

Disability and Leprosy: The Way Forward

Wim H. van Brakel,¹MD, MSc, PhD

Introduction

Leprosy is one of the major causes of preventable disability, including impairments, problems in activities of daily life and social exclusion resulting from stigma.¹⁻³ Progress in dealing with these consequences of leprosy has not nearly been as successful as the progress in the anti-bacterial treatment of the disease. There continues to be a large backlog of people with leprosy-related disability who are in need of disability prevention services and/or rehabilitation. Therefore, programmes and services dealing with leprosy will continue to need input from research to inform policy and management, and to improve coverage of services and the quality and quantity of the tools and procedures available for prevention and rehabilitation.

Current Developments Relevant to Leprosy-related Disability

When considering research priorities, a number of developments are relevant for future disability research in leprosy.

1. Besides early detection and treatment of leprosy itself, prevention of disability (POD) consists of 2 main specific components, early detection and treatment of reactions and nerve damage in and by the health services, and home-based self-care activities, usually taught by health workers, but carried out by the affected persons themselves.^{4,5} In the new World Health Organisation (WHO) Global Strategy for Leprosy Control, POD has been given a much more prominent place.⁶ Members of the International Federation of anti-Leprosy Associations (ILEP) have gradually increased attention and resources for the various aspects of POD.
2. On 13 December 2006, The United Nations General Assembly adopted a new Convention on the Rights of Persons with Disability. This document should become a powerful tool in the struggle for more attention for the needs of many people with disability, included those affected by leprosy. It is likely that the Convention will help to generate more funds for disability research to inform policy and advocacy, among other things. In addition, WHO is working on new Global Guidelines for CBR, which are expected to give a new impetus to this field. WHO is also working to produce a World Report on Disability, in which data on leprosy-related disability are to be included.
3. The WHO, several national leprosy programmes and many ILEP partners have realised that POD and physical rehabilitation are not sufficient for many people who suffer the long-term consequences of leprosy.⁷ Socio-economic rehabilitation can play a major role in improving quality of life, social integration and even in reducing leprosy-related stigma.⁸ Strong interest in community-based rehabilitation (CBR) is developing, along with a desire that people with leprosy-related disability should receive rehabilitation assistance in the context of general rehabilitation programmes. Not infrequently, however, stigma is a reason why people with leprosy-related disability are not receiving services in general CBR programmes.
4. Despite effective leprosy treatment, massive public health education campaigns, the resulting increased awareness of leprosy, and integration of leprosy work into the general health services, leprosy-related stigma is still a major issue affecting social participation of those concerned.^{9,10} In some countries or areas, stigma has lessened compared to the past, but is still strong enough to affect people's lives.^{11,12} Often stigma has changed in nature: it has moved from enacted to perceived stigma – fear of what might happen as a result of having leprosy.¹² Many (former) patients have internalised stigma and live life feeling inferior, ashamed and unworthy.¹³ Continued stigma among health personnel is an issue of particular concern. It has become clear that knowledge and awareness-raising in itself are not enough to dispel stigma and discrimination.¹⁴
5. Immunological reactions are the main cause of nerve damage, which in turn is the main risk factor for long-term disability in leprosy. Our understanding of mechanism of reactions has improved somewhat, but details are still elusive. New risk factors have been discovered, but it remains impossible to predict reactions or nerve damage with any accuracy in individual patients.^{15,16} Recent discoveries from prospective studies

¹ Royal Tropical Institute, Leprosy Unit, Amsterdam, Netherlands

Address for Correspondence: Dr Wim H. van Brakel, Royal Tropical Institute, Leprosy Unit, Amsterdam, Netherlands.

Email: w.v.brakel@kit.nl

may open up new avenues for early detection and treatment of neuropathy.¹⁷⁻¹⁹

Current Research Priorities Related to Disability

From the above a number of key research areas can be identified. These have been arranged roughly according to the amount of research currently addressing each area, starting with those receiving least attention.

1. Community-based Rehabilitation

Many tens, if not hundreds of thousands of people affected by leprosy may be in need of rehabilitation services, but only few have access to such services. However, data are lacking. Prevalence estimates of various types of disabilities and related rehabilitation needs are urgently required. Evidence is needed urgently of the effectiveness and cost-effectiveness of various CBR strategies. Particularly, the effectiveness of self-care and rehabilitation of people affected by leprosy in a general CBR setting should be studied.

2. Stigma and Discrimination

Despite the fact that stigma plays such a major role in leprosy, very little research has been done on this issue. Data are needed on types and severity of stigma. Improved understanding of the determinants and dynamics of stigma in different cultural settings will help greatly to develop effective interventions. Efficacy and cost-effectiveness of stigma reduction interventions needs to be measured. Much progress has been made in work on stigma reduction and also assessment in other fields of public health, such as mental health and HIV/AIDS. The lessons learnt and tools developed need to be tested and applied in the field of leprosy also.

3. Prevention of Disabilities

Effective techniques for POD have now been well established. However, a number of major operational problems remain to be overcome for effective wide-spread application can be realised. Operational research to address coverage and access to basic POD measures, such as self-care training and footwear, were identified as a top research priority for the coming years at the recent Consensus Development Conference in Cebu, Philippines (September 2006). Other questions include: How effective is vocational training in preventing new or additional disability in people with nerve damage? What is the cost-effectiveness of various alternative POD strategies?

4. Reactions and Nerve Damage

Given that reactions and neuropathy are still the leading cause of disability in leprosy, this area remains a top priority. A better and more specific understanding is needed of mechanisms and risk factors. The prognostic value of

early detection of sensory neuropathy using nerve conduction and thermal sensation measurements should be evaluated. The efficacy of alternative drug treatments of Type 1 and Type 2 reactions may improve prognosis and reduce the risks inherent in long-term steroid treatment.

REFERENCES

1. Srinivasan H. Disability and rehabilitation in leprosy: issues and challenges. *Ind J Lepr* 2000;72:317-37.
2. Nicholls PG, Bakirtziev Z, van Brakel WH, Das-Pattanaya RK, Raju MS, Norman G, et al. Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk. *Lepr Rev* 2005;76:305-15.
3. van Brakel WH. Peripheral neuropathy in leprosy and its consequences. *Lepr Rev* 2000;71(Suppl):S146-S153.
4. Watson JM. Disability control in a leprosy control programme. *Lepr Rev* 1989;60:169-77.
5. ILA TF. Report of the International Leprosy Association Technical Forum. Paris, France, 22-28 February 2002. *International Journal of Leprosy and Other Mycobacterial Diseases* 2002;70[1 (Suppl)]:S3-S62.
6. WHO. Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010. Geneva: WHO/CDS/CPE/CEE/2005.53, 2005.
7. WHO. Global Strategy for further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (2006-2010) – Operational Guidelines. New Delhi: WHO, 2006.
8. Cross H, Choudhary R. STEP: an intervention to address the issue of stigma related to leprosy in Southern Nepal. *Lepr Rev* 2005;76:316-24.
9. Heijnders ML. The dynamics of stigma in leprosy. *Int J Lepr* 2004;72:437-47.
10. van Brakel WH. Measuring leprosy stigma – a preliminary review of the leprosy literature. *Int J Lepr* 2003;71:190-7.
11. Croft RP, Croft RA. Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh. *Lepr Rev* 1999;70:34-42.
12. Nicholls PG, Chhina N, Bro AK, Barkataki P, Kumar R, Withington SG, et al. Factors contributing to delay in diagnosis and start of treatment of leprosy: analysis of help-seeking narratives in northern Bangladesh and in West Bengal, India. *Lepr Rev* 2005;76:35-47.
13. Tsutsumi A, Izutsu T, Akramul I, Amed JU, Nakahara S, Takagi F, et al. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. *Lepr Rev* 2004;75:57-66.
14. Heijnders M, van der Meij S. The fight against stigma: an overview of stigma reduction strategies and interventions. *Psychol Health Med* 2006;11:353-63.
15. Croft RP, Nicholls PG, Steyerberg EW, Richardus JH, Cairns W, Smith S. A clinical prediction rule for nerve-function impairment in leprosy patients. *Lancet* 2000;355:1603-6.
16. Saunderson P, Gebre S, Desta K, Byass P, Lockwood DN. The pattern of leprosy-related neuropathy in the AMFES patients in Ethiopia: definitions, incidence, risk factors and outcome. *Lepr Rev* 2000;71:285-308.
17. Smith WC, Anderson AM, Withington SG, van Brakel WH, Croft RP, Nicholls PG, et al. Steroid prophylaxis for prevention of nerve function impairment in leprosy: randomised placebo controlled trial (TRIPOD 1). *BMJ* 2004;328:1459.
18. Anderson AM, van Brakel WH, Withington SG, Croft RP, Nicholls PG, Richardus JH, et al. Prophylactic steroids to prevent nerve function impairment in leprosy: a randomised controlled trial (TRIPOD 1). *Int J Lepr Other Mycobacterial Dis* 2002;70:11A.
19. van Brakel WH, Nicholls PG, Das L, Barkataki P, Suneetha SK, Jadhav RS, 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.