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EDITORIAL

The prevention of disability as a consequence of leprosy

HUGH CROSS*
**American Leprosy Missions, 1 ALM Way, Greenville, SC 29601, USA*

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Introduction

When an effective method to halt the transmission of leprosy has finally been secured and implemented, we will then have the confidence to proclaim that disability as a sequela of leprosy will be confined to history. Until that ideal has been met we are compelled to concede that people will continue to be disabled by leprosy and that perhaps the optimal objective we can set is that the number of new cases of leprosy with visible impairments will be kept at a low level (< 1:1,000,000 population). We may find that the achievement of that objective will be dependent on commitment no less ardent than that which drove the campaign to eliminate leprosy as a public health problem. Prevention of disability *per se* is unlikely to garner anything like the same level of support that the control of a contagious disease will excite. According to the WHO, public health refers to all organised measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole.[1] Contagion threatens entire populations and therefore falls squarely under the purview of public health. Disability, on the other hand, is an individual issue and does not become a public health issue until such time as a significant section of the population is disabled.

Until the transmission of leprosy has been halted, the most effective measure that can be taken to reduce the occurrence of disability is to ensure the early diagnosis of leprosy and prompt treatment for those infected by it. Current statistics, however, suggest a significant challenge in this regard. They generally appear to show that as leprosy becomes less prevalent, the proportion of new cases with WHO Grade 2 disability rises. Whilst this is salutary it is not surprising; the erosion of diagnostic ability is an almost inevitable consequence of lower case presentations. An important challenge, therefore, is to ensure that as leprosy cases become less common, the ability to detect it early remains competent. There is a pressing need to identify innovative methods for securing early case detections,

Correspondence to: Hugh Cross, American Leprosy Missions, 1 ALM Way, Greenville, SC 29601, USA (e-mail: hcross@leprosy.org)

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particularly in countries that previously reported high prevalence, but where new case detection rates have declined significantly.

In July 2014 a meeting was convened in Delhi. It was attended by ILEP India representatives, representatives of other significant organisations active against leprosy in India, senior government health workers and the Deputy Director General of the Central Leprosy Division. This National Consultation was called so that these concerned parties could discuss innovative approaches to achieve the prevention of disability.

With the integration of leprosy treatment into the general health service in India, there was a perceived need to support health workers' efforts to reduce the burden of leprosy. With that objective, the Disability Prevention and Medical Rehabilitation (DPMR) guidelines were launched in 2007. In 2011 the DPMR guidelines were streamlined so that the quality and coverage of DPMR services could be extended.[2] Although designed to be implemented at all three levels of the Indian Health Service the general consensus at the meeting in 2014 was that whilst the DPMR initiative had resulted in a strong drive to effect greater coverage of reconstructive surgery, other effects had not been as encouraging. An aim of the meeting, and the general recommendation that issued from it, was that the DPMR should be strengthened to be more effective.

There was a strong recommendation from the consultation. It was that greater emphasis on early case detection should be made as this is the frontline intervention to prevent disability. The call *per se* did not resonate innovation, but the details that gave the call greater substance were interesting. The following points were added:

- Education of index cases to enable them to suspect leprosy in contacts.
- Advocacy with office bearers of the Rashtriya Bal Swasthya Karyakram (Government Child Health Programme) with a specific emphasis on attaining and sustaining expertise for early diagnosis and treatment of paediatric cases.
- The mobilisation of children to suspect leprosy could also be achieved through the programme.
- The mobilisation of Accredited Social Health Activists (ASHA) and community volunteers to extend outreach to remote and neglected communities.

A further point was that at every Primary Health Centre (PHC) there should be at least one person with expertise in leprosy. It was also suggested that visual aids, in the form of poster displays, had fallen from use and that efforts to restore such should be made.

Most representatives who presented overviews of their operations laid emphasis on the achievements effected by ASHAs. There was particularly strong support for recommendations that sought to mobilise this cadre of women to greater effect. The value of grass roots health workers and volunteers has also been cited as being a significant factor in other countries where the prevention of disabilities has been relatively strong. In Myanmar the role of midwives who work at the peripheral level of primary health delivery has been pivotal to the success of prevention of disability (POD) in leprosy there.[3] The efforts of general health workers at health centres (peripheral health units) were also considered to be an important consideration in explaining the relative effectiveness of POD in Indonesia.[4]

In both Indonesia and Myanmar another factor given to explain the relative success of POD in those countries was the strategic deployment of specialist leprosy personnel to support general health staff. The activities of those personnel (consultants in Indonesia and Specialist Leprosy Service personnel in Myanmar) were considered crucial for the

effectiveness of POD. The recommendation from ILEP in India that a person with expertise should be deployed at every Indian PHC is, therefore, supported by these reports from Indonesia and Myanmar.

PREVENTING NERVE FUNCTION IMPAIRMENT

After early detection, diagnosis and treatment of leprosy, the primary aim of disability prevention must be to safeguard nerve function.

By 2002, BANDS,[5] AMFES[6] and TRIPOD[7–9] had already greatly added to our understanding of the epidemiology, detection and prevention of nerve impairment and in 2005 results began to be published from the INFIR study which contributed significantly to our understanding of the order and sequence of effects of neuropathology on sensibility and motor function.[10] However, the identification of an ideal treatment to address the threat of nerve function impairment, either as a sequela of frank reaction or of silent neuritis, has yet to be accomplished.

Van Veen *et al.* recently conducted a Cochrane review.[11] The aim of the review was to establish whether there was robust evidence to support the efficacy of corticosteroid treatments as a measure to prevent nerve damage. According to their criteria, three randomized control trials provided reliable outcomes: two were components of the TRIPOD study and the third was conducted more recently by Rao *et al.*[12] The trials, however, were considered too small and heterogeneous to allow for the level of detailed analysis that might have given more compelling conclusions. Van Veen *et al.* did conclude that for the treatment of either long standing nerve function impairment or mild sensory impairment corticosteroids were no more effective than placebo (outcomes from TRIPOD). They also confirmed that the recovery of nerve function impairment appears to be dependent more on the duration and/or severity of impairment before it is treated. However, they also drew a slightly more positive conclusion: claims from other studies that prolonged steroid courses were more efficacious than short courses were supported by the findings from the trial conducted by Rao *et al.* (a short course is considered to be the standard 12 week course). Van Veen *et al.* cautiously concluded that "longer duration of Prednisolone treatment gave less poor outcomes than short course Prednisolone" (p 8).

Schreuder's finding was that 35% of nerve function impairment cases either did not improve or deteriorated and 2 ears later Croft came to a very similar conclusion.[13,14] A more optimistic perspective on these conclusions is that about 60% did improve. That optimism, however, is dampened by the probability that many cases would have improved without Prednisolone anyway.[14] Even though its' efficacy is not optimal, recourse to Prednisolone to treat neuritis remains the only ready option. In a component of the INFIR project, Marlow *et al.* sought an alternative to Prednisolone for the treatment of nerve function impairment. They compared Azathioprine with Prednisolone, but found no benefits of the drug over Prednisolone.[15]

The optimal dosage and duration of Prednisolone treatment remains elusive but that does not mean that the search has stalled. INFIR demonstrated that nerves can demonstrate subclinical damage before NFI is clinically detectable. This finding generated an interesting hypothesis, i.e. that Prednisolone treatment of early sub-clinical NFI can prevent clinical NFI. Support for that hypothesis is currently being pursued through the TENLEP study. TENLEP is also seeking to establish whether Prednisolone treatment of 32 weeks duration is more effective than 20 weeks in restoring nerve function in leprosy patients with clinical NFI.

INTERVENTIONS FOR IRREVERSIBLE IMPAIRMENTS AND DISABILITIES

Self-Care

Self-care is, and will continue to be, the essential component of POD where prevention of nerve impairment cannot be realised.

While there is some evidence of the efficacy of self-care procedures as an intervention to address ulceration, the more complex issues associated with the general impact of self-care have not been extensively researched. Most of the studies that have reported outcomes of self-care were not rigorously designed. They are pre- and post- observations of selected groups that were targeted for intervention. Positive findings from such studies do associate self-care with improvements in ulceration, but analysis is limited by methodological issues. A controlled study conducted in Nepal demonstrated reduced hospital admissions associated with an intensive self-care training programme, but a limitation was that the sampling was not randomised.[16]

The issue of the sustainability of self-care practice has hardly been approached at all. When people apply the mechanics of self-care (rest, soaking, scraping, oiling and exercise) the body is able to repair itself; if not flawlessly, at least optimally. The logic is simple and the required actions are easy, but the sustained application of self-care is subject to a very complex array of health expectations and motivational factors. Unless a concerted effort is undertaken to understand such issues and to remodel our perspectives on health delivery, the objective of sustainable disability prevention through self-care will remain unmet.

There is a continuously growing interest in self-care as an intervention of choice for people living with chronic conditions. This interest was undoubtedly fuelled by the publication of the Innovative Care for Chronic Conditions (ICCC), a model for care promoted by the WHO. The ICCC focuses on the knowledge that the impact of many chronic conditions is determined by the strength of commitment to address them from three groups working in an environment of mutual respect: affected individuals, teams of adequately prepared health workers and informed and activated communities. The model does emphasise a reliance on medical professionals to relinquish control. As consultants, professionals provide advice, guidance and encouragement for people to make the most appropriate choices. Much of the developing world, however, still adheres to an ‘Industrial Age’ model of health delivery. The dominant feature of ‘Industrial Age’ medicine is that control and responsibility, along with the status that these represent, are maintained by health professionals. Physicians and health workers are considered experts who deliver appropriate interventions whilst patients bring nothing to the interaction other than their illness. Whilst this model persists it will be difficult to realise the full potential of self-care.

No conversation on POD can be complete without recognition of the continuing necessity for the provision of specialist services. Where adverse social and environmental issues prevail, the continuous requirement for specialist services to address the issues of complicated ulcers, neurological bone disorganisation, eye impairments and the need for reconstructive surgery will not be abated. These elements of care are essential for preventing the worsening of disabilities, but the prevention of disability truly lies in preventing leprosy *per se*. When leprosy can be prevented, we will be confident that the potentially dehumanising effects of the disease will be confined to history. Until then, however, we must continue to wrestle with the complexities of nerve damage, less than optimal chemotherapy, diminishing expertise, and professional protectionism all of which are further complicated by poverty.

References

[1] World Health Organisation. Trade, foreign policy, diplomacy and health. http://www.who.int/trade/glossary/story076/en/ 2014. Ref Type: Electronic Citation.

[2] Central Leprosy Division. *Disability Prevention and Medical Rehabilitation - Guideines for Primary, Secondary and Tertiary Care*, New Delhi: Directorate General Health Services, Ministry of Health and Family Wellfare, government of India, 2012.

[3] Cross H. The prevention of leprosy related disability as an integral component of the government health delivery programme in Myanmar. *Lepr Rev*, 2012; **83**: 205–217.

[4] Cross H. The prevention of leprosy related disability as an integral component of the government health delivery programme in Indonesia: perspectives on implementation. *Lepr Rev*, 2013; **84**: 219–228.

[5] Croft RP, Richardus JH, Nicholls PG, Smith WC. Nerve function impairment in leprosy: design, methodology, and intake status of a prospective cohort study of 2664 new leprosy cases in Bangladesh (The Bangladesh Acute Nerve Damage Study). *Lepr Rev*, 1999; **70**: 140–159.

[6] Saunderson P, Gebre S, Desta K, Byass P. The ALERT MDT Field Evaluation Study (AMFES): a descriptive study of leprosy in Ethiopia. Patients, methods and baseline characteristics. *Lepr Rev*, 2000; **71**: 273–284.

[7] Richardus JH, Withington SG, Anderson AM *et al.* Treatment with corticosteroids of long-standing nerve function impairment in leprosy: a randomized controlled trial (TRIPOD 3). *Lepr Rev*, 2003; **74**: 311–318.

[8] Smith WC, Anderson AM, Withington SG *et al.* Steroid prophylaxis for prevention of nerve function impairment in leprosy: randomised placebo controlled trial (TRIPOD 1). *BMJ*, 2004; **328**: 1459.

[9] van Brakel WH, Anderson AM, Withington SG *et al.* The prognostic importance of detecting mild sensory impairment in leprosy: a randomized controlled trial (TRIPOD 2). *Lepr Rev*, 2003; **74**: 300–310.

[10] van Brakel WH, Nicholls PG, Das L *et al.* The INFIR Cohort Study: investigating prediction, detection and pathogenesis of neuropathy and reactions in leprosy. Methods and baseline results of a cohort of multibacillary leprosy patients in north India. *Lepr Rev*, 2005; **76**: 14–34.

[11] Van Veen NH, Nicholls PG, Smith WC, Richardus JH. Corticosteroids for treating nerve damage in leprosy. A Cochrane review. *Lepr Rev*, 2008; **79**: 361–371.

[12] Rao PS, Sugamaran DS, Richard J, Smith WC. Multi-centre, double blind, randomized trial of three steroid regimens in the treatment of type-1 reactions in leprosy. *Lepr Rev*, 2006; **77**: 25–33.

[13] Schreuder PA. The occurrence of reactions and impairments in leprosy: experience in the leprosy control program of three provinces in northeastern Thailand, 1987-1995 [correction of 1978-1995]. III. Neural and other impairments. *Int J Lepr Other Mycobact Dis*, 1998; **66**: 170–181.

[14] Croft RP, Nicholls PG, Richardus JH, Smith WC. The treatment of acute nerve function impairment in leprosy: results from a prospective cohort study in Bangladesh. *Lepr Rev*, 2000; **71**: 154–168.

[15] Marlowe SN, Hawksworth RA, Butlin CR *et al.* Clinical outcomes in a randomized controlled study comparing azathioprine and prednisolone versus prednisolone alone in the treatment of severe leprosy type 1 reactions in Nepal. *Trans. R. Soc. Trop. Med Hyg.*, 2004; **98**: 602–609.

[16] Cross H, Newcombe L. An intensive self care training programme reduces admissions for the treatment of plantar ulcers. *Lepr Rev*, 2001; **72**: 276–284.