

COMMITTEE 8: REHABILITATION

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We must begin by pointing out an anomaly in the use of the term "rehabilitation" in relation to leprosy treatment. By tradition all those aspects of patient care which relate to the prevention of physical disability have been grouped under "rehabilitation" along with corrective surgery and other definitive rehabilitation technics, managed by a surgeon and his staff, while the treatment of the disease itself has been managed by specialists in leprosy control. The result has often been that when a rehabilitation team is not available, the physician in charge of the control project has felt that technics related to the management of disabilities are not considered to be his responsibility. Thus patients are deprived of aspects of *primary patient care* which might have saved them from progressive crippling deformity and social, economic, psychological and vocational disability.

We wish to emphasize that the special technics that have been developed to prevent physical disability are absolutely basic to the medical care of every patient who has suffered peripheral nerve damage, whether or not a definitive rehabilitation team is available. Appropriate technics can be carried out without expensive equipment or specialized personnel. The essentials are extra time spent by the auxiliaries on each patient and additional expenditure on such devices as protective and therapeutic footwear.

The extra cost is compensated for by the improved cost-effectiveness that results from better attendance of the patients who will recognize that trophic ulcers are healed and that felt needs met, beyond which personal experience and that of their neighbors teaches it could not be accomplished by medication alone.

Conversely, the ultimate cost of caring

for the totally disabled patient whose disability has not been prevented, is many times more than the very small amount saved by withholding the care which should have *prevented* the disabilities. That the public and governments are deeply conscious of the burden of this cost of caring for the totally disabled is demonstrated by the large sums of money collected and provided for their care whether in or out of institutions as compared to the amount budgeted for the control of the disease. Moreover the continuing accumulation of newly disabled patients from among the ranks of patients treated in mass campaigns is regarded by new patients as evidence of failure of control programs. Failing to care for the patient as an individual becomes a valid reason for discontinuing treatment.

To ensure that staff, responsible for control of leprosy, assumes full responsibility for technics of disability prevention, it is essential that a new dialogue be instituted between physicians in charge of control programs and those specialists in rehabilitation who have been mainly concerned with the problems of disability. It is not sufficient to state that the responsibility must be transferred; there is a great deal of experience that needs to be communicated and every opportunity for such communication must be taken advantage of.

The total care of leprosy patients may thus be considered under the following headings:

1. *Primary patient care.* The large majority of patients need no other care than this, and prevention of disability should be carried out by all staff of the leprosy control program.

2. *Rehabilitation.* Patients with substantial, established disability require a planned program to restore maximum ability to function as self-respecting and respected persons. Frequently vocational training and counseling is required to discover means of self-support consistent with their residual abilities. Many of these activities require specialized trained personnel.

3. *Social welfare.* Given relatively limited resources, it is not feasible to attempt rehabilitation of all disabled patients. For the totally disabled it must be accepted that permanent provision for their care be made, consistent with human dignity and

decency. In principle, the creation of segregated facilities for whatever reasons for patients whose disabilities arise from a particular disease such as leprosy must be deprecated. Such facilities may have served a useful function in the past but their continued existence perpetuates a public image that leprosy is a disease apart and its victims are to be excluded from the life of the community. In addition, the influence of any type of categorical segregation facility on the patients themselves is almost always dehumanizing and unjust.

4. *Comprehensive community health planning.* The management of leprosy is severely handicapped by community social attitudes. The methodology of management has tended to place the patient at risk in regard to his self-image and that of his community which should be supportive of his welfare. Informed studies reveal that the majority of patients prefer the risk of disability to segregation and alienation from home, community and whatever margin of economic security he has been able to maintain. The patient is always a person in relationship. New forms of health care delivery systems need to be examined which will include the treatment of leprosy among other priority health needs of the community and not as a separate vertically structured program.

PRIMARY MEDICAL CARE

Primary medical care, so far as prevention of disability is concerned, begins with the attempts to prevent damage to the peripheral nerves. This depends, in the first place, on health education directed toward the patient to make him constantly aware of early danger signs and that he be prepared to report such signs to the auxiliary worker, even in the absence of neuritic pain. From the time of diagnosis the patient must learn to actively participate in his own treatment and prevention of disability. Equally important is the alertness of the medical auxiliary to understand early danger signs and to act promptly as they appear. The treatment may then consist of the use of anti-inflammatory drugs, splintage of affected parts, and in selected cases, decompression of swollen nerves or constricted blood vessels by surgical intervention. This sequence of monitoring events and timely interven-

tion is the ultimate responsibility of the supervising physician who alone can insure an inter-relationship of confidence between patient and auxiliary worker.

Primary medical care includes the prevention of *progressive* disabilities. Thus it is important that the physician aims to cater for all complications which may lead to disability, to give immediate and effective care using the most feasible methods that will enable the patient to return to normal activity as quickly as possible.

It is important to recognize that effective treatment for 90% of the complications related to eyes, anesthesia and paralysis, are simple and inexpensive, and can be administered by specifically trained auxiliary medical workers in peripheral clinics or at home. These methods have been tested and found successful in domiciliary-based leprosy control programs. The auxiliary medical worker can be trained and motivated to offer such services adequately and effectively under the supervision of a physician who himself has had adequate training and who cares. In practical terms this approach means:

1. Health education directed towards securing the patient's full participation in the methods of prevention of disabilities progressing from early danger signs of complications.
2. Immobilization of limbs with even minor injuries, wounds and ulcers.
3. Simple care of early eye complications.
4. Provision of protective footwear including suitable modifications as indicated.

Essential to the delivery of primary medical care is the adequate training of physician and auxiliary medical worker in order to fulfill their decisive responsibilities. International training centers are now available where physicians can be exposed to both didactic teaching and active demonstration programs in which management and prevention of disability is an integrated element in routine treatment. Several centers, nationally and internationally situated, offer similar training opportunities for various categories of auxiliary medical workers. However, essentially it is the responsibility of the trained physician or supervisor to provide in-service training for those for

whom he is responsible. Training is a continuous process in which every level of worker must be involved through refresher courses, training programs designed to upgrade the standard of performance, and most important of all is the need for constant interaction between the supervised and the supervisor.

REHABILITATION

Rehabilitation is the process of being involved in assisting the handicapped individual to reach his "maximum potential for normal living, physically, psychologically, socially, vocationally." However, before a patient is referred to a rehabilitation service, it must be insured that he has passed through the services of *primary medical care*, regardless of the degree of disability when first seen by a physician or auxiliary medical worker. The physician responsible for primary care must first fulfill his responsibilities in his own area of competence. Rehabilitation is a specialized activity requiring advanced skills on the part of those engaged in it.

Reconstructive surgery which has formed a large part of previous reports of this panel, is not considered in detail this year. This is not to minimize its importance, but to emphasize that it should not ordinarily be considered part of the responsibility of the leprosy control team. This is a special discipline which requires years of training. The surgeon who undertakes such training should ordinarily use his expertise for reconstructive surgery of any deforming disease including leprosy. Ideally, rehabilitation services should be integrated in order to make the maximum use of available skilled manpower. In areas of high leprosy endemicity there may be a place for a full-time leprosy surgeon, but rarely for a physician who is a part-time surgeon.

Similarly, in vocational rehabilitation, it is not ideal for a physician or even a social worker to undertake to train patients for the skills required to become self-supporting in their future life. This is a field for vocational counsellors, industrialists, agriculturalists, engineers, businessmen, marketing specialists, placement officers. Such experts may often be persuaded to give parttime service voluntarily to assist in this

important and even decisive activity in successful rehabilitation.

In the area of the specialized skills of physiotherapy and occupational therapy, training in the management of disabilities arising from leprosy is also required. However, it is a sufficiently narrow field for it to have been proven practicable to use technicians who are trained by qualified therapists, and who then devote their whole time to the physical problems of leprosy including the mobilization of stiff joints and splintage of injured limbs, reeducation after surgery and the special training of patients to work without damaging their hands and feet. Every leprosy control and rehabilitation program also needs a shoemaker. With training and experience such a skilled individual may make a most valuable contribution and should be regarded as a full member of the professional team.

Many disciplines are required in leprosy rehabilitation. It is imperative that personnel be recognized for the particular skill they can bear as a member of a team. Mutual respect among members of the team is of primary importance to insure that the patient remains the object of the care offered rather than the exercise of professional prerogatives.

We recognize that full integration is impractical at this time but as a first step, all centers that are able to offer comprehensive rehabilitation services to leprosy patients should accept a proportion of those with disabilities arising from causes other than leprosy. Centers which have so far excluded leprosy patients should similarly be encouraged to accept a proportionate number of such cases. This is not a simple matter, however. Few general rehabilitation workers and medical personnel have had experience in dealing with the problems posed by patients with anesthetic limbs. Special training of all grades of staff will be required to enable them to adapt their skills and basic technics to the needs of leprosy patients. It is particularly advocated that medical universities and teaching hospitals realize the importance of ensuring that both student and staff are exposed to the rehabilitation needs of leprosy patients.

SOCIAL WELFARE

We recognize that substantial numbers of

leprosy patients are so severely disabled that rehabilitation is not a practical possibility. They are, nevertheless, people and have a basic human right to live with dignity and self-respect. They need care. Their needs are often primarily social and thus are deserving of the best possible social welfare service that the community in which they live can provide, equal in every way to services offered those whose physical, social, and economic disabilities derive from other causes. Facilities designed for the care of only those whose disabilities arise from leprosy are to be deprecated. There is evidence to suggest that serious disadvantages arise in attempting to care for the totally and permanently disabled in institutions primarily meant for the short-term care of medical and surgical complications of patients requiring primary medical care and definitive rehabilitation services.

The social welfare services ought to be integrated, providing for the needs of those whose disabilities arise from causes other than leprosy as well as those whose disabilities do arise from leprosy. Ideally these severely disabled patients should be cared for in their own families. Where homes cannot be found or where families cannot accept the patient, substitute families should, if possible, be provided. In this connection we have considered alternate uses for the traditional type of leprosarium or sanatorium.

1. A gradual phasing out of the segregated facilities and the development of LEPROSY HOSPITALS as the base hospitals for leprosy control programs.
2. Such institutions may become hospitals that offer general medical services if in an under-served area.
3. Some may assume the responsibility for providing specialized care of the permanently disabled, regardless of the cause of disability.
4. Where there is a general hospital in the vicinity of the leprosarium, the hospital activities including short-term care of leprosy complications should be integrated with the general hospital. In some instances additional facilities will be required to become an integral part of the hospital and sharing all facilities for patient care.

COMPREHENSIVE COMMUNITY HEALTH PLANNING

It is well to recognize that in many communities, attitudes toward leprosy patients are unsatisfactorily conditioned by the presence of severely disabled patients who are nonproductive and hence a costly burden to the community. Attitudes are also conditioned by outmoded methods of leprosy control that segregate the patient and isolate his care from the public health services offered to the community for other diseases.

There is evidence to suggest that the provision of good, primary medical care that includes leprosy treatment and management, helps to change public attitudes. Prejudices fade away when the public observes that the medical profession accepts responsibility for the care of the leprosy patient as for any other patient. Community attitudes will also be favorably influenced when it is observed that the leprosy patient may continue as a self-respecting, contributing and thus, respected member of the community.

In addition, a systematic approach to health education in the community is important. This is necessary in order to ensure that the desired changes in attitudes actually take place. This will involve a careful diagnosis of the situation, preferably by social scientists with special training in this field. There will be particular emphasis on the discovery of beliefs in the community about the causation of the disease, their specific attitudes to leprosy and those whose lives have been interrupted by it, their specific attitudes toward deformity. Only through such in-depth understanding can it be expected that health education methods will be devised to alter attitudes. Leaders of community opinion will be identified and special efforts directed toward them. This must begin with the medical and auxiliary medical professions.

Diagnosis will be followed by the definition of specific measurable goals. Planning is necessary and the advice of specialists in education should be sought to determine the most suitable means of bringing about measurable changes in attitudes. The use of trained volunteers for the actual execution of the program should be explored as should the possibility of using carefully

chosen leprosy patients as health educators.

Into all such health education programs there should be built in means of evaluation to determine effectiveness and to determine needs for effective methods.

SUBJECTS FOR FURTHER INVESTIGATION

1. The problem of neuropathy.
2. A systematic and widely acceptable approach to the training of staff.
3. Operational research to evaluate the methods in use for the health care delivery systems to leprosy patients.
4. Social anthropology and patient psychology studies as a basis for a better understanding of the patients' viewpoints in order to develop better patient health education.
5. Study of comprehensive community health planning projects into which leprosy treatment has been integrated to determine whether they offer more efficient means of case-finding and case-holding as well as the prevention of social and vocational dislocation.
6. Surrounding, or in the vicinity of many leprosy institutions, communities of discharged patients have settled. In other instances there are self-made communities, in which citizenship is determined only by having had a direct or indirect association with leprosy. In many instances the members of the community will have become socially and economically marginalized by a long-term stay in a leprosy institution. How may the development of such communities be prevented? What practical methods may be used to restore individuals and families into normal community life?

RECOMMENDATIONS

1. That arrangements be made for further exchanges between personnel involved in leprosy control and rehabilitation so as to define more effectively the role of primary medical care and the prevention of disabilities in leprosy control programs.
2. That the International Leprosy Association be requested to include a

- combined meeting of panels on Leprosy Control and Rehabilitation in the next congress.
3. The problem of peripheral neuropathy is of sufficient importance to warrant the arrangement of a separate section to discuss this subject at the next congress and that the International Leprosy Association be so requested.
 4. To foster a wider dissemination of information concerning advances in management and research of leprosy, voluntary agencies are encouraged to provide subscriptions to the major leprosy journals for medical universities throughout the world.