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Rehabilitation Problems in Leprosy

A. J. Selvapandian[1]

Leprosy has had an almost world-wide distribution, although it is now largely restricted to the tropics and subtropics. Over 2000 million people live in areas with an estimated prevalence of 0.5 per thousand or higher, and in these areas about one million new cases of leprosy may be expected within the next five years. When the National Leprosy Control Program was established in India, a survey was made of the prevalence of this disease among 53.3 million people out of an estimated 300 million people living in endemic zones. This revealed that more than 550,000 persons or a little more than one per thousand in this group, were affected with this disease ([5]). It is believed that there are, in all some 11 million cases of leprosy throughout the world and that India alone "contributes" a staggering 2.5 million. The world total of registered cases is over 2.8 million. The world total of treated patients is about 1.9 million. Today only one in five leprosy patients has any hope of treatment [W.H.O. press release, Sear 922-1970 ([8])]. At least a quarter of these patients suffer from physical disabilities. The estimated number of persons disabled by this disease is almost four million, about half of them living in a higher grade of disability. An even larger number will suffer mental damage because of the attitude of society toward them and their illness.

Crippling due to leprosy is a major problem, especially in developing countries that have to cope with more pressing problems related to endemic diseases with high mortality rates and wide-spread nutritional deficiencies. The problems faced by leprosy workers, including doctors, nurses, paramedical workers and others, in locating, treating and rehabilitating leprosy sufferers, are formidable indeed. Some of these are uncommon to other public health problems. To list a few ([5]):

1. As a result of deep-rooted prejudices, fears, and belief that it is a "curse of the gods", the public does not accept leprosy as one of the myriad diseases affecting mankind. Such an attitude has inevitably led to ostracism of the sufferers. Lack of intensive education is responsible for the prevailing ignorance of the *facts* of the disease.

2. In the majority of cases, there is some degree of disfigurement and deformity, disabling sufferers and preventing them from pursuing regular occupations. Especially when such individuals belong to the low income group and are illiterates, their families are unable to feed and clothe them. Such a situation forces many of the sufferers to mendicancy.

The socially well-placed, on the other hand, who need not work to earn their living, are protected by their families in order to avert the stigma attached to the condition and run "underground". The opportunity for early diagnosis, treatment and complete cure of the disease, is completely lost. Those with the infective type of leprosy are a source of danger to the health of others.

3. The loss of enthusiasm among sufferers for seeking medical aid and treatment has been due to the fatalistic attitude and "philosophic acceptance" of the condition.

4. The occurrence of deformities and plantar ulcers, which steadily get worse during the course of years, in spite of the usual treatment, makes the sufferer indifferent and unconcerned.

5. Even when patients accept medical treatment and the disease is stabilized, the deformities and anesthesia render attempts to make them gainfully or purposefully employed ineffectual to a great extent.

EDUCATION

As in the case of every public health program, education plays a very important

[1] A. J. Selvapandian, B.Sc., M.B., M.S., F.A.C.S., F.I.C.S., Professor of Orthopaedics, Head of the Department of Orthopaedics and Leprosy Reconstructive Surgery, Christian Medical College and Hospital Vellore, S. India.

part, especially in a developing society, in educating the medical profession, the public and the afflicted. Rehabilitation of leprosy patients demands a change in the existing attitude of the public, the medical profession and the patients themselves. It is necessary to convince the public that modern methods of treatment have completely revolutionized the outlook for the leprosy patient, and that with proper treatment, which is, incidentally, simple, and training he also can lead a normal life like any other person.

Most of the leprosy campaigns we have known are aimed, unfortunately, only at the victims of leprosy. If this fact is pointed out to the public in an appealing manner, there is bound to be favorable response. The public will begin to understand leprosy as a disease caused by germs, like any other infectious disease, and believe that with early treatment complete cure is possible, and recognize that its infectivity is very low.

Educating the medical profession by means of seminars, short refresher courses, and conferences on the problem, will enable them to understand the facts of the disease better, and the general medical practitioner who is in direct contact with the patients could undertake to treat them. They should shed the fear that their willingness to treat a leprosy patient along with other patients will in any way affect their practice. It is most essential to integrate leprosy treatment with hospitals attached to medical colleges, and thus educate medical students, trainees, medical personnel, and the public in particular, to accept without reservation the fact that leprosy is just another disease and is to be treated as such. If we are not able to demonstrate this in a practical way, leprosy will continue to be considered as a disease apart.

The deformity and disfigurement involving the face, feet, and hands seem to be the chief cause for dehabilitation of leprosy patients. If the disease is allowed to advance without any proper treatment, deformity is bound to occur; it is seen in about 20 to 25 per cent of patients. The continued and careless use of anesthetic extermities causes severe mutilation, which is not directly related to the disease. Often, a neglected first ulcer of the feet, or an untreated early deformity, leads to extreme mutilation accompanied by severe disabilities. When adequate instruction for care of hands and feet is given, a significant fall in the incidence of ulceration and severe deformity of the hands and feet is seen consistently ([7]).

REHABILITATION NEEDS

Preventive rehabilitation should be our primary aim. After an individual patient receives treatment and proper advice, he should continue to carry on his usual occupation in his normal environment, evincing adequate care to avoid damage to his anesthetic limbs. This would be the practical solution, which would meet the special needs of the patient, including social acceptance and retention of his family ties. In treatment centers such a program of comprehensive care of the leprosy patient should lay emphasis on preventive rehabilitation and reeducation for a new life ([2]).

This method of training and teaching should reach a large number of patients. It should be incorporated in domiciliary treatment programs so that those who are far from treatment centers, and have limited opportunities to contact medical personnel frequently, would be benefited. The individual patient, who may suffer from early or advanced deformity, will thus be taken care of.

It is a common experience to come across patients who were previously treated successfully for plantar ulcer or deformity of a hand, returning a few years later with gross damage to the limbs and severe mutilation. On the part of the patient there is a vital need to understand the fact that he has to live with the anesthetic limbs for the rest of his life. Only with discipline and constant vigilance can he prevent the harmful effects of stress and strain of day-to-day living. The patient should clearly understand this. In a practical way many activities, simple and acceptable, could be performed, supervised by trained personnel, with suitable protective devices. Participation in such gainful activities would leave a

lasting impression on the patient's mind. Though it would be ideal to give practical training individually, for various reasons this would not be practical. A specially called group of patients could participate in such an intensive practical training.

Where facilities do not exist to extend practical training, audio-visual materials can be used successfully to impress on the patients the paramount importance of preventing injuries to their anesthetized extremities. Slides, filmstrips, flannelgraphs, posters, etc., are some of the materials that could be used. As part of any leprosy control program such a new approach is needed. In organizing such a program of group education, followed by practical training with individual attention where possible, a large number of patients could be covered.

The domiciliary treatment clinic should have trained personnel who could impart such knowledge to patients and organize practical training sessions regarding preventive rehabilitation, in order that patients may be constantly reminded to take care of their limbs. Those patients who would require plaster casts, or new chappals, or advice regarding adaptation of a tool, etc., would get prompt and proper assistance from the team, which would be able, by virtue of its own specialized training, to render the appropriate service ([6]).

SOCIAL DISPLACEMENT

The term "stigma", which is used constantly in referring to a leprosy patient, expresses the largely ignorant attitude whereby a leprosy patient is shunned both by himself and by society at large. For a leprosy patient, rehabilitation is incomplete until he takes his rightful place in the community as an independent, self-respecting and useful member. The prevention of social displacement is, therefore, very important ([2]).

In restoring the leprosy patient to the society or community to which he belongs, the team of medical personnel—social worker, employment officer and others—have to coordinate their activities to meet the particular needs of a particular patient. This calls for teamwork of a high degree of efficiency and cooperation.

INTEGRATION WITH OTHER PROGRAMS

A realistic approach to the problem of rehabilitation, especially in the developing countries, requires integration of the facilities available for leprosy-handicapped with those for other disabilities and vice-versa. It is neither economical nor practical to have separate programs ([1]).

It is now almost universally believed that a great disservice to the treatment of leprosy, as well as to leprosy patients, has been perpetrated by the provision of separate establishments, which made leprosy a disease apart. Inevitably, the patient is segregated and to a large extent neglected. This social isolation and even medical isolation are due to the fact that leprosy patients are traditionally taken care of in segregated institutions and leprosaria. This could be condoned when knowledge regarding leprosy and its treatment was limited, but not any more.

The harmful effects of institutionalizing each and every leprosy patient have added to the number of those who are identified as being "set apart", a circumstance which has greatly increased the number of those in need of rehabilitation. This eventually leads to dependency, which is one of the most difficult problems from which the cured patient is unable to break away. Sooner or later, leprosy patients should be treated for their complications, either medical or surgical, in the respective departments of general hospitals like other patients suffering from other diseases. Regular routine treatment should be given in the home environment as far as possible. At the present time, whenever a patient has no alternative other than to be treated in a leprosy hospital or regional leprosy center, this should be for the minimum possible period and for a specific purpose only.

It should be stressed that patients who have recovered from leprosy without deformity should not at any time be in leprosy institutions. If, from the very beginning, these patients are taken care of by domicil-

iary treatment or attended to at the skin clinic of a general hospital, they may not face any problem in pursuing their normal life. If they are known to have gone to leprosy hospitals for treatment, they run the risk of being socially ostracized even after they are completely cured, and the normal healthy members of the family also might be socially affected. Patients with minimal deformities who, with early treatment, recover normal appearance and function, have a good chance to return to normal life.

TRAINING PROGRAM FOR THE DISABLED

The difficulty in rehabilitating patients who are deformed and crippled is well known. The main problems are loss of self-confidence in facing the world because of the obvious deformity, a sense of inadequacy while working with healthy individuals, and the attitude of society toward them ([3]).

It is vital to determine, with the help of a social worker, occupational therapist and prevocational counsellor, the socioeconomic status, the aptitude and the attitude of the patient. Suitable training and prevocational help should be offered, depending on his physical abilities, work performance and intelligence. In this matter, the patient's family and his present or previous occupation should be taken into consideration, since the latter would be the natural course that he would wish to pursue. Restoration of his physical function and planning of a prevocational program should have a bearing on his ultimate vocation. Routine crafts, like carpentry, toy making, and matweaving, are usually taught in these places without taking into consideration whether the training he receives during institutionalization will be of help to him or not, in earning his living independently.

Agriculture and farm work of different kinds have to be taught to those who would return to their lands, and the training period should be planned to provide them with experience and knowledge to use their limbs, while in any activity, in such a way as to prevent any damage or injury. Adaptations on the implements should be simple, practical, and acceptable. While going through routine work in experimental farms under supervision, patients learn many practical points for safe-guarding their limbs while at work, and above all this gives them much needed confidence.

Those who are from urban areas need to be trained in various industries. It must be realized that in regions where there is a great deal of unemployment it is difficult to get a large number of cured leprosy patients absorbed in industries. It has also become important for us to realize that those who are already employed in industries and found to suffer from leprosy, should not be thrown out, but should be taken back in their previous occupations or in some other capacity after arrest of disease.

In this connection, there seems to be a great need for establishing *regional centers* with qualified personnel and proper equipment to train patients and teach them different occupations according to their physical and mental abilities. These could be training-cum-production centers, since viability is dependent on financial stability. The center with such a program should never become a home or colony for ex-leprosy patients.

Patients who are unable to compete successfully for outside employment on account of their deformity or any other problem could be employed in sheltered workshops. Such a workshop should employ *all* handicapped people and not leprosy-handicapped alone. It would be ideal to let these employees live in their own homes and provide for themselves from their earnings. A sheltered workshop can be: (1) a factory-style workshop employing the patients all in one place, or (2) a dispersed cottage industry where a number of workers may be employed in their own homes making different components, which are collected and assembled at a central workshop that has a marketing organization. The sheltered workshop should be used for the wider purpose of educating the industrialist, the administrator and the general public. It could also serve as a demonstra-

tion center for the public to see the handicapped at work ([4, 9]).

Leprosy-handicapped and other orthopedically-handicapped patients are employed and trained in the Swedish Red Cross Workshop at Katpadi, near Vellore in S. India. Such integration should be the aim of such a workshop. In these workshops, if a few nonhandicapped workers also are employed, it would help not only to increase the range of work projects, but also in economic and psychologic aspects as well.

After suitable training groups of patients could be encouraged to organize cooperative societies and start small-scale industries and workshops. In this way they could select occupations that could be carried out in individual members' homes. Social welfare organizations and voluntary agencies should take the lead in encouraging such enterprises and giving guidance in the selection of suitable trades and crafts, purchase of raw material, and marketing products without reference to their origin, which may be unnecessary.

A patient can return to society only if he is given some gainful occupation to maintain himself and his family. Apart from reluctance of society to accept a leprosy patient, the other main difficulty in rehabilitation is how to find work for all needy patients when there are a large number of healthy persons who are equally keen to work but are unemployed.

In developing countries, new building projects, new industries and factories, have provided employment for many people. In spite of all these, the number of healthy, unhandicapped unemployed is staggering. If the problem of finding employment for leprosy patients is examined in this context, it will be obvious that it is not possible to rehabilitate all. Within these limitations, it is necessary, however, to find employment for as many as possible. There are two ways in which employment could be provided, viz., (1) work in existing jobs, and (2) creating new job opportunities. Existing industries and factories have many job opportunities, and if a leprosy patient is trained for such jobs he can be employed. To provide suitable training and study of the job, suitability will be essential. Public sector industries (undertakings) could help in these lines and employ the physically fit and trained leprosy patient ([3]).

The concept of creating new job opportunities will be to find work in the patient's own home or environment in the form of craft or occupations suitable for rural areas like poultry farming, piggery, kitchen gardening, etc. Those who are in urban areas may go in for crafts like book binding, candle making, brooms and brush making, cloth printing, etc. The establishment of work-cum-training centers would enable suitable training and help patients start the new job.

CONCLUSION

If leprosy work could be integrated with other medical, public health, and rehabilitation programs, wastage in personnel, finances, facilities and delays could be averted, and all these resources could be utilized effectively. In order to achieve this goal, education of the people, especially the medical profession and the afflicted, is indispensable. Establishment of workshops for the training and employment of the handicapped is considered essential.

If the rehabilitation concept is to spread widely, and if every patient who comes under treatment is to be benefited, there should be enough rehabilitation workers. This category of leprosy workers should combine knowledge of the basic principles of physiotherapy, occupational therapy and social work.

SUMMARY

During the past decade, the strategy of approach to rehabilitation of leprosy patients has changed drastically. The sanatoria, leprosy settlements and care homes have given place to treatment centers where every patient is treated according to his total needs, with a view to his rehabilitation. The leprosy control program, domiciliary treatment, and preventive rehabilitation have helped to deal with the leprosy problem in a comprehensive way. In planning such programs the need of the indi-

vidual patient should not be ignored. As a means of practical solution, preventive rehabilitation should be emphasized, to help the patient return to his home environment and continue his occupation or normal work, at the same time that he receives the treatment. This approach is practical in the developing countries, since early treatment helps to arrest the disease and prevent occurrence of permanent deformities. Secondary deformities seen in the hands and feet are the result of anesthesia. They are preventable, provided the patient is given the knowledge and discipline to preserve his anesthetic limbs during the treatment period.

The ideal leprosy treatment program should provide for comprehensive preventive rehabilitation and training for resettlement. There are two aspects to this program. First, adoption of the principle and methodology of dealing with the individual patient with either early or established deformities. Second, the difficulties encountered in the practical application of such methods to a large number of patients scattered over a wide area who are unable to be in regular contact with medical personnel.

It is necessary to equip every treatment center with a trained surgeon, social worker, physiotherapist, occupational therapist and shoemaker, who could, as a team, give patients the required comprehensive care. Health education by means of simple audiovisual aids and practical demonstration is essential, since the majority of patients are illiterate.

Domicillary treatment clinics, which are conducted at regular intervals, should include in the team a physiotherapy technician, a social worker and a shoemaker. They could examine limbs, apply plaster casts for cases of plantar ulcer, issue footwear when needed, use audiovisual aids and practical demonstrations, and also supply simple adaptation for the implements used for routine work and normal activities.

Because of a paucity of trained personnel the treatment program needs to be integrated with other public health programs organized by the State Health Service. This is possible if private and Government agencies can work together.

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