Leprosy: the challenging last mile

Dr Herman Joseph Kawuma and Dr Peter Eriki expound on getting rid of leprosy in Uganda

Leprosy, also called Hansen's disease, is a chronic infectious disease that affects mainly the skin and nerves. Its clinical presentation is dictated by the ability of the infected individual to mount an appropriate immune response. The majority of individuals who get infected never develop the disease and those who do show a wide variety of clinical presentations. The presentations have been grouped for purposes of treatment into Paucibacillary and Multibacillary leprosy on the recommendation of a World Health Organization (WHO) Study Group.[1]

Interventions to prevent the occurrence of the disease have largely centred on early diagnosis and treatment of known cases. There is still no ready to use test for infection or predictor of the progression to disease after the infection. The vaccine BCG was shown in Uganda and elsewhere[2] to have a preventive effect but this was not consistent across the globe.

One of the peculiar characteristics of leprosy disease is the potential to promote the development of impairments and disabilities. These are the most important drivers of stigma, discrimination and related socio-economic burden for people affected by leprosy.

Initially the reserve of missionary and humanitarian aid organisations, leprosy control was increasingly taken on by national health ministries. In the early 1980s many African countries developed national leprosy control programmes to supplement and in some cases to replace non-governmental efforts.

Treatment

There was no known curative treatment for leprosy for decades; the situation changed after the discovery and use of Dapsone and later on the widespread implementation of WHO recommended Multidrug therapy (MDT) comprising a combination of Rifampicin, Clofazimine and Dapsone.[1] It is now recommended that a uniform medicine combination may be used for all types of leprosy but for a duration of 6 months for Paucibacillary leprosy and 12 months for multibacillary leprosy.[3] There is a firm commitment that the medicines will be made available free of cost to all endemic countries through WHO.

Leprosy is one of the neglected tropical diseases (NTDs) and belongs to case-management category of NTDs which includes Buruli ulcer, Guinea worm disease, Human African Trypanosomiasis, Leprosy, Leishmaniasis and Yaws.[4] The NTD programme in Uganda is housed by the Vector Control Division of the Ministry of Health but leprosy remains part of the National TB and Leprosy Programme (NTLP).

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Leprosy in Uganda

Organised leprosy control activities in Uganda can be traced back to the early 1990s. National surveys conducted by the health department in the 1950s already indicated the uneven distribution of the disease in the country. The national TB/leprosy programme was launched in 1990 with a Central Unit at the Ministry of Health Headquarters supported by regional and district level focal points. Implementation of the front-line activities was integrated into in the existing primary health care system although it was not possible to engage the whole system because of the uneven distribution of cases.

The target of elimination of leprosy as a public health problem (point prevalence of less than 1 per 10,000 population), declared by the World Health Assemly of WHO of 1989, was attained at national level in 1994 and at district level in 2004; this status has been sustained since then.[8]

A review of the new case detection shows a downward trend (see Figure 1). The number of new cases reported by the NTLP annually has decreased from 1,600 in 2008 to 180 in 2017. The most significant decline is in the paucibacillary type of the disease; the number of multibacillary cases has tended to stagnate, especially in the last five years.[8] Only half of the districts consistently reported new cases; just 10 districts account for over 70% of all cases notified.

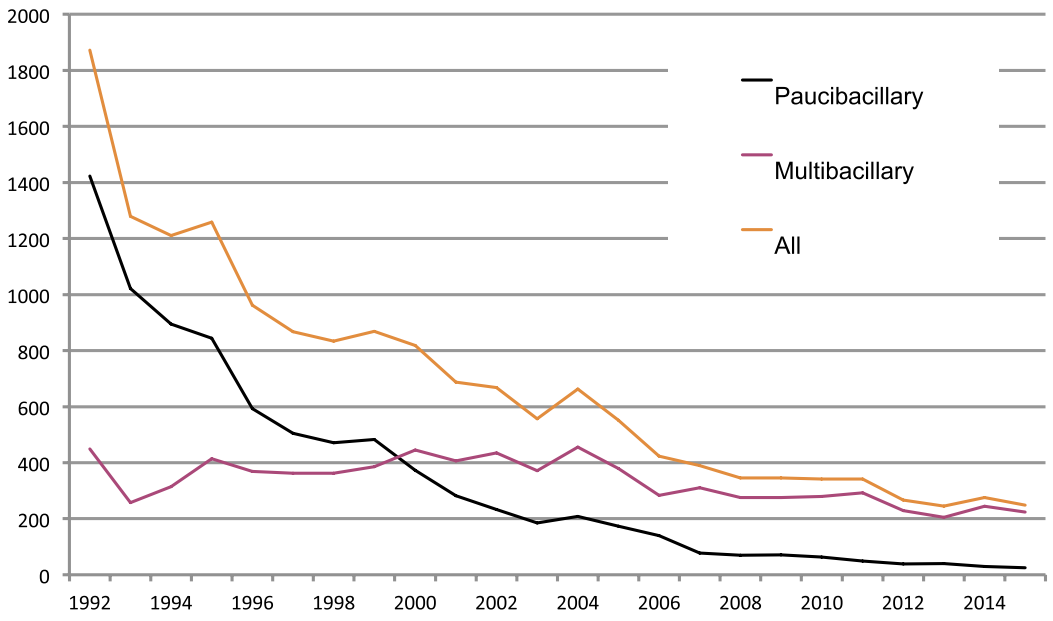
Features of the last mile

The last mile, after almost 90 years of leprosy control activities in Uganda, is characterised by several challenges that must be addressed if a clearer vision of the end is envisaged. A low level of political commitment is evident in the absence of a budget dedicated to the implementation of leprosy control activities. Funding for on-going activities is largely derived from donor sources.

New leprosy cases continue to occur and these include child cases (6% in 2017) indicating on going transmission of the disease. Figure 2 illustrates the clinical presentation of new child cases diagnosed during the latter half of 2019. High burden pockets are in the same location as refugee populations mostly from the high burden neighbouring countries of South Sudan and the Democratic Republic of Congo.

Leprosy becomes harder to diagnose as health workers and health service managers are no longer aware of its existence or its symptoms and signs as those trained are retiring.

Figure 1: Numbers of new cases of leprosy detected, 1992-2016 (NTLP)



Twenty three per cent of the new cases notified in 2017 had visible disabilities at the time of diagnosis[5] indicating unacceptable detection delay; the disabilities underlie the widespread stigma and discrimination of leprosy affected persons by their communities and some health service providers.

The new cases are unevenly distributed at national, regional, district and sub-district levels.The biggest disease burden is found in the Northern and North West regions of the country although there are scattered high burden pockets in other regions This makes it more difficult to ensure timely access to MDT services and the referral system that is essential for management of severe complications. The proportion of patients successfully completing MDT remains lower than expected.[5]

The thinking about the effect of HIV/AIDS epidemic on leprosy, a mycobacterium like TB, is still based on the result of a case-control study at the beginning of the HIV epidemic that revealed some cases of co-infection but found no significant relationship between the two diseases.[7]

Accurate data on the magnitude of the problems faced by people remaining with severe disabilities after completing treatment is still not available; there are hardly any sustainable strategies and interventions to address the medical and social needs of such people as they are not easily integrated into the organisations of people with other physical disabilities.[8]

Possible elements of the way forward strategy to address the remaining leprosy problem in Uganda.

The soon to be concluded 2016-2020 Global Leprosy Strategy[9] has a vision of: zero leprosy, zero transmission of leprosy infection, zero disability due to leprosy and zero stigma and discrimination. The targets of zero children diagnosed with leprosy and visible disability and further reduction in the proportion of new cases diagnosed with visible disability is attainable by 2030. At the moment Uganda has no legislation allowing discrimination on basis of leprosy. Basing on the three pillars for implementation of this strategy, we propose a ten-point programme:

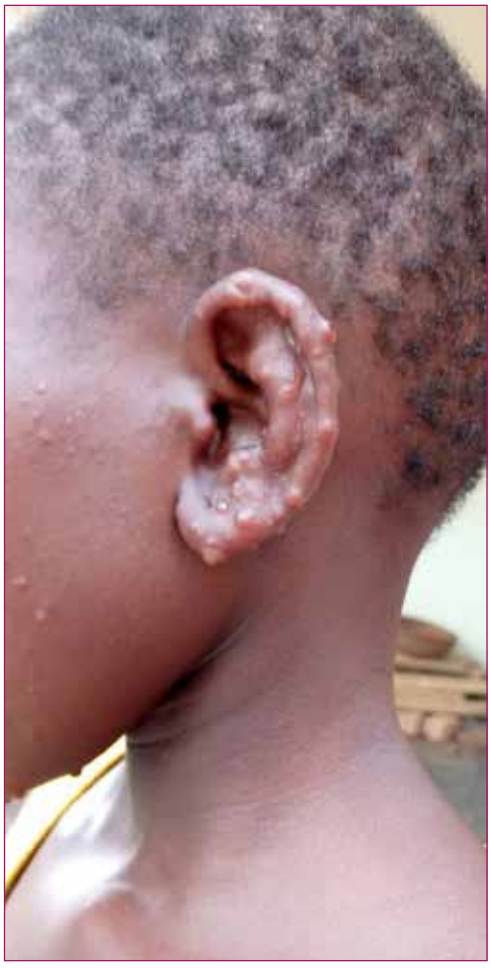
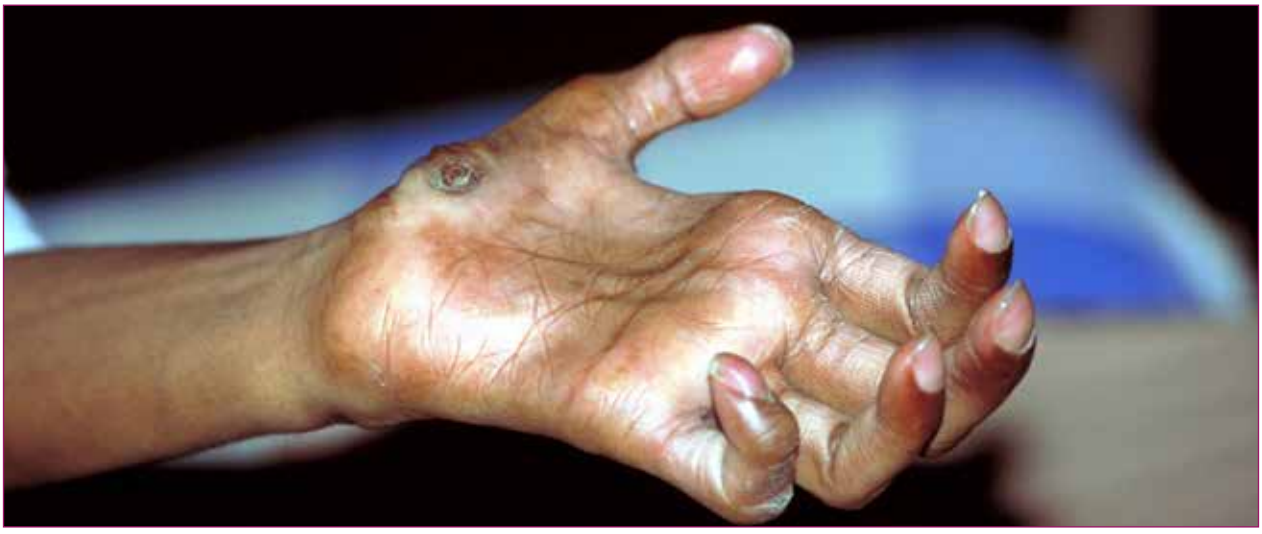


Figure 2: New MB leprosy case with nodule on the face and ears (2019)



- Using the opportunity offered by the combination with TB on the one hand and other NTDs on the other to lobby for political commitment and the mobilisation of enough resources for leprosy control activities.
- Contributing to universal health coverage with a special focus on children and refugee populations.
- Strengthening patient and community awareness on leprosy. Use innovative ways to enhance and sustain essential leprosy knowledge and skills among health service providers.[10]
- Mapping out areas according to endemicity levels for purposes of implementing appropriate interventions to improve timeliness of case detection like campaigns in areas of higher endemicity,systematic contact management in others and engaging other service providers like dermatologists.[11]
- Ensuring timely access to MDT services for patients wherever they will be diagnosed, putting in place measures to promote and monitor adherence to treatment and a referral system for management of complications.
- Promoting interventions for prevention of infection and disease including considering the appropriateness of the proposed Post-Exposure Prophylaxis with single dose rifampicin for contacts of index leprosy cases.[6]
- Empowering persons affected by leprosy and building their capacity to participate in leprosy services building from the experience of other endemic countries.
- Accelerating the formation of self-care groups by people affected by leprosy and the integration of their coalitions withother disability prone NTDs and other community-based organisations for purposes of improving their access to social and financial support services.
- Promoting community-based rehabilitation of leprosy affected persons, particularly by promoting inclusion in more mainstream CBR initiatives.[9]
- Improving the efficiency of the monitoring and evaluation component of the control programme and identifying areas for leprosy related implementation research to be included in the NTLP research agenda.

Conclusion

Leprosy is still endemic in Uganda. New cases of leprosy being notified to the Ministry of Health present with characteristic suggesting the continuing transmission of the disease in some pockets and the lack of capacity by the health system to detect and treat the new cases before they develop severe disabilities. The WHO recommended strategy is in many ways relevant to Uganda and should be taken into account when developing the next strategy for control of leprosy. Addressing leprosy challenges should be viewed as an opportunity to accelerate the attainment of universal health coverage; but when neglected, they are a potential threat.

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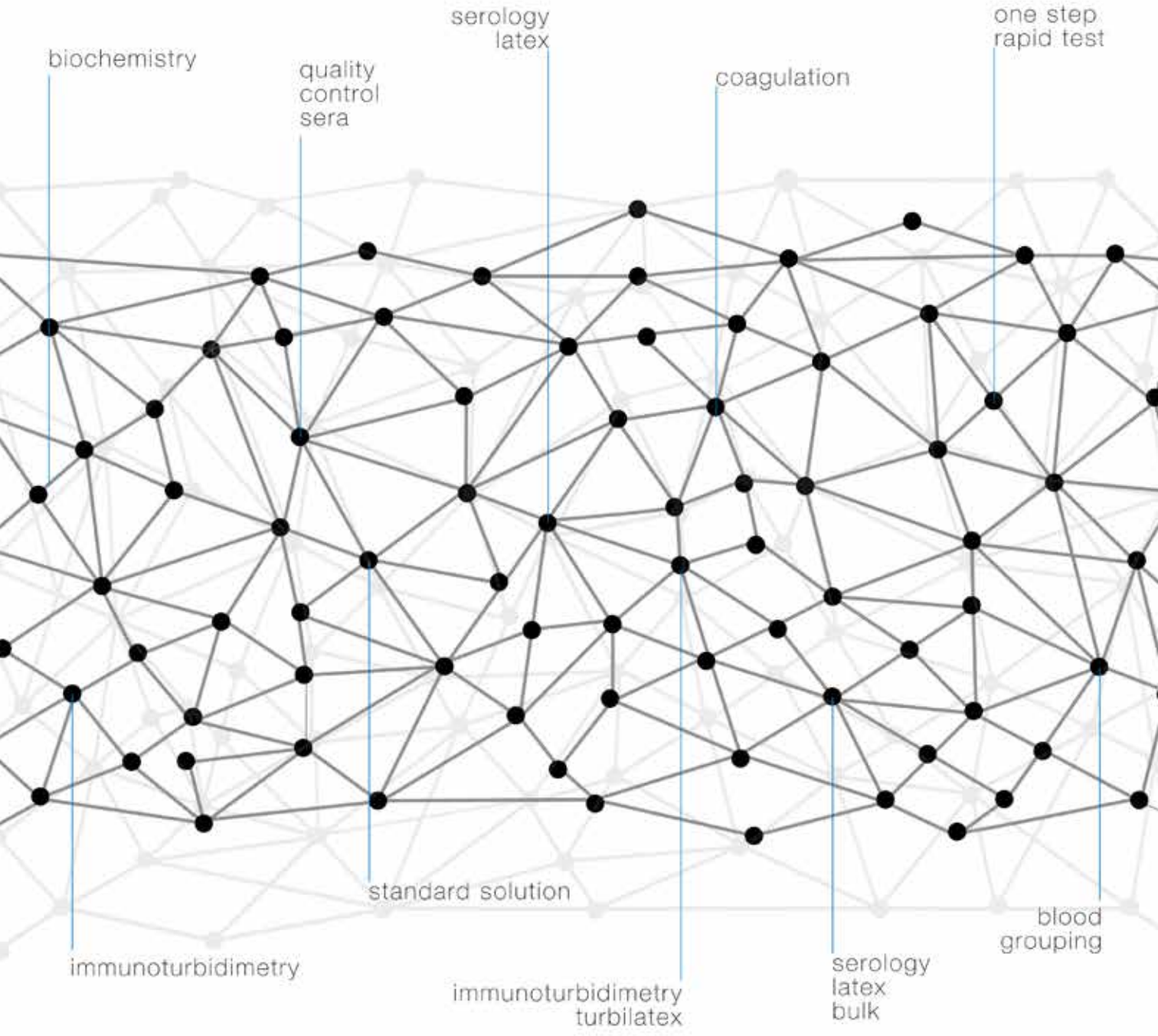
CHRONOLAB

CHRONOLAB SYSTEMS



I need you here...

Taking your HIV medication EVERY DAY can help you be here when I grow up. I heard there's a "Triple Pill" that can make it easier.

Take a Triple a Day.
Every Day.

Ask your Doctor if there is a Triple Pill for YOU.

The 2014 Namibian Guidelines for Antiretroviral Therapy and The World Health Organization recommend Fixed-Dose Combination Therapy
Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, Geneva, World Health Organization, 2013, (http://www.who.int/hiv/pub/guidelines/arv2013/en)

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