

SPECIAL ARTICLE

Prevention of disability in leprosy—ILEP Medical Bulletin

A survey of the prevention of disability policy and activities in a random sample of 200 ILEP assisted projects was conducted in 1995. This was followed by a workshop of field experts in different aspects of prevention of disability who work in different geographical regions. The survey findings and state of current knowledge on prevention of disability were reviewed during the workshop and recommendations on the planning, implementation and evaluation of simple and effective prevention of disability developed. Prevention of disability includes complex activities, such as nerve decompression and reconstructive surgery, however these recommendations focus on the simple techniques and approaches which can be implemented through leprosy control programmes, primary health care and community-based rehabilitation. These recommendations have been approved by the ILEP Medical Commission.

On behalf of the ILEP Medical Commission
Department of Public Health
University of Aberdeen
Foresterhill, Aberdeen AB9 2ZD
Scotland

W. C. S. SMITH

1 INTRODUCTION

The overall aim of leprosy control programmes is to prevent disabilities. Now is a unique opportunity to implement specific disability prevention activities as a result of the successful implementation of MDT. Stigma is reducing and the hand over to integrated programmes allows the possibility of prevention of disability (POD) being introduced at a primary care level.

The ILEP Medical Commission produced a set of guidelines for Prevention of Disability in Leprosy Control Programmes in 1993.¹ The purpose of the guidelines was to motivate managers of leprosy control programmes to establish adequate prevention of disability activities. ILEP does not routinely collect information on disability except the percentage with grade 2 disability at detection, and neither ILEP nor WHO collect routine data on prevention of disability activities. Thus there is no information readily available on what is going on in this area.

This Bulletin is aimed at ILEP Member-Associations and at leprosy programme managers.

2 REVIEW OF PREVENTION OF DISABILITY

The ILEP Medical Commission undertook a survey of a random sample of 200 ILEP supported leprosy control programmes to determine to what extent prevention of disability (POD) activities were being carried out and what, if any, difficulties and successes were being experienced. This survey was conducted between April and September 1995 and included projects supported by 9 different associations in Africa, the Americas, and Asia. The survey received a response rate of over 60% and included small and large projects which were a mixture of vertical and integrated programmes in 25 countries. The projects surveyed represented over 50,000 new patients, over 135,000 registered patients, and over 330,000 cases who had completed chemotherapy.

A workshop of experts in POD was held in London in October to review the findings of the survey, consider the latest disability data from ILEP and WHO, and to provide advice to ILEP members on the planning, implementation and evaluation of simple and effective prevention of disability. The workshop also considered the need for indicators for POD and their routine collection on an annual basis as an ILEP questionnaire. The ILEP and WHO data on impairments are broadly similar with 7–9% of newly-detected cases having WHO grade 2 disability, however this varies considerably between projects (0–79%). These data on impairments at detection can be used to give a rough estimate of the size of the impairment problem globally, however more detailed and different information is required for programme planning.

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) defines these terms as follows:

Impairment is any loss or abnormality of psychological, physiological or anatomical structure or function, *Disability* is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being, and *Handicap* is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role, depending on age, sex, and social and cultural factors, for that individual.² Deformity is a visually recognized impairment.

POD in leprosy includes activities to prevent impairment, reverse impairment, prevent increase in impairment, and prevent impairments becoming disabilities. This approach will lead to prevention of disabilities and handicaps. Rehabilitation focuses on the prevention, management and reversal of disability and handicap.

It should be noted that some of the benefits of POD are only seen after a number of years of consistent implementation. POD should not always be expected to give instant results, however any prevention or reduction of impairments will be of profound benefit to individuals and on the need for potentially expensive rehabilitation in the future.

Leprosy control programmes should work with and support the developments in Community-Based Rehabilitation (CBR) as it will provide an important potential for POD in the future. The current development of CBR is not at a stage to take responsibility for all people disabled through leprosy but it is important that those affected by leprosy are included in CBR programmes.

3 MAJOR SURVEY FINDINGS

— in 1995 there is evidence that the implementation of POD activities is now

widespread with 95% of projects surveyed reporting that POD activities are included in the organization of their leprosy control work.

- POD activities are being carried out in both vertical and integrated programmes.
- 39% of projects did not have written guidelines for POD, 99% use the WHO disability grading and 79% also have their own individual patient form for recording impairments.
- nearly all projects are using steroids to treat recent nerve damage and more than 90% treat such patients in the community rather than in hospital.
- 94% of projects train patients in self-care and almost 90% give advice on appropriate footwear.
- less than 60% of projects surveyed had a copy of the ILEP POD Guidelines.
- the survey provided detailed information about the difficulties of POD including problems in training, in assessment and recording of impairments, compliance with self-care and problems in providing a footwear programme including the issue of regular repairs.
- the survey showed that although the implementation of POD activities has begun, much more effort is needed to improve the coverage and the quality of the work.

4 RECOMMENDATIONS FOR SIMPLE, EFFECTIVE POD

A RECOMMENDATIONS ON THE ORGANIZATION OF POD

- 1 All projects should have **written local guidelines for POD**. The ILEP POD Guidelines, which are currently being reviewed, should be used as a source document for the development of local guidelines.
- 2 It is recommended that ILEP Member-Associations review the distribution of their publications and the need to re-issue key recommendations given that less than 60% of ILEP supported projects report having a copy of the ILEP POD guidelines published in 1993.
- 3 POD activities can and should be **carried out by all field staff**, but effective POD is, to a great extent, dependent on the active participation of patients. (Although therapists often facilitate the implementation of POD, they are not essential.)
- 4 Supervision of POD activities should be given a **high priority** by leprosy programme managers. The detailed supervision required is described in the Guidelines.

B RECOMMENDATIONS FOR THE EARLY DETECTION OF LEPROSY

- 5 Early case detection (before impairments develop) should be given a **high priority** in leprosy control programmes. Both programme and patient causes of delay in detection should be examined.
- 6 Leprosy must be included in the curriculum of all health workers to increase awareness and early diagnosis of leprosy. Present curricula should be reviewed and action taken to ensure that leprosy is always included.

C RECOMMENDATIONS FOR ASSESSMENT AND RECORDING

- 7 The assessment, recording, and reporting of impairments must be related to actions to prevent or treat impairments.

- 8 Sensory and voluntary motor function should be assessed at detection and ideally monthly, but not less than 3 monthly during MDT, however the methods used for these assessments will depend on the local staffing and circumstances. Both ball-point pen and filaments can provide good results for sensory testing, however, the technique of testing is more important than what instrument is used.

D RECOMMENDATIONS FOR RECENT NERVE DAMAGE

- 9 All patients must be made aware of the possibility of sudden nerve function loss and acute eye problems, and the need to report promptly for treatment.
- 10 Patients with recent nerve function loss should be treated in the community with fixed courses of steroids. (The availability of steroids is important and the use of blister packs to improve distribution of steroids and compliance with treatment should be considered.)

E RECOMMENDATION FOR SELF-CARE (EYE, HAND AND FOOT)

- 11 Self-care is the responsibility of the patient, but health workers have the responsibility to educate and enable patients in self-care. Health workers need flexibility and skills in listening and problem solving. Locally adapted booklets may be used to help patients learn and to re-enforce training.

F RECOMMENDATION FOR FOOTWEAR

- 12 The use of cushioned insole footwear should be advocated as it is effective in preventing the occurrence and recurrence of plantar ulcers. Issues such as cost, acceptability, availability, distribution, durability, repairs, and effectiveness need to be addressed locally.

G RECOMMENDATIONS FOR MONITORING AND EVALUATION

- 13 The POD aspects of leprosy control programmes should be monitored internally by the programme staff.
(Monitoring should include the early case detection of leprosy patients using WHO grade 1 and 2 at detection as an indicator; the early detection and treatment of recent nerve function impairment by comparing impairment at detection with that at RFT in cohorts of patients; self-care and footwear programmes using vision, bone loss and wound counts as indicators and qualitative assessment of POD using patient interviews.)
- 14 It is recommended that ILEP develop indicators for both the process and outcome of POD activities.

H RECOMMENDATIONS FOR POD RESEARCH

- 15 There are many research needs identified in the field of POD, such as the development of better methods of nerve function assessment, prevention and early detection of nerve damage and its effective treatment, and the improved

effectiveness of self-care and footwear. Many of these can be undertaken by simple studies under field conditions, while others may require more complex study designs and multicentre approaches.

There is a need to develop indicators of POD activities based on change in impairments in cohorts of patients. These should be piloted before being included in routine reporting systems such as the ILEP B form.

References

- ¹ Prevention of Disability: Guidelines for Leprosy Control Programmes. **ILEP Medical Commission 1993 (being revised).**
- ² International Classification of Impairments, Disabilities, and Handicaps. **WHO Geneva, 1980.**

ILEP is a Federation of autonomous anti-leprosy Associations. The advice contained in this publication is not binding on ILEP Members.

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