic sign – loss of sensation in the affected skin – is unique to the disease. All health workers can be trained in simple procedures for diagnosing the disease, and prescribing the appropriate MDT blister pack.

Eliminating leprosy means reducing the disease burden down to a very low level - defined by WHO as 1 case per 10,000 inhabitants. At this low level of prevalence, it is believed that leprosy will slowly disappear, as it already has in many parts of the world.

By the end of 2000 leprosy had been eliminated at a global level in line with the resolution adopted by the World Health Assembly in 1981. Moreover the disease has already been eliminated from 107 countries. Since 1985, the prevalence has dropped by 89% and over 11 million people have been cured of leprosy with MDT. WHO estimates that more than four million people have been protected from developing deformities. The human suffering that this has prevented cannot be captured by mere statistics alone.

Yes despite this significant progress important challenges remain. Experience in leprosy clearly demonstrates that access to treatment is a complex issue which goes beyond the issue of pricing. MDT has been available free of charge by WHO since 1995, initially through the drug fund of the Nippon Foundation and since 2000 through the Novartis donation, significant numbers of people suffering from leprosy are still not on treatment.

The prevalence rates of leprosy in the six most endemic countries are about 4 times the elimination target. In fact, almost 90% of today's patients live in just 6 countries - India, Brazil, Myanmar, Madagascar, Nepal and Mozambique. Every year about 700,000 new cases are detected, with the widening coverage of MDT services, most of whom had been suffering from leprosy for many years. In addition, there remains a substantial hidden case load - patients who are infected but not on treatment and continue to be a source of infection within their communities.

In addition to the typical problems limiting patients access to treatment, such as weak health infrastructures and inadequately staffed health facilities, there are some specific challenges relating to leprosy such as:

**Physical access to diagnosis and treatment:** Until recently leprosy treatment was only available through specialized leprosy clinics leaving many communities with very poor access to MDT services. Less than 10% of health facilities were in a position to diagnose and treat leprosy. Patients thus have to travel, and often walk, long distances for diagnosis and treatment.

**Costs for seeking treatment:** Even though MDT is free of charge, getting treatment can be expensive for patients in terms of travel and other incidental expenses as well as lost wages. As patients usually only receive a month's treatment at a time, the total cost over the full course of treatment (6 months or a year) can be substantial.

**Poor recognition of leprosy:** Poor knowledge of the early signs of leprosy among health care providers is another obstacle. Many only associate leprosy with disabilities. As leprosy has traditionally been in the hands of specialised staff, it is perceived by many to be a complicated disease and not their concern. In addition, traditional healers have a completely different perception of leprosy and often provide ineffective treatment.

**Stigma:** Leprosy is still surrounded by a web of fear, stigma, and prejudice. People at times delay seeking timely treatment for fear of social consequences as well as poor awareness of the availability of free and effective treatment. The consequences of this delay can be devastating to

individuals and their families, as leprosy can lead to progressive and irreversible deformities, often resulting in social exclusion. The deformities reinforce the fear of leprosy and its negative image.

**Information systems, logistics, weak infrastructure:** Getting MDT to where the patients are, which is typically in difficult to reach places, poses major logistical and distribution challenges. Shortages of MDT at the health centre level is a chronic problem due to poor information systems, inadequate planning, limited distribution networks, and a shortage of vehicles or fuel. This impairs the prospects of cure for patients and undermines the credibility of the health services, as well as efforts to eliminate leprosy.

## The global alliance to eliminate leprosy: A concerted effort

A concerted effort to overcome these obstacles is being made at the country level within the framework of the global alliance to eliminate leprosy (GAEL). GAEL was created by WHO in November 1999. GAEL brings together all the key partners such as governments of leprosy endemic countries, WHO, the Nippon Foundation and Novartis/Novartis Foundation for Sustainable Development. Other organisations include the World Bank and DANIDA who support elimination efforts in India.

GAEL actively supports the implementation of a common strategy, adapted to the field reality, to change the image of leprosy, encouraging people to seek timely treatment as well as bringing leprosy services closer to patients.

Capacity building to enable all health facilities, particularly in endemic areas, to diagnose and treat leprosy. Leprosy services are now progressively being integrated within the framework of general health services thus bringing leprosy diagnosis and treatment closer to communities within their local health centres. This will also ensure that local health services will be in a position to treat the new cases who will appear even after the disease has been "eliminated".

Dispelling the fear of leprosy and improving awareness of the early signs of the disease in order to motivate people to seek timely treatment. Mass media campaigns, together with posters, bill boards, and community mobilisation events are being deployed on a large-scale and have already been highly successful in encouraging people to seek and comply with treatment.

Improved logistics to ensure adequate stocks of MDT at all health facilities. New patient packs will shortly be introduced which will simplify estimating MDT requirements for local health services.

Ensuring that all patients receive a full course of treatment and are cured. Innovative approaches, such as "Accompanied MDT" helps address this problem whereby patients can take the entire course of treatment with them and someone from their family helps them comply with their treatment.

Closely monitoring progress towards elimination in order to take corrective action and find pragmatic solutions to deal with any problems. The parameters to monitor progress have been simplified so that leprosy surveillance can be integrated into the regular disease surveillance.

## Conclusion

Ensuring sustained access to treatment for any disease is too big and complex for any single agency. Different actors in society have different concepts, skills, techniques, experiences, and resources. Collaboration and coordination among these different actors can lead to synergies and a dimension of solutions not available from any individual actor, and a more efficient use of resources. Public-private partnerships need to become the preferred working method and not merely exceptions.

Achieving the goal of leprosy elimination will accomplish much more than simply resolving a public health problem. It will also enhance the credibility and confidence of local health services and put in place systems that can be used to tackle other diseases.

*\*Penny Grewal has been in charge of Health Care projects and issues within the Novartis Foundation for Sustainable Development since 1985, with a special focus on Leprosy. Contact: penny.grewal@group.novartis.com Further reading: [www.who.int/lep](http://www.who.int/lep); [www.foundation.novartis.com/leprosy/](http://www.foundation.novartis.com/leprosy/)*



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