

## The Role of the Leprosarium<sup>1</sup>

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The general public still tends to look upon leprosy with fear, and the idea of total isolation for prevention of the disease continues in the mind of the general public and at times the medical profession as well.

There has been a welcome change of outlook, however, in regard to the problem of leprosy. This, together with gradual improvement of living conditions, better roads and transportation facilities, and advancement in medical knowledge, are factors that made possible, through modern treatment, a possibility of eradicating the disease in the foreseeable future. It is, therefore, pertinent to review the position of this disease in regard to the total problem of leprosy. While it is a fact that the man in the street looks upon leprosia as institutions that separate leprosy patients from the general community, the role of the leprosia is far removed from this conception today. This change has been brought about by advances in treatment, and the general acceptance of outpatient facilities, allowing patients to remain at home. A change of the institution policies is therefore necessary in order to keep abreast with advances in our knowledge. Admittedly, it will be difficult or impossible to make sweeping changes overnight. But a constant attitude of self-reevaluation will allow gradual improvement, the rewards of which are more efficient service to those suffering from leprosy and the provision of a basis for the eventual control of the disease in the community (<sup>1</sup>).

The problems of a leprosarium are many and varied, but it seems that to some degree all share similar basic issues. Insufficient resources, a paucity of qualified workers, lack of continuity in treatment

programs, and poor public knowledge and support, are a few of the more important frustrations. Although they are also the problems of medical development in general, they are magnified to greater proportion in the leprosarium, and one of the main contributing factors in the "isolation" policy that is practiced by so many institutions. Autonomy may look good in beginning years, but in the long run it will prove to be a handicap to the leprosarium that wants to be something more than an institutional facility for those suffering from leprosy. Leprosy patients should be able to get general care at general hospitals, and routine leprosy treatment should be included in that general care. It will be recognized that it is physically impossible to have special hospitals just to treat leprosy patients adequately. The fact is that they are denied this care at local hospitals and are forced to congregate at the leprosia. It therefore becomes increasingly important for a leprosarium to identify itself with the existing medical scheme of its country and to integrate itself into the thinking of the community. (<sup>2</sup>).

What, then, is the role of the leprosarium in the community? Let us examine some important functions of the leprosarium in the light of an integration policy.

### THE LEPROSARIUM AS A REFERRAL CENTER

Leprosy, as does many other diseases, has its own specialty and the complications of the disease can often assume proportions that should be handled only by an experienced person. Such problems as erythema nodosum leprosum (ENL), drug reaction, eye problems, and nerve involvement can be best treated by a specialist in a leprosarium. Lepromatous cases are often best handled in a leprosarium until the bacterial index has been appreciably reduced (<sup>3</sup>).

It is important that the agencies of the

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community referring patients be informed as to the type of patient to be sent to the leprosarium, so that the leprosarium does not become a dumping ground for unwanted humanity. Therefore, certain protocol should be established so that funds are not wasted on needless trips to a distant center.

Leprosaria can also make use of visiting specialists from other fields, for example, pathologists, orthopedic and plastic surgeons, and general physicians who can be brought in in a consultant capacity. In this way the total picture of leprosy is integrated with the total service of the community and a more complete service can be offered to the patients in the leprosaria.

#### THE LEPROSARIUM AS A REHABILITATION CENTER

As the level of care for leprosy patients is raised, it is desirable to offer rehabilitation for those disabled by the disease. There are two reasons why the leprosarium should enter this field: (1) to allow patients a means of becoming independent, useful citizens, and (2) to help erase the pathologic dread and morbid hopelessness that many people have of the disease. Rehabilitation is a field well suited to the leprosarium, whether it is an old institution or a new and developing facility. It should be recognized that it is possible to do at least some rehabilitation in nearly any situation and that it can be developed as resources become available. Occupational therapy and disability education can be started at a low level and remain there for any length of time, the results being commensurate with the effort invested. Cloth weaving and basket making are remunerative trades that are easily learned, and the patient will have some satisfaction in doing productive work. A patient who learns a skill can teach the next patient, so that the scheme can be perpetuated with little supervision once the project is initiated. From small beginnings, occupational and vocational therapy can be developed and thus pave the way to adequate rehabilitation and ultimate absorption of patients into the community.

Lately it has become popular to undertake reconstructive surgery, and in order

that this may be complete it is essential that the patient be absorbed into society. If this objective is not achieved the whole purpose of reconstructive surgery is lost. It would be wise to advise a developing country to assess the situation realistically, for to launch out on a program of reconstructive surgery before general medical care is well established would be very short sighted (<sup>4</sup>). If such a situation exists and the supporting body wishes to develop independently, it should take into consideration the fact that it may have to maintain the work for many years before the government can absorb it successfully into its national health scheme budget. (<sup>3, 6</sup>).

Once the decision is taken to have a rehabilitation program, adequate provision should be made to reach a certain goal, viz., the production of useful, independent citizens. If elaborate tendon transplants are carried out successfully, the operated hand will still be useless unless there is adequate physical and occupational therapy to bring it through the healing phase and teach the patient to use his newly arranged muscles. And even after that is accomplished successfully, the net value of the man to himself and his community may still be naught if his social readjustment is not complete. Leprosy, being a long-term illness, has a tendency to foster a state of apathetic dependence that makes a man a social cripple. Little incentive is left after years of getting food, shelter and clothing free. (<sup>4</sup>). In addition there is the fear of returning to the "outside" world that formerly rejected him. For these reasons a social welfare department should be developed parallel to the rehabilitation program. This is a vital link between the leprosarium and the community, and can thus be one of the best ways to dispel a misunderstanding of leprosy.

Being one of the most neglected areas of rehabilitation, social reinstatement is often totally lacking as a part of the leprosy treatment scheme. The neglect is not without good reason, since it is nearly impossible to recruit a staff of social workers in the face of more elemental needs. However, one solution that has been used with success is to integrate it into the work of

local missions and service clubs if cooperation can be achieved. These organizations are already established in their communities and therefore can help in placement, job arrangements and encouragement. The leprosarium, of course, will have to assist in the establishment of operational principles of such a scheme, and some education and training will be necessary to acquaint those involved with basic methods. This, too, will be one more way in which the community can become involved in the treatment and acceptance of its leprosy sufferers.

There is considerable merit in having a strong rehabilitation program, aside from the economic and personal aspects of restoring a useful, productive person. By tradition leprosy is feared because of the deformities that occur in the neglected case. If the public can be taught that leprosy is not the hopeless disease of years past, but a malady amenable to treatment, as in the case of any other disease, it will be an immense help in obtaining cooperation in every phase of leprosy work. We must not underestimate the value of the hope that a rehabilitation scheme offers to the recovering patient. There is little that can be done for a patient who is too apathetic to cooperate. The greater the enthusiasm and hope of the patient for his treatment, the better chance there is for therapeutic success.

The surgical rehabilitation facilities need not be limited to leprosy patients, as they may be the only such facilities in the area (<sup>4</sup>). Plastic surgery for deformities caused by yaws, congenital malformations, and trauma, can be accomplished as well, and the impact for integration of leprosy treatment into the community structure will be greatly augmented.

A shop capable of producing prescription shoes is not only a good adjunct to therapy but it is necessary for the prevention of further disability. Such a shop can be staffed by patients and once in operation will require minimal supervision. As resources permit, the facilities can be expanded to include the manufacture of simple prostheses. As much as possible, these facilities should be open to cases other than

leprosy, as this will further strengthen the relationship between the leprosarium and the existing health scheme of the community.

Occupational therapy should be expanded to include vocational therapy, and jobs should be tailored to fit the disabilities of the patient. Care should be taken to find jobs that will be accepted by the community to which the patient will some day return. Literacy will be of help in giving him some status and self respect and should be encouraged by the provision of classes. Local missions and volunteer organizations will also be of benefit in organizing this endeavor.

#### THE LEPROSARIUM AS A RESEARCH FACILITY

The leprosarium should maintain a continual alertness for possible investigations of leprosy (<sup>6</sup>). This should be encouraged not only in strictly medical research but also in the associated fields of physical therapy, occupational therapy, nursing, and social work. Elaborate laboratory facilities are not necessary for significant research, but an open mind and an inquiring interest are prerequisites. Primitive facilities are in many cases the very basis for research because one must develop methods of overcoming these situations. The publication of such methods will be a help to others who are in a similar situation.

Accurate records should be kept by the leprosarium on its patients, as these may provide information for a statistical survey.

As in rehabilitation, some research can be done whatever the level of development of the leprosarium. As staff and money permit, greater sophistication can be developed, but we must not underestimate the value of even the most humble of efforts.

Good public relations can be strengthened by keeping the community informed about research progress. This will better the status of the institution in the minds of those who are better educated and will put the fight against leprosy on the same plane as other scientific endeavors.

### THE LEPROSARIUM AS A COORDINATION CENTER FOR LEPROSY CONTROL

The achievement of leprosy control in a country is a task that will require the assistance of many agencies, institutions and individuals. In many instances, the leprosarium will be the largest, most nearly complete and most nearly permanent establishment in leprosy work, and, if it is well located, it can perform a great service in the coordination of the efforts of all engaged in this work.

Accurate records should be kept, as these will prove invaluable in judging the progress and direction of eradication programs. It will probably not be the function of the leprosarium to direct the program, but it can offer technical advice, compile statistics, analyze reports and records, maintain storage facilities, and thus be a common meeting place or a clearing station for those involved in leprosy work. In this way there will be less duplication of effort, and interested persons will be sure of having a ready source of current information to use as a guide for expansion and progress.

The leprosarium itself will also benefit because it will have a better idea of where to refer its patients after they have finished their treatment in the leprosarium.

### THE LEPROSARIUM AS A TEACHING CENTER

Education is the fundamental basis whereby we can enlist the help of others in the fight against leprosy. Integration with other facilities cannot be accomplished without the consent of the community and greater understanding is the only thing that will bring consent.

If ever comprehensive care for those suffering from leprosy is to be realized in the community, the basic principles must first be established with the members of its medical profession. In spite of good education, the majority of today's medical workers have a fear of leprosy that interferes with the rational treatment of the disease. It falls to the leprosarium, therefore, to fill in those gaps of knowledge and thereby make it possible to achieve the rapport necessary for cooperation.

A good approach is to interest the doctor, nurse, or technician in the scientific aspects of leprosy treatment, and, in doing so, lectures, seminars, publications and personal contact will be valuable modalities. Each leprosarium worker can become involved in teaching within his own field and therefore each should keep up to date on the latest developments that apply to his work. In developing countries there is a demand for leprosy workers, especially where there is an active outpatient clinic scheme<sup>(6)</sup>. Traineeships for medical assistants, leprosy dressers, welfare workers and others to help in the rural clinics are needed and the leprosarium is a logical place to undertake such training. This training should not be restricted to raw recruits; schools of nursing and medicine should be encouraged to include leprosy nursing and leprology in their curriculum.

Liaison should be maintained also with medical institutions abroad to ensure an active interest in the study of leprosy. In some instances a medical student may be allowed to come to a leprosarium for three to six months of work as a special project in his curriculum. In later years such students may provide a source for staff replacement and expansion or stimulate ideas for research in leprosy.

Finally, there is the enormous task of educating a reluctant public. If one has the best hospital, the most qualified staff, and all desirable supplies, progress still will not be made without public consent and cooperation. Public talks, poster campaigns, and inclusion of leprosy in health education in schools, are methods that can be used. Equally important is the public image of the hospital. If the hospital is dirty, unkept, surrounded by high fences, and peopled with sad, unkempt wretches, the public image will be frightening. In contrast, a pleasant well kept institution where patient morale is high, will be an effective advertisement for visitors to see. And visitors should be encouraged to come!

### CONCLUSIONS

It is realized that the foregoing presents an ideal, a goal to strive for. It would indeed be an unusual institution that could

be all these things. Some writers feel that the leprosarium should specialize only in one phase, such as rehabilitation, the care of the burnt-out case, or the control of early infection (<sup>4</sup>). It may be that this is a realistic, practical approach, but the broad principles set forth herein apply in some degree to every leprosarium. Whatever the course followed, care should be taken to maintain a plan and not let the institution evolve spontaneously. The direction of effort must be tempered with the needs of the community, the resources available, and the interest of the staff and sponsors. The priority of preventive measures over rehabilitation measures should always be given its proper place, as the leprosarium should be an integral part of the eradication plan.

Finally, the principles in integration and nonisolation of the leprosarium from its environment will be found to be of value in obtaining better care for leprosy patients, as well as an increased alertness for prevention and early treatment.

#### SUMMARY

The concept of integration of the leprosarium into the community structure is discussed and the advantages of such a policy are given. The role of the leprosarium as a referral center in rehabilitation, research, leprosy control, and education, is related to community structure. Practical suggestions are given for attaining this goal.

#### RESUMEN

Se discute el concepto de integración del leprosario en el seno de la comunidad y las

ventajas que tal política trae consigo. El rol del leprosario como un centro de referencia en rehabilitación, investigación, control de la lepra, y educación, está relacionado a la estructura de la comunidad. Se dan sugerencias prácticas para alcanzar este fin.

#### RÉSUMÉ

On discute dans cet article du concept d'intégration de la léproserie dans la structure communautaire; les avantages d'une telle politique sont exposés. Le rôle de la léproserie comme centre de référence pour les activités de réhabilitation, de recherches, de lutte anti-lépreuse, et d'éducation, est mis en relation avec la structure de la communauté. Des suggestions pratiques sont émises en vue d'atteindre ce but.

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