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Preventive Rehabilitation in Leprosy

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PART I

CAUSES OF DEHABILITATION

The advent of DDS and other specific anti-leprosy drugs brought in their wake a change in the attitude towards the patients suffering from leprosy. The possibility of eradication of leprosy by early detection and adequate treatment of all patients led people to seek new methods of approach to the problem of leprosy. The age-old principle of compulsory isolation and segregation was found to be ineffective as this method encouraged the undeformed and those with no subjective discomfort to go underground and thereby defeated the purpose of such a programme. The 'Brand' era brought hope and courage to patients not only because of the achievements of reconstructive surgery for paralytic deformities, but by the recognition of anaesthesia and misuse as the major cause of the much-dreaded trophic ulceration, loss of digits, and the gross deformities that one usually associates with leprosy. This knowledge not only helped the patients to learn to protect their anaesthetic limbs from mechanical and unrecognised trauma, but also helped to take away from the minds of medical personnel and the informed public, the fear and dread of leprosy that was based on the hopeless state of the ugly deformities associated with leprosy. The mystery that surrounded the process of destruction of the limbs was solved.

Thus gradually we have begun to realise that 'Leprosy can be cured and deformities can be prevented or, if need be, corrected.' (Karat, 1966.) The policy of segregation gave place to desegregation and domiciliary treatment programmes for leprosy control. But the principles of rehabilitation have not kept abreast of the march of these events. During the last 2 decades a great deal of thought and planning has gone into devising effective ways of rehabilitating patients who had lost their 'family roots' owing to a prolonged period of isolation from their relatives and friends, and in that period had developed varying degrees of disfigurement, deformities and disabilities. Once their disease was arrested and deformities corrected, the natural sequence was to find suitable means of gainful employment and restoration to normal social relationships. This was soon realised not to be an easy task.

However, with the greater outreach of domiciliary treatment, the old concept of 'Rehabilitation' of leprosy patients was not changed. *Rehabilitation implies an already dehabilitated patient. With the changing pattern of management of leprosy patients it is inevitable that prevention of dehabilitation should be the primary first step in all rehabilitation programmes for leprosy patients.*

There are 2 aspects that need to be considered. First, the recognition of the causes for dehabilitation of a patient. Second, the early recognition of these factors, and dealing with them before they cause dehabilitation.

1. *Anaesthesia*

(*a*) *Loss of protective sensation of pain, temperature and pressure* are the most difficult handicaps for the patient to overcome. To this may be added a low threshold to injury by the tissues, and the lack of adequate inflammatory response, which is to some extent controlled by nervous reflex mechanisms. Unrecognised injury caused by sharp or blunt instruments or by repetitive minor trauma results in a primary wound which the patient is unaware of till bleeding, deformity or an ulcer draws his attention to its presence. The uninitiated patient does not know that he has to substitute vigilance and deliberate care for the protective function of a painful limb. Lack of pain and subjective discomfort result in further insults and trauma heaped on an already injured tissue and the condition rapidly deteriorates. The patient's cortical centres are 'blind' to the insults and injury that are constantly occurring in the battlefield, from which the lines of communication to the cerebrum are severed. The battered cells collapse one by one and their desperate cry from the battlefield is not heard by the office of the high command. No reinforcement, either vascular or humoral, is forthcoming, and the lonely tissues, isolated from the headquarters with no reinforcement to fight and no way of withdrawing from their battlefield to protect and treat its casualties, perish at the enemy's hand. The enemy advances and faces very little resistance till he reaches the outpost, which still retains its communications. Immediately the defence is mobilised and every possible help rushed to the scene of warfare. It is not rare to see such a patient who gives a history of grossly infected fingers with dead bone and necrotic tissue in the hand unattended for several days until infection and cellulitis ascends up the forearm to a sensitive area, where the immediate inflammatory response, pain, cellulitis and often adenitis drives the patient to travel miles to the hospital for help.

Excessive use of an insensitive limb can produce injury by deep seated blisters and necrosis of soft tissue. This method of causation of plantar ulceration is well recognised and accepted and does not need further description (Price, 1959).

(*b*) *Loss of fine touch and Stereognosis* affects finer and more delicate finger movements. Artisans like goldsmiths and watch repairers are greatly handicapped, but experience has proved that, with practice, a great amount of skill can be regained.

Loss of sweating due to destruction of the nerve supply to the sweat glands coupled with dimunition or loss of sebaceous secretion results in hard, dry skin with a tendency to hyperkeratosis. Small and large fissures develop in the affected area. Often fissures around the edge of the sole of the foot get deeper in areas of high pressure, and form the starting point of a deep perforating ulcer (personal observation).

2. *Paralysis*

Paralysis in leprosy forms the next major cause of disability. Paralysis produces both functional disability and ulcerations due to high pressure areas resulting from defective mechanics of function. The finger tip injuries in ulnar paralysis and the fifth metatarsal head ulcer in foot drop are familiar examples. In addition, neglected paralytic deformities result in secondary contractures which are often permanent and severely disabling, and in which the best surgical procedures can only produce mediocre results.

3. *Morbidity*

Morbidity due to general ill-health may also contribute to the dehabilitation of a leprosy patient. His capacity to be gainfully and competitively employed are impaired and hence he may find himself out of a job, home and family surroundings and driven to become a beggar.

The systemic manifestations of leprosy are often unrecognised. Patients with leprosy are apparently more likely to have anaemia, oedema, hypoproteinanaemia, malabsorption, kidney disorder, endocrine disturbances, amy-

loidosis, etc., which, singly or in combination with each other, reduce the longevity of patients suffering from leprosy as well as contributing to the morbidity and sub-normal health of these patients.

4. *Psychological Causes*

In spite of all the advances in the management of leprosy, the stigma and fear of leprosy are still very much ingrained in the very fabric of our society. The person who gets leprosy is often haunted by the fear of detection and isolation from his fellow men. Often, this fear of ostracism by society and the family causes considerable mental agony and psychological trauma. It is not uncommon to find a patient who has a minor deformity, but has broken down under the psychological strain and has not found the courage to return to useful living. He becomes introspective, depressed, hostile and anti-social.

5. *Inadequacies of Present Pattern of Therapy*

(i) The prolonged period of therapy needed with DDS necessitates repeated attendance and sometimes hospitalisation extending over a period of many years. This naturally upsets the patient's routine and his work.

(ii) The problem of nerve destruction even while under therapy, and sometimes due to the therapy, is often neglected, and needs further study and careful management.

(iii) The unsolved problem of chronic reactors forms a major problem for a fairly small proportion of patients.

(iv) The lack of simple care and preventive measures for anaesthetic limbs, as part of the larger control programmes, is a major defect of the present control programmes. Anaesthesia and paralytic limbs are left uncared for to run their natural course, and the limbs of an uninitiated patient are permanently and severely deformed and disfigured due to misuse and disuse.

6. *Isolation and Segregation of Positive Patients*

The age-old principle of isolating and segregating positive patients over a period of many years in sanatoria dislodges them from their family and society and makes it impossible for a large number of them to return to useful living. Lack of vocational training during this period adds to this problem. Often, a patient who has stayed in a sanatorium for many years has developed a 'deformed personality' which makes his re-entry into an unfriendly society still more difficult and isolates him further from society.

7. *Social Prejudice and Ignorance*

Social prejudices and ignorance contribute much to the dehabilitation of leprosy patients. The 'persecution' that is often meted out unconsciously by almost every section of society makes it hard for the patient to have normal social relationships. A patient with identifiable deformities, or a patient with no deformity but who attends a special clinic or hospital for leprosy patients often faces the possibility of being thrown out by his own immediate family circle and by his neighbours, and be forced to leave his home. Occasionally, patients leave their home and become destitutes and beggars in their attempt to avoid embarrassment and serious social consequence for the rest of the members of the family.

PART II

MEDICAL AND SURGICAL ASPECTS OF PREVENTIVE REHABILITATION

It is more and more being recognised all over the world that rehabilitation starts at the stage where prevention of disabilities can be effective. This should be the basis of our approach in leprosy, but unfortunately, in the large majority of areas this aspect is all but forgotten in the planning and management of both individual patients and in the leprosy control programmes.

What about patients who are already disabled and dehabilitated? There are now an estimated 10 million patients suffering from leprosy. The majority of these are in what are

called 'under developed' or 'developing' nations. The number of patients with deformities is estimated to be something between 20 and 25% of the total patient load (W.H.O.: Polambakkam). The majority of these patients are unemployed or under employed. These countries with their limited resources and a high percentage of healthy unemployed will find sheltered workshops and expensive rehabilitation projects practicable only to a very limited extent. In addition, the majority of the patients are in their fourth and fifth decades, are not amenable to learning new trades and unwilling to move out of familiar surroundings. Moreover, the sense of belonging to their families and society is one of the basic needs of leprosy patients, and tearing them away from such an environment cannot be justified even when balanced against material sufficiency and security.

In such a situation it would be considered ideal if patients could return to their own jobs, their families and social set-up, provided they have obtained special training and help to overcome their disabilities. It is such a programme that we designate as 'Re-education for Re-settlement' rather than rehabilitation.

MEDICAL MANAGEMENT

Maintenance of the integrity of the function of peripheral nerves during anti-leprosy therapy should be the concern of every leprologist. This much neglected, ill-understood and in most instances completely ignored, complication of the disease is the chief cause of morbidity in leprosy. Often the word 'neuritis' is used to indicate pain and tenderness over the nerve trunk which most often is not directly related to the functional integrity of that nerve. The insidious onset of anaesthesia or paralysis without any pain in the affected segment of the nerve is often missed. It is important to record the motor and sensory function of the peripheral nerves routinely and periodically during treatment. The need to recognise patients who show a greater predilection for nerve involvement and to treat such patients with drugs other than DDS, such as Thiosemicarbazone and CIBA 1906, during the initial 12 to 18 months should be more strongly emphasised. Anti-inflammatory drugs like Chloroquin could be usefully given in combination, sometimes preceding the institution of specific anti-leprosy drugs. All patients with borderline leprosy, patients with disseminated tuberculoid leprosy, and lepromatous leprosy with a tendency to painful enlargement of the nerves or paralysis or a previous history of ENL need such special care. In addition, acute paralysis or an acute tender nerve anywhere should be considered as a serious form of 'reaction' and a definite contra-indication to the use of DDS. In such patients anti-inflammatory drugs and such other measures to control the acute phase should be instituted in an attempt to restore nerve function. Lack of such serious notice of nerve dysfunction in the mass treatment programmes results in a large number of casualties sustaining permanent injury to peripheral nerves resulting in anaesthesia or paralysis.

This problem will continue to increase with the mass treatment programme until the medical and paramedical personnel begin to look beyond the results of skin smears for bacilli and the disappearance of skin lesions as their criteria of results of treatment, and take time and care to assess the peripheral nerve function during active anti-leprosy treatment.

Early treatment of even minor hand injuries with splinting and provision of microcellular rubber for adaptation of tools and for footwear for patients with anaesthetic feet should be available for every patient.

Every ulcer should be treated with plaster of paris immobilisation and provided with microcellular rubber footwear. The problem of dehabilitation will multiply and worsen in every control programme unless these measures are adopted as routinely as DDS therapy.

In our control programme in the Gudiyatham Taluk, a simple programme of ulcer treatment followed by the issue of microcellular rubber footwear resulted in a 65% reduction in the incidence of ulcers within 2 years, a drop in unemployment from 66% to 9% among the 101 patients cured of plantar ulceration and 90% of these patients attributed their ability

to return to work to the use of microcellular rubber footwear.

Lack of such care to prevent and treat deformities in a domiciliary treatment programme results in loss of confidence by the patient in the doctor's ability to 'cure' him with DDS. A patient who has to be persuaded to take therapy for a minimum period of 5 years or all his life does not understand the mysterious 'bacilliary index' that the doctor assures him is improving when no care is taken of recurrent trauma and infections resulting in trophic ulceration and the unrelenting progressive destruction of his limbs. To the patient, deformity is leprosy. The indisputable lack of the patient's confidence in such a treatment programme is one of the causes of the large percentage of absenteeism that is the basic weakness of every control programme.

With the advent of the effective domiciliary treatment programmes compulsory segregation and isolation as a method of leprosy control is slowly disappearing. Such a programme immediately reduces the number of patients who need special rehabilitation because of prolonged institutionalisation. All the same, the stigma and horror associated with leprosy and the resultant callous ostracism of sufferers from this disease will not change to any significant degree until such time as leprosy is recognised for what it is—namely, just a bacterial disease like any other and not a divine curse. Such an awareness and recognition must necessarily lead to the logical step of integration of leprosy into the general stream of medicine. When leprosy loses its mystic and divine connotations in the minds of professionals and laymen, then naturally leprosy treatment and control must become an integral part of the medical care offered by all general hospitals and general practitioners.

Further, the early patient with a single patch and no subjective symptoms whom the paramedical worker or the doctor has sought out and persuaded to take treatment, needs a place where he can go for treatment without the serious social consequences of being recognised as a leprosy patient and this cannot be the leprosy clinics in our present social context. Unless this problem is solved the problem of the large measure of absenteeism which is presented universally in all the leprosy control programmes will not be solved. Thus the early patient will not get the best that recent advances in leprosy work can offer.

SURGICAL MANAGEMENT

When the medical management has failed to prevent nerve dysfunction disfigurement and deformities result. The patient then presents himself with anaesthetic limbs and deformities of greater or lesser degree.

The methods of correction of paralytic deformities by tendon transfer and the correction of disfiguring deformities by plastic surgery are well established and publicised and hence do not need further elucidation.

It is sufficient to add that at present the available facilities are grossly inadequate. At the same time the correction of paralytic deformities by tendon transfer is a specialised job needing an adequate period of training and experience for the surgeons and physiotherapists who undertake this work. Each stage of the surgical management needs experience, skill and technical excellence. The criteria for selection for surgery, pre-operative physiotherapy, the high standard of asepsis needed for such surgery, the perfection of surgical technique with its necessary modifications to suit individual limbs of patients, and the all-important post-operative re-education period with constant supervision by a qualified physiotherapist and repeated survey and review by the surgeons are essential to obtain excellent results. The author has seen many a patient who sought help because a previous operation had failed. It is obvious that failure is not due to major faults in technique but due to small errors in management resulting in disastrous consequences.

Three major principles should always be borne in mind, namely:—

1. Tendon transfers and plastic operations can be done only once and re-operation on a failed procedure rarely gives satisfactory results.

2. It is not useful to do these operations unless the best possible results are obtained. A patient who had pre-operative clawing of 75° flexion is very slightly better off with an improvement of 45° flexion post-operatively and, from what we have observed, these insufficiently corrected deformities deteriorate in subsequent years to pre-operative levels.

3. The surgeon should resist the temptation to adopt the attitude that 'something is better than nothing'. Faced with a large number of patients to cope with and inadequate facilities for surgery, this attitude may appear justifiable, but in our experience insufficient correction and unsatisfactory post-operative re-education almost invariably result in deterioration of the limb to its pre-operative level. It is not uncommon to find such a hand some years after operation functionally worse than its pre-operative condition.

SUMMARY

A changed orientation in relation to the rehabilitation of leprosy patients is presented. The main theme of the paper is the prevention of 'dehabilitation' of leprosy patients by re-education for re-settlement concurrently with comprehensive medical care (including adequate facilities for reconstructive and plastic surgery) administered through the domiciliary treatment programmes.

The etiological factors in relation to 'dehabilitation' of leprosy patients are discussed in detail. A rational medical and surgical approach to preventive rehabilitation is described. Particular emphasis is laid on the careful choice of drugs in medical treatment and on the possibilities of reconstructive surgery both as a procedure to restore normal and near-normal function and as a 'salvage' procedure.

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