

Ruth Butlin reviews the challenges involved in fighting leprosy today

# LEPROSY REVISITED

## key points

- Because leprosy progresses very slowly there is a paucity of data. Individuals often prematurely give up treatment and health professionals are often tempted to move on to seemingly more pressing issues.
- Although leprosy may be an 'idle' disease health professionals should not be idle about confronting it and helping sufferers rebuild their lives.
- Jesus' command to care for the leper has never been rescinded. In God's new creation, leprosy – along with all sickness and suffering – will be no more.

The leprosy bacterium is a lazy micro-organism, not in any hurry to grow or multiply or mutate. It takes about a fortnight to proceed from one cell division to the next, and only manages that when embedded in a living cell of another species (usually a human one). Its genome is rather degenerate, making it dependent on other cells for certain essential metabolic pathways, so one might even consider the bacterium as 'disabled'. Because of its slow growth, in humans the incubation period of leprosy runs into years. In fact because the bacterium is relatively non-toxic, it multiplies up to enormous numbers without making the host unwell (a good strategy for a parasitic organism). Even with a high bacterial load, most clinical manifestations result from host immune responses rather than from direct action of the bacteria or its products. These host responses vary between individuals (determined by genetic factors and prior exposure to other mycobacteria).

Leprosy develops slowly, the insidious onset of signs and symptoms often result in delay in presentation to health services. There seems to be no cause for alarm: a slowly-expanding non-painful non-itching skin patch or a gradual thickening of the skin with coarsening of facial features, thinning of

eyebrows, lumpiness of earlobes. Sadly, it is also common to see delays in diagnosis because the health workers do not immediately recognise the signs of leprosy. Hence by the time a diagnosis is made there may be extensive spread of bacteria in the person's body and immune recognition has become established.

Leprosy epidemics progress slowly, the time scale is quite different from an epidemic of cholera or influenza. Looking at the world-wide situation, there have been waves of leprosy passing over Europe and other parts of the world, the prevalence rising and falling over centuries (unimpeded by chemotherapy or immunisation). The current global 'epidemic' has probably passed its peak (not necessarily as a result of medical interventions), the number of new cases found each year is much less than it was 20-30 years ago. However the trend has recently plateaued: it is no longer falling annually as public health experts had hoped it would. Maybe it is too soon to draw conclusions or extrapolate; predicting the future course of the public health problem is risky when the data is not wholly reliable.

One of the big problems with data on leprosy is that only for a short period (about 1985 to 2005) was it collected routinely, in a detailed consistent

format, in most countries with a large burden of disease. Before that, where there were leprosy control units or clinics people kept adding new patients' names as they were diagnosed and deducted them again only at death, so the data was on 'cumulative prevalence' (how many people in the population had ever had leprosy) then it was gradually switched to registering only 'current cases', deleting those who were 'released from treatment' – and so how long one stayed on the register depended on how long a course of treatment was recommended at that time. The slowly metabolising bacteria only slowly respond to chemotherapy, so courses of treatment have tended to be very long: when only dapsone monotherapy was available courses ranged from three years to lifelong, when multidrug therapy entered the field the shortest course was six months but some patients still had many years of treatment.

So patients with leprosy have to be very patient. They do not see any dramatic change in their signs and symptoms when taking the medicine. In fact when they are told they have 'completed treatment' they may still have the same patches or nodules or madarosis as before. It is a matter of having faith in the health worker's claim that 'the bacteria have been killed' and 'you are not infectious now'. Over the next few months and years their patches may fade away and lumpy thickened (infiltrated) skin return to a normal appearance.

What does not disappear is the structural damage to extremities resulting from injuries to limbs or eyes affected by peripheral nerve damage: the scarring from trophic ulcers...the loss of digits...the neuropathic disintegration of bone in the ankle...the clouding of an exposed cornea unprotected by blinking. These things last a lifetime. Often the disabilities and deformities increase over time.

The WHO tells us<sup>1</sup> that in 2013 there were 215,656 new cases of leprosy reported in the world and amongst them 13,289 had acquired 'Grade 2 disability' before treatment. In the public health arena the proportion of Grade 2 disabled amongst new cases is significant as an indicator of 'late case detection', a health system failure to diagnose these cases earlier. But for the individuals concerned, the significance of Grade 2 disability is its permanence – often it is not only irreversible but progressive. The WHO reports that amongst the new cases 9.2% were under 15 years old at diagnosis. If the children have a similar proportion of Grade 2 disability to the adults, that means that over 1,000 more children with life-long disability due to leprosy were found, in only one year. Every year more are added.

Some of those disabled by leprosy can be helped by reconstructive surgery, such as those who have footdrop or lagophthalmos, but only if they can access one of the few specialist centres offering it. Most could benefit from teaching about self-care and provision of aids such as protective footwear, but only a fraction will have easy access to these things. There are probably at least 2-3 million

people living with residual morbidity due to a past leprosy infection, and these people will be with us for many years to come.

The leprosy bacterium may be an idle creature, but we cannot afford to be idle: we must help these people along with helping people disabled by other diseases or by accidents. The surgeon Jonathan Hutchinson said (over 100 years ago) 'The problem of leprosy is not for the idle-minded. It is full of intricacy and difficulty'.<sup>2</sup> The fact that it is a difficult medical problem is largely the result of its being such a slow-motion disease with long-lasting effects, that any research has to be conducted over long periods of time and does not soon bear fruit, while some health workers lose patience and do not persevere with studying the disease. At the same time many leprosy-affected people, disappointed at their own slow response to treatment, give up hope of recovering from the impact of the disease.

In the face of the ongoing epidemic of disability due to leprosy, several specialist non-governmental organisations are persevering with good work. Notable among them is The Leprosy Mission International, which has just celebrated its 140th anniversary. Its aim as ever is to minister in the name of Christ to meet the needs of individuals and communities affected by leprosy, working with them towards the eradication of the disease.<sup>3</sup> In his instructions to his followers Jesus specifically told them to address the needs of people with leprosy-related problems,<sup>4</sup> and that command has not been rescinded.

Human beings whose bodies have been damaged through leprosy, can be seen as specimens of God's beautiful handiwork which have become marred. Such people still bear the stamp of God's image: their situation can be compared with that of old money. After rough handling in circulation a coin may become worn, chipped, dirty – but even a damaged coin has the same monetary value as a new one. Although the monarch's image imprinted on it has been defaced, a Coin of the Realm still holds its value.

Whereas worldly individuals may discount 'damaged goods' as worthless, and blind evolution sacrifices the weaker members for the good of the race, Christians believe people who have been damaged (by accident, disease, abuse or neglect), should not be thrown out of society, but rather should be helped towards healing of mind and body. It is a Christian's privilege to share in God's work of restoration, anticipating his New Creation where there will be no leprosy bacteria.

**Ruth Butlin** works with *The Leprosy Mission International* which recently celebrated its 140th anniversary.

## fact box

It was Gerhard Henrik Armauer Hansen who in 1873 first described the leprosy bacillus. The expert consensus seems to be that the Bible uses 'leprosy' as an umbrella term for infectious skin disease, but this would have included sufferers from Hansen's disease.

Leprosy is mentioned over 60 times in the Bible. Healing stories about lepers appeal to the Christian imagination and have spurred missionary work among lepers.

The leprosy bacillus destroys nerve endings. When these people cannot sense touch or pain, they are at risk of injuring themselves and may be unaware of injuries. Paul Brand (1914-2003), a missionary doctor of world-renown who worked with leprosy patients, illustrated the value of sensing pain.

Human beings whose bodies have been damaged through leprosy can be seen as specimens of God's beautiful handiwork which have become marred. Such people still bear the stamp of God's image

## references

1. World Health Organisation, weekly epidemiological record, 5 September 2014
2. Quoted in 'For the elimination of leprosy', newsletter of the WHO ambassador for leprosy, published by Sasakawa Foundation
3. [www.leprosymission.org](http://www.leprosymission.org)
4. Matthew 10:8