

WANTED—A LEPROSY POLICY

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My visits to a number of treatment centres for leprosy in different countries during the past few years give me the impression that there is need for a redefinition of the purpose of treatment in leprosy. This is particularly true insofar as it applies to 'Settlements' or 'Leprosaria' where patients are fed, clothed and housed for long periods. In some cases, it is not clear what policy is being pursued, and questions do not always elicit a coherent answer.

Much of this confusion is due to the changing emphasis in leprosy treatment that results from new knowledge and understanding of the disease. A further cause is the fact that many leprosaria are supported by Missions or philanthropic institutions and have often grown up round the personality of one or more devoted workers whose personal inclinations may dominate any constructive policy. Furthermore, Missions in particular are not so committed to bodily healing as are purely medical institutions and are willing to keep patients because of the spiritual or educational benefit which it is hoped the patient may derive or because, for humanitarian reasons, it seems difficult to insist on a patient returning to his home community.

However, conversation with those responsible for the work at these centres reveals frequently a feeling of frustration and dissatisfaction with things as they are.

With these things in mind, an attempt is made here to outline a leprosy policy that meets not only the humanitarian and Christian principles that direct many such institutions, but also provides a medically sound basis for action, in any leprosy programme.

What is the Aim?

There are three major needs in the majority of countries where leprosy is a health problem. These are, first, *the control of early infection*; this is specially desirable as it is generally agreed that early effective treatment will avoid the great majority of disabilities and deformities due to leprosy and in general result in cure. Second, the restoration of those who are moderately handicapped or disabled; and third: the care of those who are too disabled to be rehabilitated and are in effect permanent cripples.

The planning of a coherent plan for all three needs is the responsibility of the Medical Service of the region concerned. An isolated 'Settlement' should be perfectly clear, by a conscious act of decision, which of these it is to meet.

The most satisfying policy is to choose one and do it as well as possible; the least satisfying and the most frustrating, is to attempt

all three with limited personnel and funds and end in a morass of medical ineffectiveness and financial embarrassment.

It is regretted that too many of the 'Settlements' visited by the writer belong to this last group.

How to Choose

The first emphasis is on the fact of choice. It is very unwise to have no policy and just drift into a given situation owing to confusion of ideas and the force of circumstances.

The choice should be conscious and definite. Little is gained by hesitating between two or three possibilities over a period of years. For this reason, it is usually wise for the decision to be taken by a group of people, who should include one representative of the Medical Service responsible for the overall planning for leprosy.

The group should include someone of long experience in the many claims of leprosy sufferers, and also representatives from existing leprosy treatment centres.

The major decision must then be taken whether to concentrate on the effective treatment of early cases; or the rehabilitation of the partly disabled; or the care of the totally disabled. The early treatment is the least costly and probably the most fruitful, but it entails frequent travelling and work in uncongenial circumstances.

The rehabilitation programme makes the greatest demands on staff, building and equipment but avoids a considerable waste of young life and is the most gratifying to the worker. The care of total cripples is a work of charity but is the most costly, and is difficult to carry out with efficiency and devotion.

The Facts to Consider

Modern studies of leprosy make it possible to lay down certain basic principles which should guide all planning. These include:

I. With modern therapy, leprosy is a non-fatal, self-healing, chronic, infectious disease.

Leprosy proceeds in general slowly and quietly, interrupted by bursts of activity, to its final eradication by the body processes.

The damage it may do to limbs and face during this period may be considerable and may leave the patient a cripple. A few cases may develop serious complications and a few appear to live with their leprosy as a source of contagion all their lives.

II. The control of infective cases and the eradication of leprosy do not comprise a practical aim for many.

Although the control of infective cases is the only way to eradicate the infection from a community, the discovery and isolation of a sufficient number of cases to alter the general risk of infection is not practicable for many at present, in most countries where leprosy is endemic. The difficulty of finding and of recognizing the infectious

dimorphous cases, the expense and personnel that would be necessary and the impossibility of isolating the many thousands that would be discovered have led to the abandonment of the ideal of 'isolating infective cases'. Also, experience in the similar condition of tuberculosis has cast doubt on the value of such isolation. In a well-known experiment at Madras it was found that the contact-rate of cases carefully isolated at considerable expense was little different from those left at home in their families and treated where they live.

The moral is that the proper treatment of infective cases is to find them, treat them at home and keep a careful watch on contacts. These latter will be immediately treated on the first sign of infection. Prophylactic sulphone therapy is not yet known to be of value.

III. There is little value in treating a patient with anti-leprosy drugs, if the leprosy has already died out spontaneously.

This rather obvious 'truth' is emphasized because of the number of cases that can often be seen in 'settlement' who come into this category. Anyone treating leprosy should be perfectly clear as to when a case of leprosy is 'active', 'quiescent', 'arrested' or 'cured'. These are states well-defined in current textbooks and should be scrupulously observed. Cases of 'burnt-out' leprosy should not be kept on unnecessary treatment in order to qualify for money for their upkeep from philanthropic or government agencies.

The present section describes briefly the possible policies that can be followed. It is better to do one well than two poorly or all three badly.

The Control of the Early Case

In the present state of knowledge, and in the circumstances of many countries where leprosy is a problem the control of the early cases is the most profitable and satisfying way of using a limited amount of money. The essentials of this method include:

- (i) regular visits to the places where people live,
- (ii) particular attention to the examination of the young,
- (iii) careful examination of the body,
- (iv) a treatment policy for early cases.

The need for visits at intervals of six months limits the area that can be properly supervised with the personnel and funds available, but such a policy can be expected to bring about a notable reduction in leprosy within 20 years. The frequency with which leprosy begins in the young means that the schools should be especially visited. The tendency of leprosy to appear first in special areas (e.g. buttocks) underlines the importance of proper examination of the patient and the microscope is an essential part of equipment if early bacillus-positive cases are to be recognized.

It must be decided what should be done with early cases. This is a personal decision, because there is not yet general agreement on how to treat the early tuberculoid case. Many untreated cases, if followed year by year, recover completely without treatment. The writer suggests that a register be kept of all early tuberculoid cases and that they be re-examined without treatment at more frequent intervals (e.g. every two months) to follow the development of the case.

If however the total number of cases is small, such cases may reasonably be given full treatment from the start.

All treatment which consists only of the giving of tablets should be undertaken at home, without interruption of the patient's normal occupation. Particular care should be taken to begin sulphone therapy with a carefully graded series of doses so as to avoid complications of early overtherapy.

The occasional occurrence of incidents that cannot be managed in the patient's home will make some type of temporary hospitalization necessary. The best place to do this is the local general hospital if the prejudice against leprosy among patients and medical staff is not great.

To bring such patients in to a central 'settlement' is expensive and entails the risk that the patient may not return home readily after treatment and that his family may not welcome him home again. It should be avoided if at all possible.

The Rehabilitation of the Partially Disabled

At the present moment it is fashionable to emphasize the value of rehabilitation in leprosy and its value is undoubted.

However, proper rehabilitation is of value after any chronic disease and many countries do not have the resources to undertake much rehabilitation at the present moment.

The objective is to rehabilitate leprosy patients in the same medical service that serves other paralytic conditions, such as poliomyelitis and traumatic lesions of limbs and spine. Until this is possible it is permissible to undertake special care for leprosy; but this must be recognized as a temporary measure and large sums of money should not be spent in buildings in remote areas that cannot be used profitably for other purposes. The experiences of western countries with tuberculosis sanatoria is a healthy reminder of what *not* to do at the present time. If rehabilitation is to be undertaken it should fulfil the following conditions:

- (i) Rehabilitation must accompany control of the disease.

If there is no adequate control of the disease in a community then rehabilitation of a small number of cases has limited value and is ultimately frustrating.

- (ii) Rehabilitation must include care of hands, feet and eyes simultaneously.

It is of little value to spend much time over hand repair if the patient is allowed to become steadily blind, or crippled in his feet. No care is properly undertaken that does not include regular inspection of hands, feet and eyes.

(iii) Rehabilitation is largely non-surgical.

The urge to achieve a spectacular surgical 'miracle' must be kept in control. Surgery has a definite (limited) place in a planned scheme of treatment. It has no place as an isolated tour-de-force, stimulated by the reading of a paper in a medical journal.

Non-surgical rehabilitation includes normal physical therapy exercises, movements and such helps as heat (waxbaths, etc.) or electrical stimulation of muscle. Because of the frequency of plantar ulceration, plaster therapy and a sandal-making department are essential. Limb-making enables more serious cases to be treated.

The training of the patient in the care of his anaesthetic limbs is an important part of therapy. It is the writer's experience that where a patient is unable or unwilling to understand how he damages himself and how to avoid further damage, it is better to abandon this patient and concentrate on the more co-operative and intelligent. It is common for women of low education to be particularly unco-operative in this respect.

(iv) The 'surgery of repair' is a special technique.

The operations involve tendon transfers, skingrafting and such bone-interventions as arthrodesis. Apart from the necessary skill in what are essentially skilled procedures, the facilities for adequate surgical sterility in the operative field must be present. Infection that would pass unnoticed in abdominal or general surgery can wreck the delicate mechanisms of the hand and a partly paralysed hand is of more use to a patient than a hand completely crippled by ill-advised surgery. No one should attempt surgery of this kind who has not seen what is involved by experience at a centre where these procedures are normally undertaken; he should have become competent not only in the procedures themselves but in the maintenance of sterile theatre technique and the associated physical methods of rehabilitation.

The Care of the Totally Disabled

No one can fail to be moved by the sight of patients totally disabled by destruction of hands, feet and eyes in leprosy.

Obviously, something should be done to help them. But the worst thing is to allow policy to be directed by emotion and not by intelligence. The following considerations must be borne in mind when such work is being considered:

(i) Some damage is irreparable.

A patient with practically no fingers, with grossly distorted feet and partially or totally blind is probably a complete loss from a

medical point of view. This does not at all detract from his value as an individual, but it is wise to accept what is medically inevitable. Usually his leprosy is 'burnt out' and further leprosy treatment is uncalled for. The treatment of these cases is a problem in social welfare and not in medical care. In a modern Welfare State, these patients will be helped but it is not wise to use any notable part of a limited medical budget to attempt what is medically impossible, if by so doing those who can be saved are deprived of treatment. This applies not only to the use of money but also to the use of personnel which is also limited in most places.

It is the opinion of the writer that it would advance the cause of leprosy treatment to separate these cases, mentally and physically, from other patients and consider them as a special non-medical problem.

(ii) Some damage which is 'irreparable' may be reparable with new techniques.

A good example of this is the patient with grossly damaged feet who may become rehabilitated when cheap and effective artificial limbs become available. Present developments, especially in plastics, make it possible that at any time now these useful appliances may become practicable and cheap and attention should be paid to journals that describe them. It is regrettable that professional appliance-makers tend to emphasize their elaborate (and expensive) products and do not pay sufficient attention to the provision of cheap efficient ones.

There are also many cases in which techniques exist but are not readily available, locally. A good example of this is the repair of the collapsed nose of leprosy which is a considerable handicap to a young patient, especially a girl. The plastic repair of this is, to a plastic surgeon, a fairly simple procedure. Unfortunately the great majority of patients needing this intervention are far from centres of specialists who can perform it. The damage is therefore irreparable in the circumstances.

(iii) Some patients do not want to be rehabilitated.

No one can be helped who does not want to be helped; and it is an unfortunate thing that many patients view the prospect of rehabilitation (and the possibility of being asked to return home) with positive fear. Anyone with experience in leprosy knows of patients who will purposely damage their hands or feet, or provoke a reaction by overdoses of sulphones so as to avoid being considered as suitable for return home.

The blame for this is partly on the community at home who may not welcome him, but a share must be taken by ourselves as medical men who have (albeit in all good faith) built up a tradition in which leprosy patients expect to be cared for till death.

It is human weakness to prefer to be fed, clothed and housed without personal trouble, than to have to get up and make an effort for these things. This is true whether a person is affected with leprosy or not. We must accept part of the blame for having encouraged this, and do what we can to reverse the process. The problem is often more psychological and spiritual than physical.

Summary

1. The need of a clear policy for treating leprosy is emphasized.
2. The main needs are for: the control and treatment of the early case, the rehabilitation of the partially disabled, and the care of the totally disabled.
3. These basic schemes are discussed and the importance of a clear and intelligent choice is underlined.

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