THE STIGMA OF LEPROSY

It is trite to remark that the sufferer from leprosy has to bear a double burden—the disease itself, and the stigma that goes with it. In this issue of Leprosy Review contributors with different backgrounds examine the concept of stigma in leprosy, share their personal experiences of its reality, make suggestions for modifying or removing the disfiguring disabilities that characterize the disease, and, finally, enter an impassioned plea for the abolition of the term “leprosy” (and its cognates) in the hope that this will reduce its stigma.

Stigma is a complex thing. Originally, the word denoted marks made by a pointed instrument or a heated iron. It thus took on the meaning of branding of the skin of man or beast to indicate ownership or subjection. It could be a sign of guilt or disgrace, of infamy or shame. More recently, the root etymological meaning has been extended to embrace any departure from a physical norm, or any obvious defect suggestive of a certain condition or disease. A stigma is undesirable, reprehensible or objectionable. As used in regard to leprosy, stigma refers not only to the characteristic visible physical signs of paralysis, ulceration, and deformity associated with advanced peripheral neuropathy, but also by extension to the whole gamut of irrational fears and prejudices under which the leprosy victim suffers. Some folk even claim that leprosy has its own special “smell”—nauseating and repelling. The invisible can be more dreadful and more dreaded than the palpable—and equally stigmatizing.

The historical association of visible blemishes with ceremonial defilement also plays a part in the development or persistence of stigma in many cultures, and not only in the Judaeo-Christian. It is noteworthy that in the course of centuries an enhanced dread of “leprosy” has emerged pari passu with a diminution of the ritualistic “uncleanness” of, say, mildewed cloth or fungal plaques on damp walls. Yet for most people in the Western world, the stigma of leprosy depends less on personal encounters with the condition than on hearsay and folklore. Amongst the educated strata of society, not excepting medical men, a curious dichotomy of thought is frequently to be observed: there may be a conscious and intellectual acceptance of the scientific facts about leprosy, and at the same time a subconscious rejection of these facts in favour of traditional beliefs.

There are, of course, other conditions besides leprosy associated with stigma; for example, epilepsy, facial disfigurement from whatever cause, mental defect, and congenital deformities. Other groups of people suffer social or psychological disabilities to a degree that depends on subjective factors; blindness, for instance, enlists more sympathy than deafness, and the victim of poliomyelitis than someone suffering from a venereally-acquired disease. The degree of stigma may be partly correlated with nomenclature and semantics: the “lunatics” and “consumptives” of a former era certainly had their cross to bear. Some skin abnormalities may be stigmatizing by reason of diagnostic confusion or
uncertainty: the "white leprosy" of India and countries of the Near East makes of vitiligo an abhorrent disease, and infuses psoriasis with an unwarranted morbidity and contagiousness.

Stigma in leprosy is determined by a wide range of changing variables. It may be completely absent in some communities where the prevalence is so high that "everybody gets these light patches on the skin sooner or later, but most of them go away on their own." Although no stigma may attach to the hypopigmented cutaneous lesion, the fear of the discharge from ulcerating extremities may be such that when that stage is reached the victim is abandoned in the bush to fend for himself, or to die. Similarly, with madarosis: to some, absence of eyebrows is a sign of active leprosy, and is feared; to others, accustomed or not to the cosmetic plucking of the eyebrow hairs, it carries no stigma. In countries where saddle-back nose is more frequently due to tertiary yaws than to leprosy, this deformity has no stigmatizing character. In some situations, other skin diseases—especially if ulcerating, obvious, chronic, malodorous, or occurring on the face—may be more potentially stigmatizing than leprosy.

In some localities, other conditions which occur in people suffering from leprosy are part and parcel of the stigma of the disease, for example, enlarged cervical nerves, wasting of the first interosseous space, hanging ear-lobes, gynaecomastia, etc. They are recognized by the laity as due to leprosy, and frequently regarded moreover as evidence of active disease. Protective footwear and such appliances as foot-drop springs may stigmatize the wearer as suffering from leprosy.

If the stigma of leprosy varies with the population concerned, it is generally true that leprosy is characterized by a fear unparalleled in any other condition, and associated in the lay mind with the deformities of advanced nerve damage. Folklore lends widespread support to this view. The possibility of deformity, even the inevitability of deformity, looms large in the individual and corporate subconscious. The prospect that the disease will progress and lead sooner or later to social rejection, unemployability, starvation and physical suffering, is reinforced by observation and by communal lore. Even when treatment becomes available, these fears of recognizable stigmata often prove impossible to eradicate. Patients themselves may imagine slight departures from the normal in their physical appearance, and between them build up a corpus of beliefs about the stigma of their common disease.

Again, stigma in leprosy may be created de novo where it did not before exist, by the well-intentioned efforts of those concerned to do something for a neglected human problem. By concentrating on the relief of patients in one category—to the disregard of those suffering from other widespread endemic diseases or from malnutrition—such activities may inculcate the concept that leprosy is after all somehow different, and requires its own medical and organizational control procedures. Over-emphasis by visual misrepresentation or emotive phraseology may actually confirm prejudices, and so render the educative task of diminishing stigma the more difficult and protracted.

Voluntary agencies thus have a difficult rôle to play in their continuing and just concern that the victim of leprosy shall be regarded like any other human being, able to get treatment and employment. Their propaganda and fund-raising activities must eschew the easy way that may, as an undesirable side-effect, tend to increase the stigma (and hence the suffering and resentment) of those they purport to be helping. It is not easy, in focusing attention on a single problem, to
avoid perpetuating the stigma of leprosy, just as the maintenance of specialized
and rehabilitation services may have the same unwanted result. They should view
their particular interest in the context of related medical and social needs. With
equal cogency, it may be added that governments that subscribe to the Bill of
Human Rights and supported the Human Rights Year sponsored by the United
Nations might enquire if in law and practice there is in their countries any
discrimination against those who suffer from leprosy, whether or not they bear
any disfiguring marks attributable to the disease.

Personal observation reinforces information from reliable sources that to this
day in some countries the branding of any citizen as a “leper” in practice
automatically means that he is deprived of all human rights—to hold property, to
marry or remain married, to work, to live where he wishes, to obtain medical
treatment. He is deprived of liberty and livelihood. Stigma means cruelty and
suffering.

For some, stigma resides rather in words than in the disease itself, more in the
accumulated pejorative connotations of “leprosy” than in the actual physical
manifestations of the disease or its sequelae. The weight of this argument is felt
particularly by our South American colleagues. Perhaps the word “leprosy” needs
rehabilitating, deprived of all stigmatizing content and given international
respectability. If we could by education remove the accidentia of the word
“leprosy”, perhaps the stigma would go and the social part of our task would
lessen.

. . . . “That which we call a rose
By any other name would smell as sweet.”

As Dean Swift so rightly enquired, “If the physicians would forbid us to
pronounce the words [of certain diseases], would that expedient serve like so
many talismen to destroy the diseases themselves?” The epithet gets attached to a
person of normal appearance, who at once becomes invested with the imagined
signs of advanced disease. The label sticks. The dog is given a bad name, whether
it deserves it or not. The word “leper” is officially banned; should not “leprosy”
go the same way?

Another area of conflicting assumptions related to the stigma of leprosy is
concerned with the increasing secularization of the disease. As in many countries
and in many cultures the traditional association of leprosy and Divine displeasure
becomes more tenuous and less tenable, so the aura of mystique will diminish and
the linking of stigmatizing deformity with morality and punishment will tend to
disappear. Voluntary agencies, which still account for a much-appreciated
proportion of funds and service devoted to leprosy and leprosy sufferers, should
be relating their publicity and fund-raising activities to the changing situation if
their appeal is to retain its credibility and impact. Similarly, segregation of
patients in leprosaria for long periods may perpetuate the stigma as well as
constitute a permanent charge on government or donor agency.

Sir Winston Churchill’s fine dictum about crime and criminals might with some
justice be adapted to stigma in leprosy: “The mood and temper of the public in
regard to” its attitude to leprosy and those who suffer from leprosy “is one of the
most unfailing tests of the civilization of any country”.

This, then, is the situation as depicted in the articles that follow, and this is the
task to which all who work in leprosy must not fail to address themselves. To
diminish fear, to remove prejudice, to educate the public (not forgetting the
doctors, the politicians, and the rising generation), to mitigate surgically the physical bases of stigma, and to prevent their occurrence by proper medical treatment—these together should reduce the burden of stigma which far too many leprosy sufferers are still compelled by society to carry.
News and Notes

HIND KUSHT NIVARAN SANGH

The only report for 1970 of the Tamil Nadu (Madras) State branch of the Hind Kusht Nivaran Sangh gives a factual and readable account of the activities of Government and voluntary agencies within the State. The good hand of Professor T. N. Jagadisan, the honorary secretary of the branch, is evident in the accounts given of good work done, and of the happy co-operation of voluntary agencies and the Government in leprosy control programmes, in teaching, and in research.
Are Deformities Stigmatizing?
A Surgeon's Approach*

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Disability in leprosy is often equated with the degree of obvious deformity. The patient's psychological approach to his disease influences his disability. The reconstructive surgeon can in many cases assist in rehabilitation by correcting stigmatizing deformities that constitute an obstacle to the patient's acceptance in the community.

The non-leprosy worker hears much about the disabilities that result from leprosy and comes to assume that every patient is excluded from normal social intercourse because of this disease. However, persons with marked disabilities of many types from causes other than leprosy appear to be fully accepted by their fellow men.

The leprosy patient is very self-conscious of any sign of the disease that he feels, may advertise to others that he has or has had leprosy. His association with other leprosy patients and his own experience of the disease make him very aware of any small change in himself, and he assumes that everyone he meets will conclude that this change is due to leprosy.

Enquiry amongst mixed groups of young people, mainly students in Hong Kong, reveals that most of them have no real concept of the specific signs of leprosy. "The claw hand" is the commonest sign quoted, but this would only be recognized in its gross form and would probably include lesions from other causes that result in stiffening of the fingers or marked flexion in even a functional position. "Stumps and amputations" are also mentioned—but again no differentiation between surgical or accidental amputations could be made.

Much of the problem connected with stigma is in the minds of the patients themselves—who pass on to one another all the stories they know of people who have been rejected and ostracized, and assume that they face a real problem in trying to be accepted by society. Some will not even try to be accepted, but those who do are often very surprised. For example, a young man with five lesions of the borderline-tuberculoid type on his face was asked to see his ex-employer with a view to resuming his old job. The lesions, although fading, were still erythematous and visible; yet his employer was not concerned about the patches.

It would appear that although leprosy, "Ma Fung" as it is locally called, is still greatly dreaded by the older generation, it is feared less by those under the age of 30 who would not recognize the less severe deformities, and certainly do not worry about a disease called "leprosy" unless personally confronted with it by name.

* Received for publication, 14 February, 1972.
Yet for many patients the presence of any obvious lesion of the skin, or other physical deformity, is an insurmountable obstacle to acceptance. For many of these, surgery will help the psychological problem, for they think that if they are questioned about the lesion, they can say they have had an operation or an accident, and show the scar as proof.

In other countries, the signs of leprosy are of different stigmatizing import. For example, in some areas of New Guinea it is a social custom to cut off fingers as a sign of mourning; the loss of fingers is therefore not necessarily connected with leprosy. In countries where people are greeted by placing the palms of the hands together in a “salaam” (e.g., Thailand), the presence of a crooked fifth finger is a real disability and the patient may ask for it to be straightened by arthrodesis, though not in a position of function, so that he may feel socially more acceptable. Social customs do influence the patient’s attitude to the disease and must be given due weight when deciding on the course of treatment to advise. The same basic problems are present in all the countries of South-east Asia. However, their incidence varies in different countries; this may be due to racial differences in the host-parasite relation.

Some of the methods of correcting the common deformities are described by Antia and by Brand in *Leprosy in Theory and Practice* (Eds. Cochrane and Davey, 1964). Many other procedures are described in surgical text-books and journals; only a few references will be given in this paper. The most common deformities about which a surgeon is consulted are those affecting the face, the hands, and the feet.

1. THE FACE

Even if the patient has multiple deformities, he is usually mainly concerned about those on the face, since he feels they are the most obvious and hence carry the greatest stigma.

The surgeon who is interested in restoring a face to social acceptability must study the faces of the community from which the patient comes. He will be surprised at the variations present in a national group that may at first sight give the impression of uniformity of features.

(a) *Nose.* Deformity may vary from scars, due to ulceration, to total collapse, with or without loss of the columella. In lepromatous leprosy destruction of the septum is a comparatively late complication, but the skin of the nose is usually still intact and a post-nasal epithelial inlay allows the contour to be built up with the aid of a graft of bone or cartilage. In selected cases, an internal prosthesis may be used instead of the bone graft. Although Crockett’s method (Tovey, 1965) may save time, the two-stage procedure gives more reliable results in the hands of the occasional operator. From experience it may be affirmed that these procedures give a cosmetically acceptable result that provides permanent improvement in a patient in whom the disease is fully controlled. Mongoloid races usually ask for a straight nose but do not require a high tip, and a columella strut is therefore rarely required; the latter is more important for races with more prominent noses.

(b) *Eyebrows.* Partial or complete loss of the eyebrows is a common result of long-standing lepromatous leprosy in all races, and especially worries those who have bushy eyebrows. It is not a problem with Chinese women, who often pluck their normally scanty eyebrows.
The method of replacement will depend on the quality of eyebrows required—thick ones require temporal artery island grafts, but scanty ones will often look more normal if replaced by individual hair follicles or punch grafts such as are now used for baldness of the scalp. In the Chinese, free grafts of post-auricular hair-bearing skin provide soft, fairly thin grafts which are very acceptable (see Fig. 1). If the patient can be induced to wear heavy-rimmed glasses many people will never notice defects of the eyebrows, eyes or nose (Fig. 2).

Fig. 1 (a & b) Loss of eyebrows replaced by free grafts of hair-bearing post-auricular skin.

Fig. 2 Defect of eyebrows and right eye are not obvious with heavy-rimmed glasses.
Although loss of eyebrow hair appears to be a universal complication of lepromatous leprosy, scalp baldness is not. Alopecia due to leprosy does, however, affect the Japanese, and was a real problem until wigs became popular and fashionable.

(c) Ears. Residual bagginess of the ear-lobes is easily trimmed by routine plastic measures, but such bagginess is not a stigma in Dyaks and other peoples who stretch the ear lobes (Fig. 3).

![Fig. 3 Baggy ear lobes—before and after trimming.](image)

(d) Facial palsy. This may often affect an eye and/or the mouth, and may be unilateral or bilateral. Facial paralysis from many causes is common in Asia, and many sufferers do not realize that anything can be done to relieve the inconvenience of constant dribbling from the mouth, and difficulty in eating and drinking. Constant watering of the eye and conjunctivitis are accepted as inevitable, and when ignored frequently result in blindness or diminution of vision.

Patients on whom temporal musculo-fascial transfers have been performed are generally grateful for the improvement in appearance and comfort, even if normal facial movements cannot be restored (Fig. 4). In the older age group, active muscle transfer may not be practical and in these patients with temporary paralysis of the orbicularis oculi, tarsorrhaphy will help preserve vision. Internal tarsorrhaphy (Warren, 1966) provides a more cosmetically acceptable procedure than lateral tarsorrhaphy.

Surgical procedures aimed at preventing blindness are a very important part of the surgical programme; it is not always possible to prevent diminution, or loss, of sensation, but the combined problem of blindness associated with loss of feeling in hands and feet should be forestalled.

(e) Facial skin scars are often difficult to remove, but the more severe ones can sometimes be improved. A face-lift may help to rejuvenate the prematurely aged. Patients develop an amazing trust and confidence in the surgeon and expect wonders to be performed. Their enthusiasm needs to be curbed! Deformities may also be due to non-leprosy causes; these may need to be dealt with before the patient can be confident that he will be socially accepted again.
Fig. 4 (a) Facial palsy—notice drop of lip on patient’s right side and increased width of palpebral fissure; (b) same face after use of temporal musculo-fascial transfer to the eye and a fascial slip to elevate the angle of the mouth.

2. THE HANDS

The commonest deformities for which correction is sought are loss of lumbrical function and loss of thumb opposition. These can be corrected by such routine methods as the Brand "many-tailed" procedure, using a wrist extensor as a lumbrical replacement and a sublimus tendon to provide opposition of the thumb. However, before any surgery is begun the hand should be carefully assessed for muscle power and mobility, and a surgical plan devised. Instability of the thumb metacarpo-phalangeal joint may result from ulnar-nerve involvement and may on casual examination appear as loss of median-nerve function. It can best be dealt with by an arthrodesis of the affected joint, providing a strong stiff thumb. The patient may request arthrodesis of the interphalangeal joint in these cases, but if this is done more disability may result. Flexion and extension of the interphalangeal joint of the thumb is a very useful function and should be maintained if possible.

Even in the replacement of a lumbrical loss, consideration should be given to the patient's use of his fingers. A lumbrical inserted on the ulnar side of the index finger may provide good adduction and so improve the ability of the Indian patient, for example, to pick up rice balls, but will be a disadvantage to the Chinese patient who needs to abduct the index finger to use chopsticks. Hence in Chinese patients the index lumbrical should be placed on the radial side of the finger. "Claw hand" is stated to be the most easily recognized stigma, but few people seem to differentiate between the true claw hand, resulting from median and ulnar paralysis, and fixed flexion deformities from other causes. Many patients with badly deformed hands have no desire for reconstructive surgery, since they have learnt to cope with them as they are; this would suggest that at least for them the stigma is no great problem.
However, patients do present asking for surgery for what we may think are minor problems—crooked fingers, enlarged nerves on the hands, and wasting of the hands due to atrophy of small muscles. Chinese leprosy patients are very conscious of wasting of the muscles of the thumb web; the cavity thus formed is known as “Tiger’s mouth”. Methods of filling out the space are sought and many patients are seen who have had a paraffin injection into the space. This frequently results in a hard mass which contracts and tethers the thumb in the adducted position, and this mass may have to be removed before any real reconstruction can be attempted. Contracture of the thumb-web from any cause limits abduction of the thumb; to achieve a full range of movement, a skin graft is often desirable, but this is frequently refused as the patient feels the graft is more stigmatizing than the limited movement of the thumb, and one may have to be satisfied with doing a Z-plasty to deepen the web and give a little more range of movement (Fig. 5).

Dermofat grafts have been used to fill out the space, but many of these are absorbed after a few years and the deformity recurs; or else they become small

Fig. 5 (a) Typical “Tiger’s Mouth” due to atrophy of small muscles of thumb web; (b) pellet that has resulted from use of Ivalon to fill out space; (c) web filled with Eicon.
hard masses. Plastic and silicone materials have been tried, but again, some of these tend to form hard pellets. The ideal material must remain soft, be non-reactive, and permanent. The nearest approach to this is a Japanese material, Elicon, which we have been using for the past 6 years.

Most patients, unless they are resident at a centre where a considerable amount of reconstructive surgery is done, have little or no idea of the possibilities and are very hesitant before allowing their hands to be operated on, until unfortunately these have become almost useless. Those who have seen what can be done come to expect miracles, and believe that any crooked finger can be straightened and restored to normal function.

Sometimes it is a matter of increasing the deformity in order to decrease the disability, as in the case of complete, or almost complete, loss of the length of all the fingers and the thumb. This leaves a stump of a hand that cannot by itself hold anything. Removal of one or more metacarpals will create a cleft that changes the stump into a two-finger hand—or "lobster hand" (Bunnell, 1944)—with which a patient can feed and dress himself and may learn to write, weave, or do other handwork [Fig. 69(b)].

3. FEET

Very few patients spontaneously present themselves seeking removal of stigma of the feet, probably because much can be hidden by shoes and trousers. They do
not seem to worry about dropped feet as long as they can get around, and rarely seek help until marked disability from ulceration and infection has occurred. They dislike wearing toe-raising springs as they feel these will advertise their disease, though once admitted to a sanatorium or hospital they will acknowledge that the spring does make walking easier. In leprosy, the feet frequently become deformed to a degree where normal shoes cannot be worn without causing more ulceration. Special orthopaedic footwear may be ordered, but here in Hong Kong, and in some other countries, this footwear will not be worn as the patients feel it advertises their disease. Hence we have adopted the routine of remaking the feet so that normal soft shoes can be worn. "Make the foot fit the shoe—not the shoe to fit the foot." In this way a period of 3 to 6 months' hospitalization allows for healing of ulcers and surgical reshaping of the feet so that the patient is able to go home in soft-topped shoes with resilient rubber soles that can be bought "on the street". They are easily replaced and are not as expensive as orthopaedic shoes would be, even if these were available and acceptable. Sandals are not acceptable in this area, but a wide range of soft-topped shoes is available, and these have proved very satisfactory and are socially acceptable.

It is interesting to notice how attached patients are to deformed toes, even when these are of no functional use whatsoever and are constantly being traumatized by the footwear. They are most hesitant to give permission for amputation, although this would frequently result in a foot that is much more easily cared for. But many patients do request the amputation of a problem foot—if they have no other deformity—as they feel that in this way they are removing what stigma they themselves recognize. It is often difficult to assess the advisability of such an amputation, since the calf and even the thigh may be anaesthetic; the fitting of a prosthesis is thus a real problem.

**Conclusion**

The reconstructive surgeon who seeks to aid leprosy patients will never be without a challenge to his ingenuity. There are about half a dozen main basic reconstructive procedures which when mastered will meet the requirements of some 70 to 80% of leprosy patients. The remainder will set the surgeon exploring the literature for new methods and techniques to solve problems of the individual—loss of the helix, loss of the columella nasi, contractures of wrist in flexion or fingers in extension, clawed toes and inverted heels—yet the patients develop a real faith and trust in one who tries to help, and often take failures in good part, realizing that some are inevitable. Though some seem to expect to be helped and never express gratitude, many are most profuse, and even overwhelming, in their thanks and some come back years later with a thank-offering to let you know they are still well and the deformity has not recurred. As a group, one could not hope to find more grateful patients. The greatest thanks one can receive is to see a patient who was previously afraid of the world, going back and making good, remembering to care for his hands, feet and face, so that he keeps them in as good condition as possible and so obviates the necessity of further reconstructive or salvage surgery.
References


The Stigma of Leprosy—
A Personal Experience

A MEDICAL MAN

(who, for obvious reasons, writes anonymously)

Leprosy is one of several conditions which the majority of people place in a category apart—and "place apart" is what they do their best to achieve.

From the time when I worked in a leprosarium in Africa, and since then as a doctor in general practice, I have had many opportunities of discussing attitudes to illness, speaking at length and in depth with people who were suffering from infectious diseases which others shun. Leprosy is probably the most feared of all diseases, feared even by those who have never met anyone actually suffering from it.

The potential ravages of leprosy, vividly overdrawn by certain advertisements and fund-raising propaganda, evoke a complex of fears and reactions which other diseases may partly share but none can match. Most of the patients I knew in Africa were outwardly stoical from childhood, taught not to reveal their feelings. As we lived among them, friendship grew and later we gradually learned their inner thoughts. Their experiences differed, naturally. Some had known of several cases of leprosy within their immediate family, or in the locality. Although skin injuries and blemishes are very common, when a pale non-itching area on an African’s skin persists or enlarges, the probability grows that it could prove to be serious. A knowledgeable friend or a visit to a dispensary would allay the suspicion, or confirm it. Sometimes patients were so terrified that they hid themselves until signs of advancing disease made their appearance. In that event, they were usually urged to seek treatment at the leprosarium.

For the patient himself, the future might be bleak and the prospects unthinkable. With little to show in the way of physical signs, they found it difficult to believe that the disease was really leprosy, and some patients refused to believe it for weeks or months.

Then what? Much depends on the family and on local feeling. Some patients were from the first excluded from the family, and deprived of possessions and inheritance. A few had their children taken away and shared out, like orphans, among relations. The wife might be sent back to her own home, possibly in disgrace. In any case, the other members of the family who remained at home shared in the disgrace, and also the fear that they, in their turn, might show the signs of the disease. In some areas, despite willingness on the part of the healthy members of the family to look after a sick relative, local opinion could be so hostile that he or she was forced to leave, to avoid personal danger and the risk of harm to the rest of the family. Sometimes a small group of patients from the same area would travel together to the leprosarium. They had been rejected, sometimes

* Received for publication 22 March, 1972.
reviled, deprived of inheritance, and could look forward to no future. As they met and began to share their troubles, the painful experience of one became the feared expectation of the others.

About 70% of our patients came on foot, some from comparatively nearby, some from distances of up to 300 miles; others managed to obtain lifts on lorries. On the way, they found little sympathy. If they admitted they were going to the leprosarium they would be told stories of hunger and wild animals on their way, to add to their misgivings.

Leprosy patients the world over know despair and bitterness. For them, what is there left to live for? The depth of bitterness they feel has to be experienced personally to be appreciated. You are unwanted, separated from your family, unable to get work; you lose the ownership of your land which provides your food; you have an illness which won’t kill you, like typhoid or malaria, but which is likely to destroy your feet, your hands, and perhaps your face.

For those who arrive at the leprosarium with just a patch or two on the skin and are otherwise perfectly fit physically, it comes as a dreadful shock, as they mix with other patients, to see what might happen to themselves. On the other hand, some were quite unmoved on being told that they had leprosy. There were even patients who seemed pleased. “No more income tax to pay: a blanket free every year; and food when I’m a cripple. I’m better off than I used to be.”

What a cruel disease! True, many are fortunate enough to get treatment, a treatment that is by no means expensive or complex by Western standards, and for the sequelae (such as anaesthesia of the hands, or feet) there are simple remedies such as gloves, wooden holders for kitchenware and cups, easily made sandals, etc. For the more serious complications, such as claw hand, dropped foot, loss of eyebrows, etc., ingenious operations are being devised. With the correction of these obvious marks of leprosy, the cured patient will be much more likely to be accepted in the community.

Regrettably, for the majority of leprosy sufferers in the world today, the attitude of society to the physical disabilities of leprosy and to the sufferer himself is scarcely that to be expected in the 20th century. The title of this article refers to the “stigma” of leprosy. “Stigma” is “a mark branded on a slave; disgrace, infamy, etc.”. I am sad that this still is applied to those with leprosy; it is completely undeserved. Though on the one hand I am ashamed that many continue to suffer physically when medicines and skilled help exist, on the other I am glad that the fight against this disease is steadily being won with advancing research and new treatment. More stable politics and economics, and better health education, would ensure more progress than there is at present.

Many of those who now care for sufferers from leprosy were inspired by Christian motives. They are now being joined by government Health Departments and international relief organizations, as they tackle the huge task of diagnosing and treating the disease and educating ordinary people to admit the innocent sufferers of this slightly contagious disease into the circle of humanity where they belong.
The Phenomenon of Leprosy Stigma in the Continental United States*

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Recent studies on leprosy stigma in the continental United States are presented and critically reviewed. In view of the strong concern about stigma expressed by patients and leprosy workers alike, it is interesting that strong public stigma has not been actually demonstrated scientifically. The evidence is equivocal; leprosy may be stigmatized to some extent, but so are other chronic diseases. The paper advances a social and psychological explanation for some of the more important peculiarities of the phenomenon of leprosy stigma, and concludes that those responsible for the treatment of patients may need to think in terms of alternatives to presumptions of public stigma.

Introduction

Reliable data on leprosy stigma in the continental United States are sparse. Some published reports by patients have provided some information, but such self-reports are subjective and often highly emotional. The other side of the picture, i.e., views of leprosy and leprosy patients by the public, is provided by a number of studies since 1955, although the specific objectives and methods employed have been quite varied. In general, available data, although of various degrees of reliability and validity, present a conundrum: health workers and potential employers feel that leprosy patients are stigmatized, although perhaps professional health workers do not make statements as strong as do non-professionals. Members of the public, on the other hand, seem much more neutral in their attitudes than many have believed. Further, patients report a rather wide variety of experiences, in some of which they were stigmatized, in others not. In this paper we present the available evidence, provide an evaluation of it, and suggest an explanation for some of the more important peculiarities of this phenomenon of leprosy stigma.

Recent Studies of Stigma

In 1959 Shearer and Hoodwin reported a "spot survey" of 149 non-professional and 55 professional workers in the California Department of Public

* Received for publication, 28 March, 1972.
Health. Respondents' reactions to 14 statements such as: "All persons with leprosy should be isolated", "Would you mind working next to a person who had been treated for leprosy?" and "Would you mind waiting in a doctor's waiting-room with a patient with leprosy?" were analysed. "Responses of 80-90% of the professional group were in accordance with accepted current medical knowledge" in most respects. The authors then contrasted responses of professionals to those of non-professionals to items in which professionals were below 80-90% affirmative (see Table 1). The authors summarized their findings with the statement "... the non-professional response seemed to be more closely associated with a general public viewpoint and the professional responses reflected the thinking of a high percentage of medical personnel". No evidence is given, however, on what the "general public viewpoint" is, although it is implied that it is quite negative. There is no description of how respondents were selected or of how representative of public health workers they might be. The paper is also largely admonitory rather than scientific.

### Table 1

<table>
<thead>
<tr>
<th>Items</th>
<th>Professionals</th>
<th>Non-professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients should not be isolated</td>
<td>74</td>
<td>40</td>
</tr>
<tr>
<td>Patients should be sent to Carville</td>
<td>50</td>
<td>82</td>
</tr>
<tr>
<td>Patients should be treated at home</td>
<td>71</td>
<td>38</td>
</tr>
<tr>
<td>It is all right for people being treated for leprosy to work around other people</td>
<td>69</td>
<td>32</td>
</tr>
</tbody>
</table>

A study of public attitudes about mental illness by Nunnally (1961) included an item on leprosy. The respondents were from an "opinion panel" of 400 people in central Illinois who are "an approximate miniature of the United States population in terms of education, sex ratio, income, religious affiliation and age". The questionnaire utilized the semantic differential scale developed by Osgood et al. (1957) for the analysis of connotations attached to concepts of various persons, objects, topics, or institutions. The technique asks respondents to rate subjects such as "an insane man", "someone with tuberculosis", "a leper" and the like on 16 seven-point scales in which a rating of 1 represents a very unfavourable view ("bad", "weak", "sad", etc.), while a rating of 7 indicates a positive concept ("good", "strong", "happy", etc.). A rating of 4 would be considered neutral. The 16 scales and average scores for the study are given in Table 2, as are results from a replicative study by Ebner (1968). The Nunnally average scores are based on responses of a panel of at least 50 judges carefully selected to be representative of the general public. The Ebner scores are based on 98 respondents in Baton Rouge; this is discussed later. The similarity of the mean scores is noteworthy. No statistical tests were employed because variances were not available for the Nunnally data. There are some discernible differences, however. For most scales the average scores for "leprosy" are lower than those for "a leper", which is probably indicative of less rejection of the person (leprosy patient) than of the condition. Particularly on those scales which are most
TABLE 2

Average scale scores for leprosy on the semantic differential (from Nunnally, 1961; Ebner, 1968)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Average score</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nunnally (1961)</td>
<td>Ebner (1968)</td>
</tr>
<tr>
<td>(1) Foolish—Wise</td>
<td>4.26</td>
<td>3.78</td>
</tr>
<tr>
<td>(2) Sad—Happy*</td>
<td>2.48</td>
<td>*</td>
</tr>
<tr>
<td>(3) Passive—Active</td>
<td>2.86</td>
<td>3.63</td>
</tr>
<tr>
<td>(4) Insincere—Sincere</td>
<td>5.17</td>
<td>4.39</td>
</tr>
<tr>
<td>(5) Ignorant—Intelligent</td>
<td>4.62</td>
<td>3.91</td>
</tr>
<tr>
<td>(6) Unpredictable—Predictable</td>
<td>4.38</td>
<td>3.24</td>
</tr>
<tr>
<td>(7) Weak—Strong</td>
<td>3.00</td>
<td>2.34</td>
</tr>
<tr>
<td>(8) Slow—Fast</td>
<td>3.07</td>
<td>3.24</td>
</tr>
<tr>
<td>(9) Delicate—Rugged</td>
<td>2.71</td>
<td>4.10</td>
</tr>
<tr>
<td>(10) Cold—Warm</td>
<td>4.21</td>
<td>3.87</td>
</tr>
<tr>
<td>(11) Dirty—Clean</td>
<td>4.02</td>
<td>3.52</td>
</tr>
<tr>
<td>(12) Dangerous—Safe</td>
<td>3.62</td>
<td>2.63</td>
</tr>
<tr>
<td>(13) Tense—Relaxed</td>
<td>3.26</td>
<td>3.15</td>
</tr>
<tr>
<td>(14) Worthless—Valuable</td>
<td>4.26</td>
<td>3.67</td>
</tr>
<tr>
<td>(15) Sick—Healthy</td>
<td>1.79</td>
<td>2.08</td>
</tr>
<tr>
<td>(16) Bad—Good</td>
<td>4.52</td>
<td>2.88</td>
</tr>
</tbody>
</table>

* This scale was not included in Ebner’s study.

pejorative are the Ebner averages lower—e.g., Dirty-Clean, Dangerous-Safe, Bad-Good. In any case, these data are not considered evidence of strong stigmatization of leprosy.

Barker (1964) further analysed Nunnally’s data. He used the average score on each of the 16 scales as an observation and then calculated the product-moment correlation coefficient of each of the 20 subjects, pertinent to the illnesses used by Nunnally, with each other. A correlation coefficient of 1 indicates that the scale average for the two subjects being correlated tends to increase or decrease together, while a coefficient of zero indicates no systematic relationship in the scale scores for the two subjects. Barker found that the subject, “a leper”, received semantic differential ratings significantly correlated with a number of other subjects (see Table 3). Barker concludes that “The popular concept of leprosy is almost identical with that of tuberculosis and is also related to concepts of other purely physical ailments and to that of nervous breakdown”.

Ebner (1968) studied attitudes about leprosy relative to several other diseases in Baton Rouge, Louisiana, near the leprosarium at Carville. The sample consisted of one respondent from each of 130 randomly selected city blocks. Interviews were conducted in person and averaged 75 min in length. Most respondents either did not mention leprosy or did not consider it undesirable in answering an open-ended question, “What diseases or illnesses stand out in your mind as being the worst or least desirable?” Respondents were then presented with a prepared list of 10 diseases and asked to rank them from 10 to 1, i.e., from the worst disease to the least undesirable from purely medical considerations, then, later, from purely social or personal considerations. The mean rankings of the diseases by those respondents are given in Table 4. It should be noted that leprosy does not change its relative position in the two sets of rankings, although those diseases
TABLE 3

Correlation coefficients of "a leper" with other subjects
(from Barker, 1964)

<table>
<thead>
<tr>
<th>Correlation Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Someone with tuberculosis</td>
</tr>
<tr>
<td>Person who has cancer of lungs</td>
</tr>
<tr>
<td>Person with broken leg</td>
</tr>
<tr>
<td>Person with brain tumour</td>
</tr>
<tr>
<td>Someone who is dying from cancer and doesn’t know it</td>
</tr>
<tr>
<td>Person who has recurrent attacks of malaria</td>
</tr>
<tr>
<td>Person who lost both eyes in an auto accident</td>
</tr>
<tr>
<td>Someone who was born blind</td>
</tr>
<tr>
<td>Someone with a stomach ulcer</td>
</tr>
<tr>
<td>Person with a nervous breakdown</td>
</tr>
<tr>
<td>Someone who lost eyesight because of severe case of syphilis</td>
</tr>
</tbody>
</table>

TABLE 4

Mean rankings by Baton Rouge respondents of indicated diseases on the basis of medical and social considerations (from Ebner, 1968)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Medical considerations</th>
<th>Social considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcoholism</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Arthritis</td>
<td>4.5</td>
<td>1</td>
</tr>
<tr>
<td>Cancer</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Heart disease</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Leprosy</td>
<td>6</td>
<td>5.5</td>
</tr>
<tr>
<td>Mental illness</td>
<td>4.5</td>
<td>9.5</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>2.5</td>
<td>7</td>
</tr>
<tr>
<td>Poliomyelitis</td>
<td>7.5</td>
<td>3</td>
</tr>
<tr>
<td>Syphilis</td>
<td>2.5</td>
<td>9.5</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>7.5</td>
<td>5.5</td>
</tr>
</tbody>
</table>

often considered by the public to be socially undesirable but not medically serious reverse their positions—e.g., alcoholism, mental retardation, and syphilis. The equal ranking of 5.5 for leprosy and tuberculosis on social considerations reinforces Barker’s conclusions noted above, namely that leprosy is seen as being similar to tuberculosis.

In the same study, a more intensive analysis was made on knowledge and attitudes about leprosy relative specifically to cancer and mental illness. In general, respondents exhibited least knowledge about leprosy, although there were some differences by social class and educational levels. The criterion employed for level of knowledge consisted of the information published by the National Association for Mental Health, the National Cancer Society and the United States Public Health Service Hospital at Carville, all generally available to the public.
Attitudes toward leprosy relative to cancer and mental illness were measured for 98 respondents completing the scales through the use of the semantic differential, as in Nunnally’s study, where the subjects to which the scales applied were “cancer”, “leprosy”, and “mental illness”. When the totals for each of the 16 scales for each subject are summed and a mean attitude score calculated, leprosy and mental illness are found to tie with the same mean, 4.28, while the mean for cancer is 4.10. These means could hardly be considered different from each other on a 7-point scale, and they are all close to a neutral attitude value, 4.0 (Ebner, 1968).

An additional set of semantic differential scales incorporating connotations deemed particularly relevant to leprosy was also administered by Ebner to the same respondents for the same items; the scales and mean scores for mental illness, cancer and leprosy are compiled from Ebner’s data and given in Table 5. The small differences between the highest means and the others on each scale must be considered. What is interesting is not that leprosy tends to be higher, but that it is so little higher than the others. Leprosy is strange, mysterious, contagious, and to be avoided, relative to mental illness and cancer, but not strongly so on this type of measure.

### TABLE 5
Mean scores for respondents on indicated semantic differential scales for three diseases (from Ebner, 1968)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mental</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familiar</td>
<td>5.16</td>
<td>3.97</td>
</tr>
<tr>
<td>Understandable</td>
<td>4.75</td>
<td>4.47</td>
</tr>
<tr>
<td>Chronic</td>
<td>4.56</td>
<td>3.78</td>
</tr>
<tr>
<td>Certain</td>
<td>5.48*</td>
<td>4.66</td>
</tr>
<tr>
<td>Beautiful</td>
<td>4.41</td>
<td>5.21*</td>
</tr>
<tr>
<td>Sacred</td>
<td>3.90*</td>
<td>3.67</td>
</tr>
<tr>
<td>Approach</td>
<td>4.18</td>
<td>4.56</td>
</tr>
<tr>
<td>Family</td>
<td>4.03</td>
<td>3.38</td>
</tr>
<tr>
<td>Non-contagious</td>
<td>2.79</td>
<td>3.04</td>
</tr>
<tr>
<td>Hopeful</td>
<td>2.76</td>
<td>3.46*</td>
</tr>
<tr>
<td>Virtue</td>
<td>3.87</td>
<td>3.89</td>
</tr>
<tr>
<td>Non-fatal</td>
<td>3.24</td>
<td>5.16*</td>
</tr>
<tr>
<td>Reveal</td>
<td>3.59</td>
<td>3.34</td>
</tr>
<tr>
<td>Curable</td>
<td>2.59</td>
<td>3.80*</td>
</tr>
<tr>
<td>Accept</td>
<td>2.93</td>
<td>2.94</td>
</tr>
</tbody>
</table>

* Indicates highest average for that scale.

A more detailed analysis by Ebner, utilizing analysis of variance, indicates that anxiety, as measured by the semantic differential using all 30 scales, is higher for cancer and mental illness than it is for leprosy among women, Caucasians, the better educated, and the middle and upper classes. That leprosy is neither imminent nor salient to people in the United States, while cancer and mental illness are, might be a necessary and sufficient explanation for these findings.

In a study in 1968 by Moskal and Nolen, 188 respondents from Baton Rouge and Shreveport, Louisiana, indicated agreement on 21 declarative statements
about characteristics of leprosy and other conditions and about people with these conditions. Supposedly a stratified random sample of households from these two cities, the sampling procedure was not appropriate and non-respondents were not evaluated, even though the overall response rate was only about 42%. The study indicated no differences in attitudes about leprosy by city of residence, by social class, age, education or sex. On the other hand, Negroes seem to be more positive in their attitude than whites, and non-married people (generally younger) more positive than the married.

Since most respondents indicated a low positive or low negative attitude, there is no basis for asserting that strong stigma exists. Unfortunately, the authors give no analysis of leprosy relative to the other conditions they secured information about, making it difficult to establish the meaning of their study. Further, more powerful analytical techniques should have been employed.

Brown (1969) studied attitudes of health workers—physicians, nurses, nurse-aides, and social workers—toward leprosy relative to other conditions, namely nervous breakdown, diabetes, amputee, burns, tuberculosis and Von Tulow's neuroplasty (fictional). The health workers returned 80 mailed questionnaires out of the 279 sent out; 21 were returned out of 150 mailed to physicians, 26 out of 50 by nurses, 17 from nurse-aides, and 16 from 29 social workers. No analysis of bias due to non-returns is given.

The instrument (also used by Rolston and Chesteen, discussed below) presented a very short sketch of seven job applicants with one of each of the conditions noted. Each condition was then paired with every other, and the respondent was then asked to indicate the one of the pair less acceptable for employment and to give his reasons for rejecting the applicant. Six reasons for rejection were provided, and the respondent could use any or all of them. The reasons were: (1) possible increase in insurance costs; (2) fear of contagion for self or employees; (3) would make customers uncomfortable; (4) you really believe he is not capable of doing the work; (5) condition would not be acceptable to other employees; (6) condition might become worse.

Leprosy was consistently rejected by all four types of health workers. While there were some differences between types of workers in their reasons for rejection, the patterns here were also quite consistent. In order of frequency used, the principal reasons were: might make customers uncomfortable (No. 3), not acceptable to other employees (No. 5), danger of contagion (No. 2), condition might get worse (No. 6).

The structure of the study required the respondent to imagine how employers might feel; whether or not this taps the respondent's own feelings is debatable.

Rolston and Chesteen (1970) later employed the same instrument used by Brown in a study of employers in Louisiana. However, two additional names were used for leprosy—Hansen's disease, and "bacterial neurodermatitis"—and thus three different versions of the questionnaire, otherwise the same in all other respects, were mailed out. A total of almost 1600 questionnaires, about 533 of each version, were mailed over a period of a year. Although the returns were meagre (17%), the authors believed that "... since the cumulative results remained constant with successive groups of returned forms ... we could validly project results from the smaller sample", that is from those returned. The authors found that regardless of which of the three names was used for it, leprosy always received the highest rejection rate by employers. On the other hand, the different names for the disease influenced the reasons for rejection of leprosy patients. The
names "Hansen's disease" and "bacterial neurodermatitis" were almost identical in their patterns in reasons for rejection (see Table 6). For these two names, employers tended to be more concerned about the applicant as a person and about the customers; whereas for the name "leprosy" their concern was for the other employees and customers. The three highest ranking reasons for the three different disease names are in italic in Table 6.

**TABLE 6**

*Percent distribution of reasons for rejection of the leprosy employee applicant for the three disease terms used (from Rolston and Chesteen, 1970)*

<table>
<thead>
<tr>
<th>Reason</th>
<th>Leprosy</th>
<th>Hansen's disease</th>
<th>Bacterial neurodermatitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) You really believe he is not capable of doing the work</td>
<td>5</td>
<td>9.8%</td>
<td>1 34.6%</td>
</tr>
<tr>
<td>(2) Would make customers uncomfortable</td>
<td>2</td>
<td>26.1%</td>
<td>2 19.3%</td>
</tr>
<tr>
<td>(3) Condition might become worse</td>
<td>4</td>
<td>11.5%</td>
<td>3 16.6%</td>
</tr>
<tr>
<td>(4) Condition would not be acceptable to other employees</td>
<td>1</td>
<td>28.1%</td>
<td>4 15.9%</td>
</tr>
<tr>
<td>(5) Fear of contagion—self or employees</td>
<td>3</td>
<td>19.3%</td>
<td>5 7.7%</td>
</tr>
<tr>
<td>(6) Possible increase in insurance costs</td>
<td>6</td>
<td>5.2%</td>
<td>6 5.9%</td>
</tr>
</tbody>
</table>

In general, the samples are suspect in most of these studies, although the studies by Ebner and Nunnally are probably acceptable because their procedures tended to deal with bias. But even in these cases, the samples are small. The other studies either used faulty sampling procedures, or the response rate was low, and no attempt was made to evaluate bias, although Rolston and Chesteen's variant of sequential sampling seemed to produce consistent results for employers.

In our view, the Nunnally, Ebner, and Barker studies do not demonstrate any strong leprosy stigma relative to other conditions; neither does the less acceptable study by Moskal and Nolen. Brown's study of health workers, and also that of Shearer and Hoodwin, seem to support the idea that non-professional health workers stigmatize leprosy more than do professional workers, but, aside from the question of sampling problems for both studies, it is not at all clear that Brown's respondents gave their own views. On the other hand, there may be a rather strong projection of stigma on to the public by Brown's respondents, such as we have implied for Shearer and Hoodwin and their non-professional respondents. Employers, however, seem to be afraid of presumed customer reaction—another projection.

In summary, we feel that the evidence from these studies is equivocal; leprosy may be stigmatized to some extent, but so are mental illness, cancer, tuberculosis,
syphilis, etc. In view of the concern about such stigma expressed by not a few leprosy patients and leprosy workers, it is interesting that strong public stigma has not been actually scientifically demonstrated.

Discussion

Obviously the phenomenon of leprosy stigma is a complex one. A plausible explanation necessarily involves several dimensions on several social and psychological levels. Here we will allude to only a few of these. First, as is true for much attitude measurement in the social sciences, the measures employed may be either imprecise or unreliable, or unduly affected by the vagaries of mood and situation. The results of the semantic differential, however, have considerable face validity for conditions other than leprosy and we see no reason to reject them for leprosy. The high variability of respondents' attitudes was taken into consideration in Ebner's analysis, where leprosy does not compare unfavourably with mental illness and cancer—and with tuberculosis (Barker, 1964).

Second, in the United States, leprosy patients known to the staffs of treatment centres come largely from the lower income, lower educational, and less prestigious occupational categories: many of them are from minority groups (Rolston and Chesteen, 1970). In our experience the problems of coping, and of stigma, of these patients may be at least as much a consequence of their general level of social functioning as it is of the disease itself and especially if they are trying to function outside their usual social circles. Furthermore, in the United States with its social emphasis on physical comeliness, disfigurement and deformity, whatever their source, pose adaptive problems. When coupled with disability, there is additional jeopardy (Gussow and Tracy, 1969).

Another set of factors are contagion and strangeness; Ebner's study indicates that these are strong components in people's views of leprosy (see Table 5). Strangeness, of course, is a result of its low prevalence rate in the United States and higher prevalence in the non-Western world (Gussow and Tracy, 1970; Gussow and Tracy, 1971). Public concern with contagion, on the other hand, may be the result of the practice of isolating patients at certain stages, of the very existence of the leprosarium, and of the equivocal stance of medicine and public health about contagion (Gussow and Tracy, 1971). Concern with contagion does not necessarily imply stigma, although the concern may be considerable, providing the aura of mystery is lifted from transmission and immunology.

The social institutionalization of leprosy treatment is another consideration. World-wide, since the middle of the 19th century, the staffs of most leprosy treatment centres have had strong religious affiliations, and this is still true today even in instances in which public health authorities have primary responsibility. The peculiar institutionalization of leprosy treatment has been discussed at length elsewhere (Gussow and Tracy, 1970, 1971). The principal social mechanisms involved in this institutionalization, in addition to the services of religious affiliates, are the isolation of patients in leprosaria and colonies, the isolation of the disease from secular modern medicine and, particularly in the United States, the special "ward status" of patients (Gussow and Tracy, 1971). In our view, then, there is a rather long-standing and pervasive premise about leprosy held by leprosy workers. Two strong components of this belief are, first, feelings that leprosy is stigmatized and that patients should be protected and, second, that
leprosy could develop epidemic proportions, especially in "fresh" populations. The latter element derives from the standard epidemiological model of infectious diseases. Since the true epidemiology of leprosy is unknown and there are periodic leprosy alarms, the stance constitutes a defensive posture. The late 19th century panic about leprosy undoubtedly still influences thinking and attitudes, particularly for older leprosy workers.

A final point is that there does seem to be a "generation lag" in attitudes to leprosy. Many leprosy workers and the older members of the public express sentiments that are traditional in the sense indicated above. Young people, on the other hand, who tend to be better educated, seem to be more open and neutral about many things, including leprosy. This statement is buttressed by noting that a young patient from the United States Public Health Service Hospital at Carville, who was known to be from there, secured a degree in sociology at Louisiana State University and in his senior year was president of the Sociology Club. He was also instrumental in organizing several trips to the hospital.

A categorical, strong public stigmatization of leprosy has not been demonstrated. Those who are responsible for treating patients may have to think in terms of alternatives to presumptions of public stigma.

References

The Stigma of Leprosy—in Four Countries*

J. C. PEDLEY

United Mission Hospital, Tansen, Palpa, Nepal

"The International Leprosy Association should be dedicated to the protection of leprosy victims against superstition or erroneous popular concepts regarding the disease." So wrote the President of the International Leprosy Association in 1970.

One of the "erroneous popular concepts" about leprosy is that which has been passed from generation to generation of workers in the field of leprosy, namely the hypothesis that leprosy is spread by skin-to-skin contact. This concept (which the writer admits he himself used to believe) has probably done far more than is realized to promote in the minds of the public the idea that a patient afflicted with leprosy is discharging bacilli from the pores of his skin. Recently this hypothesis has come under very close scrutiny (Pedley, 1970a, b), and strong evidence has been adduced that leprosy bacilli seldom, if ever, emerge from intact lepromatous skin.

Four examples may be given from my own experience in China, Nepal, India, and England that indicate that not only the public but also the medical profession believe that bacilli are discharged from the skin of people suffering from leprosy.

China

Nearly 30 years ago, when I was a medical missionary in China on the staff of a general hospital with a leprosarium, an educated youth employed in the local branch of the Bank of China presented with early signs of lepromatous leprosy. This was in the days before the sulphones were available. The disease rapidly progressed until it could no longer be hidden, and he was obliged to give up his job. He embraced the Christian religion, and in order to learn more about the Bible he applied for enrolment in a Bible Correspondence Course, the head office of which was in the capital city of another province about 1000 miles away by road. To this office an enrolled member had to send his answer-papers for correction. When it became known that he was a patient in the leprosarium, I received a letter from the Director of the course regretting that he could not be enrolled on the grounds that he was suffering from leprosy. At that time letters were taking about 10 days to travel between the two places. Even so, the fear that the leprosy germs, supposedly sticking to the answer-papers, would still be alive by the time they reached the examiner was so great that my patient was debarred from taking the course.

* Received for publication, 25 November, 1971.
Nepal

The second incident occurred 18 months ago in the hospital where I am now working. It concerned the little daughter of one of our European couples, who while playing outside in the hospital garden happened to drop her toy on the grass outside the pen in which she was enclosed. One of my patients who was working nearby, saw the toy on the ground, came over and picking it up dropped it back into the pen. The mother, seeing this happen, came at once to me and enquired anxiously if it was safe for the child to continue playing with the toy. Although the man had atypical lepromatous leprosy, I knew that his skin was intact and his nasal mucus contained no leprosy bacilli. I assured the mother than the child was in no danger from infection.

India

An Indian leprosy worker of international repute told me that in the State where he lived there was a government office where a person who had suffered from leprosy, and whose disease had become arrested after treatment, could obtain a certificate of non-infectivity. The government doctor who issued the certificate sat on one side of a counter surmounted by a screen with a small opening through which the one applying for a certificate made known his request. Having satisfied himself that the request was valid, the doctor proceeded to make out the certificate, which was then handed to the applicant through the opening in the screen. My informant told me that if the applicant noticed that the doctor had omitted a certain detail on the form, he was not allowed to hand the form back to the doctor. Instead, he was instructed to tear it up and drop it in a wastepaper basket provided on his side of the counter. The doctor then made out another form which was again handed to the applicant. "Obviously," said my informant, "he had no faith in his certificate of non-infectivity."

England

The last incident occurred less than a year ago when on leave in England. I asked a friend in the typewriter business if he could have some repairs done to my portable machine. He gladly undertook this but when handing the typewriter to his mechanic he inadvertently remarked that it had been used by a doctor working among "lepers". Whereupon the mechanic refused to touch it for fear of contracting the disease. It was only after much persuasion and assurance that he would not run any risk, that he did at last agree to repair the ribbon reverser, but the general cleaning and overhaul, which would have involved considerable handling, he firmly refused to undertake. When I subsequently asked my friend if he could sell the machine for me he regretfully replied, "Unfortunately no, as it has already leaked out that it belongs to a 'leper doctor'."

References

The Serious Latin-American Problems Caused by the Complex "Leprosy: The Word, The Disease" and an Appeal for World Co-operation*

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Two Brazilian Congresses of Hygiene (in 1968 and 1970) agreed that a substitute name for "leprosy" would have psychological advantages in health education, facilitating preventive measures and alleviating the stigma. Accordingly, 3 state health services, the chairs of dermatology and many of neurology and preventive medicine of 27 medical schools in Brazil have already adopted the educational formula "hanseniasis, formerly called leprosy", aiming at a gradual elimination of the stigmatizing term leprosy. The complex "leprosy: the word and the disease" is also a problem for other countries of Latin America: education on "leprosy" there was a failure, as recognized by the Guadalajara (Mexico) Seminar of the Pan-American Health Organization (1968). The complex affects also the Gulf States of the United States of America, Portugal, Spain and Italy. Many specialists of Asia, Africa, the Western Pacific and Eastern Europe are already not insisting on conserving in our language a stigmatizing form which in any case does not belong to theirs. Many Europeans and Americans, whose countries do not suffer from an active endemic, are aware of the damage the word is causing to millions in our areas. The solution is relatively easy and consists simply in extending to the root "lepra" the international condemnation of the pejorative "leper". Usual objections against this extension are presented and rebutted.

The Seminar on the Prophylaxis of Leprosy (Hanseniasis) of the 18th Brazilian Congress of Hygiene (S. Paulo, 1970) considered that changing the term "leprosy" and its derivatives "would be constructive as a psychological step towards health education, facilitating the measures indicated for the control of the endemic and contributing to eliminating the social stigma hanging over the patients and their families".

This strengthened a conclusion of the 17th Brazilian Congress of Hygiene (Bahia, 1968) on these same lines. Previously, the dermatological societies of the Brazilian states of Minas Gerais and Rio Grande do Sul had given support to a new educational technique adopted in 1967 by the Secretary of Health of the State of S. Paulo, based on the provisional formula "hanseniasis, formerly leprosy", aiming at the gradual obsolescence of the ancient term. To date, two more state health services (Espírito Santo and Amazonas), the chairs of dermatology of 27 Brazilian medical schools and the departments of neurology and preventive medicine of

* Received for publication 15 March, 1972.
some of these, adopted the formula and are gradually discarding the word “leprosy”. The Seminar on Prophylaxis of Hanseniasis of the Brazilian state of Parana also recommended a new terminology.

It is not surprising that these recommendations and deliberations were taken in a country where the words “lepra” and “leproso” (leper) are commonly used as terms of insult; where in 1965 the Nomenclatura Dermatologica substituted “Morbus Hansen” for “leprosy”, a substitution that should, according to Rabello (1955), “mark all the difference between a disease so often benign and curable and the fearful Biblical leprosy”; where Souza (1940) considered the term “lepra” a common cause for suicide and crime, Letayf (1955) “a trauma that disintegrates the patient”, and Diniz (1965) “a nightmare, a terrible shock”; where standard dictionaries give as synonyms for “leprosy” . . . filth, abhorrence, defilement, vilness, viciousness, etc.: and from where 62 out of 65 specialists responded favourably to a questionnaire (Rotberg, 1969) referring to the elimination of the word from the medical literature. Lacaz (1970) advocates the substitution of “hanseniasis” for “leprosy” in all dictionaries, and Becker (1971), who prefers “hansenosis”, writes that “leprosy” is a “vague name associated with mediaeval darkness and millenary maledictions and superstitions”.

**Education Unsuccessful Against “Leprosy”, an Anti-educative and Stigmatizing “Label of Primary Force”**

The alternative, which was to continue educating and teaching on “leprosy”, was discarded as it has been proven useless up to now, except in some very limited areas (as the “leprosy” personnel themselves). The educational techniques that had been employed with more or less success in the past to enlighten the public about tuberculosis, venereal and other diseases, have failed almost completely where leprosy is concerned, and this difference is not difficult to explain. Whereas the public’s attitude to health education about these diseases varies from indifference to all degrees of acceptance, sometimes even to sympathy and co-operation, “leprosy” constitutes a remarkable exception.

The word provokes an immediate and uncontrollable rejection: it is described as “horrifying” by itself. “Lepra” and “leproso” bring to mind immediately all the false notions and superstitions that have plagued the disease for centuries in this country (Brazil). They are used and abused by writers, journalists, reporters, actors, radio and TV personnel when it is necessary to emphasize what they consider the worst defects of persons and organizations, football teams, industrial products, political movements, and even animals. Huge front-page headlines announce that there are “LEPERS IN THE STREETS!” and that “HIPPIES SPREAD LEPROMSY!” (Fig. 1a, b). Young children learn very early the insulting force of the words “lepra” and “leproso”, made stronger at the reading age and in their first contacts with religious texts. As is known, “leprosy” figures in the Old and New Testaments as something vile and degrading, whose victims had to be banished “outside the camp”; or as an incurable disease that only the miraculous powers of Christ could cure. As though this were not enough, every year, at Easter time, the cinema provides for the biggest audiences the superstitious and stigmatizing fantasies of “Ben Hur”. European and American fiction best-sellers in which “leprosy” and “leper” are the most degrading epithets are widely read and aggravate the situation.

In short, “leprosy” is, in Brazil, an anti-educative and stigmatizing “label of
Fig. 1. Two examples of the powerful and permanent anti-education in Brazil. (a) Lepers in the streets of the city! 350 patients frequent cinemas and restaurants. (b) "Hippies" spread leprosy! A threat to all countries of the world.
primary force” that ostracizes and causes immense suffering to patients and contacts, blocks any attempts to enlighten the public at any level, and hinders seriously the development of the prophylactic and social programmes, which are based on early diagnosis and treatment, leading to integration and acceptance by society.

The Adoption of the Provisional Formula “Hanseniasis”, formerly named “Leprosy” and the First Favourable Results

Unable to compete against such odds, the “working group” of the extinct “Leprosy Department”* discussed and accepted the idea of a substitute name. The substitution was to be for the patients a well-grounded measure and a good omen for co-operation, as they have long campaigned publicly for just such a step in this country (appealing later to the Madrid Congress, 1953) and in the United States of America (appealing to the Havana Congress, 1948, as well as frequently through the magazine, The Star, published by the patients of Carville, Louisiana). Furthermore, a substitution had already been internationally recommended by the Conference of Manila (1931), ratified by the International Congresses of Havana (1948) and Madrid (1953), namely, that of “leprosy patient” for “leper”; but this did not, unfortunately, have any practical effect, most probably because of the permanence of the root “lepra” and of its derivatives “leprotic”, “leproma”, “leprous”, etc. The modification of the word “leprosy” itself was a recommendation made by a significant group of the Pan-American Health Organization’s Seminar on Administrative Methods for Leprosy Control Programmes (Guadalajara, Mexico, 1968).

Many substitute terms were studied, but finally those derived from the name of Hansen were preferred. In spite of the inconvenience of eponyms, they have in their favour the fact that the terms “Hansen’s disease” and “hansenosis”, as well as being acceptable to the patients, have already acquired some degree of scientific acceptance, both international and regional, for they figure in the Brazilian Nomenclatura Dermatologica and are often employed by Brazilian and foreign authors in medical articles and text-books. As the Mycobacterium leprae is also known alternatively as “Hansen’s bacillus”, it was thought that “hanseniasis” (as in leishmaniasis, psoriasis, elephantiasis) was a good choice. As it is pronounced in Portuguese (hansen-ee-ah-se) it is more euphonic than “hansenosis” and, in spite of some lexicographic defects, it was preferred by a majority of physicians and patients consulted. A whole set of substitutes was coined later with the help of hansenologists of other countries and the São Paulo State Council of Health.

The next problem was how to carry through the new educational techniques. Although some of the more enthusiastic advisers preferred to drop the word “leprosy” at once, the majority were of the opinion that this could be highly inconvenient as it would be a source of confusion, some of the results being socially and psychologically dangerous to the patients themselves. It was decided, then, that the programme should begin with a “transitional phase” when both words would be used together as synonyms. “Hanseniasis, formerly leprosy” was the educational formula adopted, based on the proven techniques of national administrative authorities when implanting new values and names for money

* Comprising Souza Campos, Souza Lima, Martins de Barros and Rotberg.
currencies. “Hanseniasis”, it was explained, became the new name of a curable and mildly contagious disease, which used to be called “leprosy” when there was no treatment and patients were isolated, etc. The aim is to make the term “leprosy” gradually obsolete with the minimum possible embarrassment, but the date when it can be finally discarded is unpredictable. It could take some years, in the absence of international co-operation for this regional measure.

Even though the old name has not been completely eliminated the results, so far, may be called “good”. Dermatologists, general practitioners, patients, and contacts are now more co-operative with health authorities who demonstrate concern for their emotional and social problems. It is now possible to give lectures on “hanseniasis, formerly leprosy”, in a more informative and scientific way, different from the superstitious atmosphere usually aroused by naming the topic “leprosy”. Integration within general public health services has been facilitated. Medical students accept “hanseniasis” as “a disease like any other”, and wonder that we are still using the term “leprosy”. Our reasons for keeping it in this “transitional phase” have to be explained repeatedly.

Latin America, the Major Victim of the Complex “Leprosy”: the Word and the Disease

Obviously, the word “leprosy” can do harm only where it exists, so excluding Asia, Africa, the Western Pacific and Eastern Europe; or where there is an active endemic and a large number of patients and families to be branded by it—that excludes most of the United States of America, Canada, the United Kingdom and France. In Russia, the word “leprosy”, used occasionally, does not there have any shameful meaning; the regional stigmatizing and ostracizing word “prokaza” is never used in scientific writings (Torsuev, personal communication). Brazil remains as the largest and most populated area where the word “leprosy” stigmatizes, affects patients and contacts emotionally, blocks education, and hinders prophylactic programmes; but other countries of the Americas could be included as shareholders in this serious “semantic-prophylactic” problem—the complex “leprosy: the word, the disease”.

When the Seminar of Guadalajara admitted that health education programmes about “leprosy” were unsuccessful, a group of 18 Latin Americans (including one Brazilian), representing almost half the participants, attributed the lack of success to the use of the word “leprosy”, and “recommended a study for its possible modification”. In Argentina, Quiroga (1968) spoke of the “malignity that seems to accompany the word leprosy”, and the inquiries of Mangiaterra (1970), a teacher of educational sciences, demonstrated the stigma attached to the word. She writes: “‘Leprosy’ and ‘leper’ have a tremendously negative emotional charge that originates from the time when the patient was just a God-stricken, undesirable, horrifying, dirty, repulsive and marginal thing. No evidence can change those unfavourable feelings about these prejudiced terms. ‘Leprosy’ is incorporated in children’s language with ‘linguistic precedence’. They use it in a pejorative sense, with all the magical meaning that this word bears and before they know what it means; when they learn the truth, it is too late, and even long and costly educational campaigns will do nothing more than reduce, sometimes, the intensity of the prejudice.”
Personal correspondence from Latin American countries* is further evidence of the problems caused by the word leprosy. Also, at a recent Ibero-Latin American Congress of Dermatology (Caracas, Venezuela, 1971) and on the trip back to Brazil, through Colombia, Peru, Bolivia and Paraguay, I was able to confirm directly with colleagues and lay people the seriousness of the problem. This fact is not denied by any author in Latin America, although some of these still believe in the possibilities of education, or in the technique of using “leprosy” so often and frankly as to “wear it out” of its pejorative connotation.

Other less endemic areas are also victims of the word “leprosy”, such as the Gulf States of America, Portugal, and the Latin countries of the Mediterranean. This is confirmed by the persistent campaign by the patients of Carville, Louisiana, favouring the adoption of the substitute “Hansen’s disease”; by a recent study of the School of Social Welfare of Louisiana State University (Chesteen and Rolston); by Portuguese articles like those of MOURA (1968) and Fonseca (1970), the latter suggesting the word “hansenia” (like “diphtheria”); and by personal correspondence.†

The Co-operation of Countries not Affected by the Complex
“Leprosy: the Word and the Disease” Would be Welcome

Latin American countries and other areas victimized by the complex “leprosy: the word and the disease” might eventually follow the three Brazilian states and 27 medical schools whose health services and dermatological clinics have already adopted “hanseniasis”. Peru seems to be the first in line with “hansenosis”, which was recommended to its Ministry of Health by a National Seminar held at Pucallpa in 1971; and the dermatological department of a Buenos Aires general hospital has recently accepted the word “hanseniasis”.

However, even a unanimous Latin American agreement to cancel the word “leprosy” as a medical term would have to face serious difficulties ahead. Medical text-books and periodicals from Europe and the United States circulate widely in the region and enjoy considerable authority. It would not be easy to consolidate a new non-stigmatizing terminology if it had to compete with the continued use of “leprosy”, “leprotic”, “lèpre” in English and French writings, aggravated by the use of the banned word “leper”, fortunately rare now in medical English but still quite frequent in French (“lèpreux”, corresponding to the ultrastigmatizing insult “leproso” of the Portuguese and Spanish languages).

Therefore, a European and American decision to adopt any agreed substitute term would certainly be greatly appreciated by the large number of patients and their contacts who live in the area stretching from the Gulf States to Argentina, and by those authorities who find it impossible to enlighten their public about “leprosy” and accept it as “a disease like any other”. It would also convince some still reluctant Latin Americans who, although aware of the problems caused by

* Argentina (Ambrosetti; Baina; Bergel; Borda; Casala; Grinspan; Jonquieres; Kaminsky; Kriner; Lucena; Mangiaterra; Manzi; Marzetti; Nedemberg (B); Pecoraro; Pierini (L); Pomposiello; Tello). Colombia (Londoño; Muñoz Rivas). Costa Rica (Elizondo Salazar). Mexico (Salú). Nicaragua (Esquivel). Panamá (Escartin; Tapia). Paraguay (Medina Garcia; Schmidt). Peru (Neyra Ramirez). Venezuela (Convit; Scannone).

† Portugal (Barbosa Leitão; Basto; Cruz Sobral; Esteves; Farrajota Ramos; Fraga Azevedo; Gomes Nicolau; Martins Barbosa; Menezes Ferreira; Norton Brandão; Novais Rebelo; Poiares Baptista). Italy (Baccaredda-Boy).
the word, are of the opinion that any change must have some kind of international support.

This U.S.-European co-operation could be postulated. Authors in these continents have protested in the past against the medical use of “leprosy”: an “ugly name” (Faget, 1947); “a tragic name”, “a curtain of terror” (Lendrum, 1945, 1952); a “shame for the patient and his whole family” (Lichtwardt, 1948); an “odious name, synonymous with something vile” (Burgess); “ignominious” (Feldman, 1953); a “horror based on a confusion of ideas” (Gramberg, 1960); a name that has to be changed “very urgently” (Swellengrebel, 1960); “a word that does carry a conditioned adversive connotation” (Rolston, 1968). Out of 44 specialists of these regions, 17 have responded favourably to a questionnaire (Rotberg, 1969) suggesting “hanseniasis”, and personal correspondence* also points towards the possibility of co-operation. Mallac (1971) considers our terminological changes as “a long-awaited move to alleviate and eventually clear, inter alia, the complex background of hanseniasis”, and writes that “we, as medical men, owe humanely, morally and professionally such a breakthrough to the millions of hansenians in other parts of the world who, to use the words of a well-known hansenologist, are the victims of an acid-fast bacillus made more virulent by ignorance, prejudice and fear”.

Names for diseases have changed for less important reasons. “Moniliasis” became “candidiasis” naturally, just to accompany the new name of the causal fungus. The current trend to substitute “exceptionals” for “mentally-retarded”, as well as “convulsive syndrome” for “epilepsy”, has the same humanitarian background and is not facing any serious reaction. The public in our areas should not be led to imagine, as many seem to be in Latin America, that changes in terminology are only acceptable when they are important to the more developed countries. This is a most unfounded suspicion, as it is known that the banishment of the insulting word “leper” was the recommendation of three international meetings, none of them held in Latin America or under Latin American leadership or influence.

Unfortunately, that well-intentioned banishment did not have any practical effect in Latin America, as the accepted terms “doente de lepra” or “enfermo de lepra” are employed only by an insignificant minority. “Leproso” (leper) continues as the general stigmatizing term, demoralizing patients and blocking their co-operation with health services. Therefore, the desired international next step would be the recommendation of a substitute name for the disease itself, to be used together with “leprosy” for some time, in order to establish synonymity and prevent misunderstandings. A “transitional phase”, normal in all terminological changes—medical, monetary, industrial and administrative—should be short, and should cause fewer difficulties than when a whole system of classification of forms of the disease was substituted, 19 years ago.

Colleagues in Eastern Europe, Asia, Africa and the Western Pacific areas, also free from the complex “leprosy: the word and the disease”, could co-operate. The Graeco-latin root “lepra” and its derivatives are not part of their languages, and they are probably not going to object to the banishment of that root on the same

grounds that Latin Americans would not oppose the substitution of *kusht*, *duudzam*, and other designations for the disease, if regional health authorities decided that such substitutions were necessary. "Mongolism", a term that is unfair and depreciative to the people of a large area of the world, is now being called "Down's syndrome", with support of non-mongolic people who understand their emotional and social problems.

There is no doubt that this Latin American problem is being understood by the public of the Eastern world. When the Japanese Leprosy Associations decided to discuss and to put to a vote the above-cited questionnaire about substituting "hanseniasis" (or other) for "leprosy", 3 members accepted the change and 30 did not, but "saw no objection to the use of 'hanseniasis' as a common term, while keeping 'leprosy' in the scientific language". It is evident that our Japanese colleagues were aware of our specific problems and willing to co-operate. From Dr Nishimura's letter reporting the meeting it is not clear whether or not they were considering "hanseniasis" as a common term for Japan itself, as a substitute for the local name of the disease.

Personal correspondence from those regions,* accepting the new term "hanseniasis", or sympathetic with the change,† is further evidence that support for Latin America health and social measures may be awaited from regions where the Romance languages are not spoken. It must be recalled that Manila, Philippines (1931), was the location of the International Conference that first recommended the substitution of "leprosy case" for "leper".

**Objections and Rebuttals**

The main objections to a terminological change are based on the somewhat contradictory assumptions that (1) the fear of "leprosy" is caused by its deformities and disabilities, not by its name: (2) that the fear of the name can be erased by education; (3) that any substitute name will sooner or later acquire the perjorative overtones of "leprosy"; (4) that eponyms are not the best substitutes; (5) that the names of earlier writers, not only Hansen's, should be considered for eponyms; (6) that the name "leprosy" is not a problem for the vast majority of patients in Asia, Africa, and the Western Pacific; (7) that an efficient form of treatment of the disease is the real solution; and (8) that the experience of Hawai in changing the name "leprosy" to "Hansen's disease" was unsuccessful.

(1) I understand, from what I read, that patients of the East and Far East fear far more becoming deformed and crippled than they fear regional labels for the disease, but this is certainly not true in Brazil and other Latin American countries, where the word "leprosy" is a "psycho-social disease" by itself, usually much more feared than the physical ailment. People would rather be victims of the worst handicaps and deformities caused by poliomyelitis (or other neural conditions), leishmaniasis, pemphigus, accidents, etc., than to bear a small involuted skin lesion or a simple flexure of the left little finger under the shameful and ostracizing diagnosis "leprosy". All prophylactic programmes based on early diagnosis and treatment are prone to fail, as there is no prevention without

† India (Nimbkar).
co-operation, and no co-operation while that stigmatizing word is used. There are no “early cases of stigma”.

2. Education about “leprosy” was unsuccessful in the Americas, according to the Seminar of Guadalajara in 1968, and not a single fact has occurred since to modify that gloomy conclusion.

3. The worst of substitutes would have a chance of success in renewed educational programmes, but “leprosy” never would. “Leprosy” is a millenary invincible “label of primary force” whose terrifying powers are increasing continuously, through all media of communication. “Lunar lepers to be isolated by double-thick glass plates when they return”, is how the international press reported the first landing on the moon. The most sophisticated technological achievement of Man thus destroyed, in one single day, years of hard and patient work trying to enlighten the public about “leprosy”. Would “lunar hansenians” have the same sensationalistic impact? Not even a freshman in journalism would employ such a “cold” word. It is unbelievable that any future dictionary will apply to an agreed substitute the same connotation used now in connection with “leprosy” and “leper”.

4. and 5. As stated before (Rotberg, 1969), “hanseniasis” is a suggestion that happened to be satisfactory to many, including Rabello (1970) who substituted it for the former “Morbus Hansen” in the Brazilian Nomenclature Dermatologica. The Journal of the American Medical Association (1970, 211, 2023), although not accepting the change “at the moment”, asked if “someone could not suggest ‘fracastoriosis’”. But eponyms are not necessary. The School of Social Welfare of Louisiana State University, in a recent study of rehabilitation in the United States of America which concluded that the name “leprosy” is harmful for the patient, employed the terms “bacterial neurodermatitis” and “Hansen’s disease”. “Mycobacteriosis” might be the solution if tuberculosis and others are excluded by general agreement. The final objective is to banish “leprosy”, not to implant “hanseniasis”.

6. If the word “leprosy” is a problem for a continent of 300 million people, an estimated 4 million contacts and 800,000 patients, most of them non-diagnosed or hiding from the stigma, it is a problem for the small world we live in. As stated above, the rest of the world, not directly interested, could, and is expected to, co-operate by the simple measure of extending to the root “lepra” the condemnation already existing of the word “leper”.

7. While we wait for more efficient drugs—which may take some years—patients must not be scared away by the extremely high cost of our present treatment: social ostracism and economic collapse. For our precarious sulphones, we ask them first to register as “leprosy patients” (in practice “lepers”), then we complain that they do not show up and that the endemic spreads. It is very unlikely that they will even be interested in a future “magic bullet” at such high cost—the “leprosy stigma”.

8. I have no way of knowing exactly what happened in Hawaii, but it is certain that there is not the slightest resemblance between the social, racial, cultural, religious and epidemiological conditions of Brazil and that State. In any case, the official change there in 1949 proves that the word “leprosy” was troubling Hawaiians too. But, we ask, was everybody co-operating, as necessary, to implant and consolidate the new term “Hansen’s disease”? A search of the literature points in a different direction, suggesting the existence of a determined opposition by at least one influential author (Skinsnes. 1966).
Did the Hawaiian authorities institute a “transitional phase” and did they strive enough to educate on a formula similar to “Hansen’s disease, formerly called leprosy” to prevent confusion? One thing I am certain of: if the word “leprosy” circulates among the heavily infected racial groups of Hawaii with the same pejorative overtones attached to it in Latin America and the Gulf States of the United States of America, its reintroduction is not at all helping Hawaiian educational programmes but, on the contrary, aggravating stigma and hindering prevention.

References


Technical Remedies for the Severely Deformed Foot in Leprosy*

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In this further paper from the orthopaedic workshop the author describes a second walking aid for the leprosy patient with a severely deformed foot, or feet. It can be made from locally available material, costs less than the stay in hospital which would be otherwise necessary, and moreover gives the patient earlier freedom of movement.

While it is widely accepted that the priority in treating leprosy patients lies in the field of prevention, it is still the leprosy patient with a severe foot deformity and consequent recurrent ulceration that draws a considerable amount of money away from the funds allotted for the treatment of leprosy. Such work is essential, but largely ineffective if not backed up by a base hospital which can care for acute and chronic cases. It is at the base hospital, then, that the beds are very soon filled up with patients with severe foot problems. In many of these patients the feet are in such a condition that even with intensive teaching, provision of moulded shoes or sandals, and the best co-operation of the patient himself, the problem is still not solved. The five most common foot problems are as follows:

(1) Feet which are grossly absorbed. The weight-bearing area which remains is too small to tolerate normal use of the foot. The stress of (the body weight’s) deceleration and acceleration forces is a common cause of re-ulceration in such cases.

(2) Severely deformed feet for which surgery is not indicated, either because of a recent episode of osteomyelitis, fractures or ulceration, or because the patient is unwilling to have the operation, or is medically unfit for correction of the deformity (Fig. 1).

(3) Combined deformity and absorption to such an extent that the “foot-stump” is totally unfit to tolerate the weight of the body in normal walking, even if the stresses of deceleration and acceleration were eliminated (Fig. 2).

(4) A recent history of fracture or of tarsal bone disintegration without concurrent ulceration (Fig. 3).

(5) Destruction of the os calcis (Fig. 4).

* Received for publication 26 April, 1972.
Fig. 1
These deformities are always closely linked with diminished or absent sensation. Unless an above-knee amputation is performed, the problem of weight-bearing by anaesthetic skin remains. It is only transferred to a more proximal area.

If our aim is to make the Leprosy Home a hospital, what are we doing with the group of patients just described above? Any hospital will be fully occupied by inmates like these within a short period. During the last 4 years various experiments have been carried out at the Schieffelin Leprosy Research Sanatorium, Karigiri, in order to find solutions for these foot problems. The aims of our approach have been:

1. To prevent recurrent ulceration and/or further tarsal disintegration in the feet.
2. To design orthopaedic appliances which can be manufactured with locally available material.
3. To provide aids which are inexpensive in comparison with the cost of keeping a patient in hospital for some time because of ulcer problems.
4. To provide appliances which keep the patient ulcer-free and yet permit him to carry out his daily activities.
5. To stimulate through this work possible professional rehabilitation for the patients.
6. To demonstrate that in many cases amputations are not necessary for rehabilitation purposes.

The results of our efforts have been 2 types of caliper, which we have developed towards standardization, viz. the fixed ankle brace walker and the patella-tendon bearing shell.

**THE FIXED ANKLE BRACE (FAB) WALKER (Fig. 5)**

This type of caliper has been a real break-through in dealing with various kinds of foot problems. Its design is based on the experience gathered over many years.
Fig. 5
TECHNICAL REMEDIES IN LEPROSY

with the application of Plaster of Paris (PoP) for ulcer treatment, and was fully described in this journal (Lepr. Rev., 1971, 42, 158).

While the patient with extensively deformed feet remains ulcer-free in a PoP cast which is accurately moulded to the foot, he does not however remain ulcer-free in an equally accurately moulded shoe. The reason for this is that while wearing a moulded shoe, during the walking cycle the foot experiences selected high pressures, especially during deceleration (heel-strike) and acceleration (push-off). These forces are exerted on 2 limited weight-bearing areas of the foot, namely the heel and the metatarsal heads, which in addition may already be scarred or adversely affected by underlying fragmented bones. Tissue trauma and necrosis are common results. Often such a foot may also have lateral instability or be imbalanced (inversion of eversion deformity), for which a moulded boot provides no remedy. Our splint utilizes the same principle as the PoP cast, immobilizing the foot, transferring the walking cycle to a bottom roll, and assuring almost complete contact of the mould to the foot during the entire walking cycle. In addition, the foot is laterally stabilized and well protected from external trauma. In cases of recent failure the significance of this splint is its prolonged protection of the tarsal or metatarsal bones during the acceleration phase. It has been our experience that patients can safely use ordinary footwear after having been protected with a FAB Walker for a period of 12 months. On the other hand it has been quite common for patients with heel or mid-tarsal fractures, after discharge from hospital without such an aid, to return later with an even more serious condition.

THE PATELLA TENDON BEARING (PTB) SHELL

In feet in which tissue and bone absorption is so great that in spite of accurate moulding the plantar surface is still not fit to tolerate the patient’s weight, an attempt is made to transfer the weight partially to the condyles of the tibia and patella-tendon area of the leg. The apparatus designed is called the Patella Tendon Bearing (PTB) Shell (Fig. 6).

The specially designed FAB Walker and PTB Shell ensure the possibility of full knee flexion when squatting, since we found that this was one of the chief essentials in persuading the patient to accept this type of footwear. The PTB Shell (Fig. 7) shows an area posteriorly cut-out and deep enough to allow full flexion of the knee. Furthermore, it was essential to construct the PTB Shell in such a way that the dimension for weight-bearing cannot be altered while the patient is taking off or putting on his Shell. The assurance of correct weight distribution must not be governed by the patient's ability or disability in putting on his splint.

POST-FITTING CARE

While all other patients with normal sensitivity will quickly respond to the discomfort of high pressure caused by an appliance, a leprosy patient with anaesthesia cannot so respond. It is therefore essential that every patient be carefully checked for a period of 6 weeks in order to ensure that no major problems will arise as a result of prolonged wearing of his appliance. To this end we have established the following routine. For 2 weeks the patient is seen twice daily, forenoon and afternoon, at the workshop. The pattern of the stockinethe he wears will show as an impression on his skin and indicate whether these patterns are occurring over areas suitable or unsuitable for weight-bearing. Immediate remedies in case of blister formation or skin abrasion are applied.
After a period of 2 weeks, during which the patient is doing only normal everyday activities, he is sent for a so-called "stress-walk". In this, according to his general physical ability, he will have to cover a distance of between 1 and 4 miles daily. This is to test the functioning of the appliance under conditions which the patient is likely to meet in a rural surrounding. It is planned in the form of graduated activity, starting with 2 miles the first day and progressively increasing as long as no problems arise. If any evidence of high pressure develops, the area concerned can be at once relieved of this pressure before ulceration causes irreversible damage.

MATERIALS USED

In most of our cases we have used locally available materials such as upper-leather, sole-leather, mild steel, and waste-tyre. For the PTB shells stockinette impregnated with polyester resin is used. While the leather material is cheaper it is not very long lasting, whereas resin, though a little more expensive, lasts longer and is relatively free from need of repair.

CONCLUSION

The average costs for the above described orthopaedic aids range between 10 and 20 dollars (USA), which is approximately equal to the cost of keeping a
patient for 18 to 36 days in a hospital in South India. The author hopes to have demonstrated that funds spent for rehabilitation projects are actually helping to save money, i.e., by making it possible to discharge patients who without the service of orthopaedic workshops would otherwise be unfit for discharge. What it means to the individual patient to be able to live his life independent of a hospital cannot of course be expressed in terms of money.
Book Review


Andrews was a Salvation Army doctor whose life was cut off in its prime. His selfless gallantry under fire rescuing the wounded earned him a posthumous Victoria Cross.

Andrews was followed by many others, including some who have made their mark in leprosy. The name of Nagercoil in Kerola spells reconstructive and plastic surgery for leprosy patients. It stands for teaching of skills to surgeons and nurses. Chikankata stands for leprosy control in Southern Zambia.

A series of short biographical sketches, vignettes of healing, make up this interesting little book.

*S. G. Browne*
Abstracts


This paper outlines the basic facts of leprosy as presented to doctors applying for a medical licence to practise in Hawaii. The text is unexceptionable, apart from such debatable statements as these: the incubation period of leprosy is said to be "not uncommonly . . . 10 to 25 years", or "even longer"; "leprosy, undoubtedly, was present" among the ancient inhabitants of Palestine; there were, by the middle of the twentieth century, "only a few known cases on the continent of Europe" [there are at present over 50,000]; indeterminate leprosy is characterized by "moderate numbers" of bacteria and is "about half way between the lepromatous and tuberculoid forms".

Leprosy was probably introduced into Hawaii around 1830, by the Chinese. After a period of rather rapid extension—culminating in the much-publicized events on Molokai—segregation of leprosy sufferers appeared to result in a falling incidence. There are at present about 400 known cases of leprosy, and some 16 new infections are recorded each year, only a few of which are detected through contact clinics. Liberalized legislation, recently passed, reflects a more modern and realistic approach to leprosy control. Some 170 patients remain in Kalaupapa (in about 40 of whom the disease is still active), and 40 in Hale Mohalu.

S. G. Browne


The authors give a good clinical description of an African female patient, aged about 45 years, who had treatment for early lepromatous leprosy from 1954 to 1958. She apparently remained well until 1966, when signs closely resembling the classical features of the acute exacerbation of Lucio leprosy began to appear. The histological picture in the blood vessels of the dermis was confirmatory. The patient responded well to dapsone, given at first in small doses, which were prudently increased. Corticosteroids were not needed.

This is the first reported instance in Rhodesia of a patient exhibiting many of the clinical and histological features associated with the Lucio phenomenon in diffuse lepromatous leprosy.

S. G. Browne


This study on the use of the diacetyl derivative of dapsone, acedapsone (CI 566, DADDS, Hansolar) was carried out in the Karimui region of New Guinea from November 1967 to November 1969. The drug was put up in a benzyl benzoate/castor oil suspension containing 150 mg per ml, and intramuscular injections were given every 75 days to 327 patients suffering
from various types of leprosy, each injection consisting of 225 mg for adults and 150 mg for children under the age of 6 years. The injections caused minimal discomfort and no injection abscesses occurred. Response to treatment was satisfactory clinically and bacteriologically. Leprosy reactions were noted in one-third of those in the borderline and lepromatous groups, but were mild to moderate in severity and did not cause any interruption of treatment; no reactions occurred in the indeterminate and tuberculoid groups. No bacterial resistance was encountered in spite of the low dosages of sulphone.

The authors are hopeful that this line of treatment will revolutionize the management of leprosy in underdeveloped countries.

W. H. Jopling


This unemotional administrative account of the transformation of the leprosy service in Hawaii provides the necessary complementary information to the reports that have appeared in the lay press.

The strict segregation policy instituted in 1865 was based upon the best advice then available (and obtained) in Europe and Asia, and sought to deal with an indigenous leprosy problem made worse by leprosy occurring among immigrant labourers. Molokai became notorious, until redeemed by the dedication of Father Damien and the pen of R. L. Stevenson. Now the old-type Kalaupapa Leprosy Colony at Molokai is to be phased out, despite opposition from the pensioned leprosy patients and some disquiet expressed by neighbours.

The Health Department, conscious of the importance of public relations, has leaned heavily on the advice proffered by a Citizens’ Committee, and the co-operation of officials and community has produced a sound and acceptable scheme for the control of the diminishing problem of leprosy. Out-patient care is now available, and leprosy has a place in the teaching of medical students.

S. G. Browne


This important paper records the carefully-documented results of the use of acedapsone (DADDs) in the treatment of all known patients suffering from leprosy in a circumscribed area in Micronesia and also, in the same dose, of the entire exposed population. The drug was administered to adults in the usual recommended dose of 225 mg in a benzyl benzoate/castor oil suspension every 75 days for 3 years. With only 2 exceptions, all 68 patients with leprosy showed consistent clinical and histological improvement.

Of even greater interest is the fact that, instead of the 35 new cases of leprosy that, on statistical grounds, would have been expected to appear during the trial period, only 6 actually did appear, and all of these were discovered during the first year of the trial. Thus, although the population (of 1400) had been exposed to leprosy up to the beginning of the trial, the dissemination of viable bacilli had so diminished or the prophylactic value of the injected drug was so marked, that the numbers of new overt clinical infections were one-sixth of those expected.

S. G. Browne


(i) This is a study, carried out in Atlanta, U.S.A., on the effect of clofazimine (B663;
Lamprene) on footpad infections in mice, the drug being administered prophylactically and therapeutically for various periods. It was found that continuous administration from day 70 to day 140 after infection prevented subsequent growth of *Mycobacterium leprae*. When given for 2 days a week over a 7-week period, growth eventually occurred but only after a delay of more than 400 days. When given for 2 days every 4 weeks, growth was delayed 189 days. A single 2-day period of therapy was not effective when given 70 days after infection, or 35 days before infection, but it had a distinct effect when given on the day of infection.

(ii) B1912 is a newly synthesized type of rimino compound which has roughly the same activity as clofazimine against tubercle bacilli in mice. Like clofazimine it is highly pigmented and very slowly excreted, and the authors show that it is very similar in its effect against leprosy bacilli in footpad infections in mice.

W. H. Jopling


Lymphocytes, obtained from a human being or animal who has developed a specific immunity, when exposed to the specific antigen release substances called lymphokines. The authors obtained leucocytes from the blood of rabbits and men, and removed the majority of the lymphocytes and granulocytes. “80-90%” of the remaining cells were monocytes which, when cultured, developed into macrophages. Mixed leucocyte cultures (MLC) were prepared by mixing equal numbers of leucocytes from 2 rabbits. When supernatants from these MLC were added to a culture of macrophages obtained from one of these rabbits, the yield of macrophages after 8 days was increased from $3 \times 10^3$ to $9 \times 10^3$ cells, and the macrophages developed intercellular cytoplasmic bridges and giant cells. Lymphocytes were cultured from pairs of patients with tuberculoid and lepromatous leprosy. To a culture of macrophages, obtained from one of the patients with tuberculoid leprosy, were added killed *Mycobacterium leprae*. When MLC supernatant was added, the yield of macrophages after 10 days was increased from $4 \times 10^3$ to $18 \times 10^3$ cells, and the macrophages developed intercytoplasmic bridges and giant cells. However, if lymphocytes were initially removed from the MLC, the supernatant did not stimulate multiplication. Macrophages from the patients with lepromatous leprosy when exposed to *Myc. leprae* and then to MLC supernatant did not increase in numbers. *Myco. microti* and *Myco. lepraemurium* multiplied in rabbit macrophages in the presence of unmixed leucocyte supernatants, but were inhibited in the presence of MLC supernatants. With filtered and unfiltered supernatants the results were identical. The authors state that these observations demonstrate clearly the lymphocyte dependence of macrophage proliferation. Also the inhibition of intracellular multiplication of mycobacteria observed in this study indicates that the lymphokine mediated lymphocyte-macrophage interaction could be a potent antibacterial principle, at least against slowly growing intracellular bacteria. They also suggest that “there is an impairment of the *M. leprae* induced lymphocyte-macrophage interaction in patients with lepromatous leprosy.”

[These revealing experiments open new fields for leprosy research, as well as providing fundamental information on lymphokines.]

C. S. Goodwin


The new riminophenazine derivative, B1912, has been reported to produce lower tissue levels but higher serum levels than clofazimine (B663). Mice were infected with *Mycobacterium lepraemurium* and then fed on diets containing either B663 or B1912. The drugs were either
administered from the day of inoculation and then continued for 3 weeks or 3 months, or else the drugs were not given until 2 months after inoculation and continued for 3 months thereafter. In a fourth group, animals were treated for 5 months after inoculation and then observed for another 5 months without treatment. Two doses of each drug were used in each group, 0.005% or 0.01% in the diets. There was also an untreated group of mice.

At the end of the experiments the organs were examined for *Myco. lepraemurium*. Both doses of B663 and the higher dose of B1912 showed "marked suppressive activity", while the smaller dose of B1912 was "slightly less effective". All the treated animals developed a yellow coloration of the skin on the ears, feet and tail. The subcutaneous fat appeared yellow after 3 weeks' treatment, and orange after 3 months. After 3 months the coloration of the animals receiving the larger dose of B1912 was more marked than that of those receiving the same dose of B663. However, in the group observed without treatment for 5 months after initial treatment, the yellow coloration had virtually disappeared in the animals which had received B1912, but was still present in animals that had received B663, especially those that had received the larger dose. The author concludes that B1912 showed less drug accumulation and a faster rate of drug elimination than B663.

*C. S. Goodwin*
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Printed in Great Britain by the Whitefriars Press Ltd., London and Tonbridge