

WORKSHOP 8: PREVENTION AND MANAGEMENT OF IMPAIRMENT IN LEPROSY

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Great strides have been made in the chemotherapy of leprosy but despite adequate treatment, including multidrug therapy (MDT), patients continue to develop incapacities. Limited and unreliable information is available about the disability pattern in this new group of patients either active or discharged from treatment. Where leprosy is common, it is identified as deformity and disability by the public. The failure of control programs to master the problem of deformity is seen by the public as failure to cure the disease. Discharge of patients from the register of MDT removes the stigma of deformity only from statistics. It remains and accumulates in the sight of the public and of new patients who need treatment. Only if disability is controlled will leprosy control programs win and maintain the confidence that is essential to success.

Treating and preventing disability should be an integral part of any control program. We also strongly support the long-term follow up of patients released from MDT programs in regard to appearance or worsening of disabilities in spite of "bacterial cure." Regular testing should include accurate measurement of nerve function in the eyes, hands and feet and recording of other disabling or stigmatizing physical signs in the face such as nose collapse and loss of eyebrows. Every effort should be made at this stage to ensure that treatment and preventive measures are available to the disabled patients who are no longer on the active register.

Training of personnel working in leprosy but, specifically, in the areas of prevention

and rehabilitation is of utmost importance. Too big a gap continues to exist between available knowledge and implementation. For this we need support and funding. Education in rehabilitation and prevention should start at the top with health care and government officials and administrators, and also reach the heart of medical schools and allied health training centers. The well-known training centers should be better supported, and probably a few secondary ones developed. Cooperation and communication among the major training centers should be stimulated. More time devoted to presentations on disability, rehabilitation, and prevention should be made available at leprosy congresses.

In spite of past efforts in education and training, there is still stigma in the disease, even among health care personnel, and we should continue on all fronts in our education program. No special status or financial benefits (such as automatic pensions) should be given to the patient solely on the basis of the diagnosis of leprosy. Doing so only adds to the problems already present in trying to rehabilitate these patients, especially in the social and vocational areas.

There is a need for a more workable disability grading system for control programs. We recommend that the modified grading system presented at the March 1987 WHO Consultation on Disability Prevention and Rehabilitation in Geneva be implemented. This grading system only uses grades 0, 1, and 2, eliminating the existing confusion about grades 2 and 3. We would like to suggest that the term anesthesia should be replaced by an objective measurement rep-

resenting protective sensation. However, specifically for control, prevention and management of disability we need more detailed testing systems. Control program records should have provision for initial and follow-up nerve function examination. It is recommended that a range of filaments be used to identify levels of normal, diminished, and lost protective sensation. Since successful treatment of peripheral nerve impairment requires the early recognition of changes in nerve function, this will allow treatment for the nerve before the damage becomes irreversible. Only regular and accurate testing of nerve function will alert us in cases of nerve impairment without symptoms. The role that physical and occupational therapists could have in all of these areas needs to be stressed.

A program treating and preventing disability successfully, as a back-up to the control team, will give credibility to that control program. Foot care, in particular, is an aspect of treatment that patients notice and it can help to promote compliance and confidence in the program.

The loss of sight is the most devastating disability in leprosy because it most often is associated with loss of sensation in hands and feet. Basic screening of eye function and status is easy and quickly done. Every leprosy worker, at all levels, should be trained

in the basic examination of the eye. Every patient has to have an eye examination initially, and all multibacillary patients should have an eye examination at regular intervals. Routine prevention and treatment is possible in the vast majority of cases by specially trained paramedical workers. Medical officers can be adequately trained to deal with the more complex problems and supervise the eye program by training in special centers.

We would like to emphasize again that leprosy is not a disease of just the skin, but also of the nerves and that it produces social, emotional and physical disabilities. These can be prevented in many cases by appropriate measures at the appropriate time. When already established, rehabilitation is more difficult, but these cases must also be treated. No patient should be denied his right to these modalities of treatment, but he also must be made an active and responsible participant in his treatment and prevention program. Many patients can be taught to recognize "reportable events" like changes in eye, sensory or motor function, and nerve pain, and look for help as indicated, but monitoring is still necessary in most cases because many patients are not aware of ongoing changes, as in the "silent neuritis."