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Alternative approaches for the prevention of disability in leprosy

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Summary Cost-effective programmes for the prevention of disabilities in leprosy require active involvement of the patients and their families as well as an integrated team approach. This paper presents the views and recommendations of a group of 35 experienced leprologists who met at a workshop, reviewed the current scenario and worked out specific objectives, strategies and the reorganization required in the existing infrastructure. Three tiers of workers are suggested: village volunteer; paramedical worker; and the professionals at the base hospital. All three levels should work together at the start of a programme as well as for periodic monitoring and evaluation.

Introduction

Nerve damage in leprosy leading to deformities and disabilities is mainly responsible for the prejudice against leprosy. The effects of these deformities in terms of disability as well as stigma causes great concern among patients who are affected and generates a sense of fear in the minds of general public.[1] Social displacement, vocational loss and destitution perpetuate the above situation.[2] Thus apart from being a medical and a public health problem, leprosy poses issues relating to the social aspects of the patient.

Early diagnosis and early treatment is still the best strategy to primarily prevent the onset of nerve damage and thereby prevent disability. However in many cases the situation is already advanced to the state of established nerve damage and hence the need for other input to prevent the progress of established physical deformities and to protect the individual from suffering social and vocational disadvantages.[3]

At present few leprosy control programmes are structured to carry out disability prevention. This aspect of leprosy urgently needs to be addressed. The programmes should also be designed to cover the multifaceted nature of disabilities in leprosy as described above.

A group of 35 leprologists and related professionals working to prevent disability in leprosy met at the Schieffelin Leprosy Research and Training Centre, Karigiri in June 1996 to discuss how best to give the much needed thrust for disability prevention to be given a multidimensional approach. The main objectives of this workshop were to develop a

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prevention of disability programme from its very basic issues, to identify lacunae relating to disability prevention in the existing leprosy programmes, and to suggest new strategies for effective implementation of a programme addressing all components of disability in a multidisciplinary, practical team-oriented approach.

The workshop consisted of group discussion around a set of structured questions followed by a presentation and discussion of each group's findings in a plenary session.

Terminology

The terminology decided by rehabilitation technologists (WHO) which includes impairment, disability and handicap was accepted by all the participants.[4]

Evolution of disabilities

Tissue impairments in leprosy lead to physical disabilities which in turn place the patient at social, vocational and psychological disadvantages. Even though physical impairment is the starting point of other disabilities, there is no established pattern of evolution of disabilities. This would largely depend on the patient's socioeconomic status and literacy. The various disabilities due to leprosy can be linked together but it is difficult to prioritize them.

Existing situation in disability prevention

PRIORITY

At present, many leprosy programmes do recognize the importance of disability prevention and are making efforts to incorporate prevention of disability policies, objectives and strategies outlined in booklets such as ILEP's *Prevention of Disability Guideline* and WHO's *Guide to Eliminating Leprosy as a Public Health Problem.* All leprosy programmes will be required to incorporate prevention of disability (POD) activities.

PARAMEDICAL WORKER

At present the paramedical workers' efforts are mainly focused on drug delivery. In some centres paramedical workers are being sensitized to the need for POD activities in the field in addition to drug delivery.

EARLY RELEASE OF PATIENTS FROM CONTROL

Multidrug therapy (MDT) is very effective in rendering the patients disease free in a short time. Coupled with early diagnosis, MDT is one of the effective tools to prevent disability. However MDT does not help the cause of disability prevention because patients are released earlier from treatment and surveillance after MDT, and it will not be possible to monitor these patients for disability prevention over a longer period, especially those with established impairments.

'EDUCATION' COMPONENT OF MDT

The education component of the 'survey, education and treatment' mandate of the MDT programme has also been restricted mainly to the mere transfer of knowledge, which may or may not result in the much needed behaviour change.

TOTAL CARE OF PATIENT

While the health team stresses self-care activities as a priority for patients, patients' more pressing needs may be social or economical or a combination. There is a need to look at the total care of the patient rather than just be concerned about the physical aspects. This is especially true because we believe that leprosy is not only a medical and a public health problem but a human problem affecting relationships in the families and societies.

COORDINATION OF EFFORTS

At some large centres there are various professionals working to prevent disability in leprosy, such as doctors, physiotherapists, social workers. These professionals have a tendency to work individually, seeing disability problems through the eyes of their own profession and this has not helped the cause of the total care of the leprosy patient.

STANDARDIZATION

Standardized methods of impairment assessment and recording are in practice in many centres and other centres should be encouraged to follow.

PARTICIPATORY APPROACH

The main approach has been nonparticipatory with the health team holding the knowledge and technology instead of including the patient and making him responsible for his care. The programmes also have a mass approach to the problem rather than an individualized/ personalized care.

MOTIVATION

There is lack of motivation for prevention of disability in both the patient and the health team personnel. Family support for preventing disability is often lacking.

Suggested changes in the present programmes

HEALTH SYSTEM

Encourage the reorganization of the control programmes from state level downwards; and as a priority to implement the prevention of disability activities.

Standardize procedures, monitoring and records so that there is uniformity and direction to the programmes.

Involve the voluntary and the nongovernmental sector in the prevention of disability.

Enhancing mobile services to seek out patients requiring disability prevention.

HEALTH TEAM

Adopt a multidisciplinary approach in addressing all the disability issues of a leprosy patient. Encourage a team-oriented approach.

Include the patient and his family in the programme so that they are participating.

Let the care be for the individual rather than the group.

Retrain all the staff, and particularly those who can be identified as working specifically for disability prevention.

To concentrate on both high risk groups and on the younger age groups.

PATIENT/HIS FAMILY/COMMUNITY

Get patients to accept responsibility for their own care in preventing disability by empowering them with required knowledge and skills.

Motivate them to have a positive outlook towards leprosy and their life.

With the above suggested changes a broad goal for the prevention of disabilities and a set of objectives were worked out.

Main goal for prevention of disability

The goal of prevention of disability programme in leprosy would be to prevent development of impairments, to correct or halt progress of established impairments so that they do not develop into disabilities and to address any disadvantages (handicaps) that may have arisen because of impairments or disabilities, thereby helping the integration of the patient into the society psychologically, vocationally, socially and functionally.

Specific goals

To prevent the onset of impairments in leprosy patients by early case detection, early diagnosis and treatment of neuritis.

To correct established impairments whenever possible, limit their progress and prevent secondary complications.

To motivate the patient to face the disease and its possible consequences in a positive state of mind and to avoid psychological disturbances.

To help the patient to be accepted socially in his own family and in the community.

To help the patient to be employable by training or by helping to change their vocation.

To make provisions for the patients who are physically and economically dependent.

Reorganization and constraints in implementation

The present infrastructure is sufficient to be able to incorporate the changes suggested and to be able to implement the set objectives. Since MDT has reduced the workload on the village-level health worker, it was felt that he could be trained to implement disability prevention activities. Redeployment and redefining jobs may be necessary. The mobility of the village worker also needs to be increased by provision, e.g. of a bicycle.

Since the programme is going to be participatory, it was felt that a volunteer from the village could be selected and trained and be given the responsibility of disability prevention in his village.

As for psychological, social and vocational aspects it was decided that the volunteer from the village can be trained in the basic aspects of identifying problems. These problems then can be referred to professionals based at the base hospital or main centres for appropriate action.

So the programme will have three tiers of POD workers. The first level being the village volunteer, the second level being the paramedical worker and the third level, the professionals at the base hospital. However it will be necessary for all three levels to work together at the beginning of the programme and for monitoring and evaluation from time to time.

Conclusions

Being a multifaceted disease leprosy needs a multidisciplinary approach. Prevention of disability involves more than one aspect and more than one professional, so for effective implementation of the programme a team approach is needed. Since the success of the programme depends mostly on the patient the programme should be participatory with the patient and his family taking responsibility for preventing disability. Finally the programme should be aimed at an individual level rather than a group.

References

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