LEPROSY TODAY

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Leprosy can be a severely disfiguring and disabling disease but for most of the 15 million sufferers of leprosy in the world it is the stigma that is hardest to bear. The Shorter Oxford dictionary gives two relevant meanings for the word stigma: the first 'a distinguishing mark' (applied to the characteristic signs of the disease); the second (relevant to the almost universal contempt for the disease) is 'a mark of disgrace . . . a sign of severe condemnation'. It is interesting to trace the possible origins of the second namely the social stigma of leprosy.

The Origin of the Social Stigma

There would appear to be three closely related constituents; a Primitive Fear, a Rational Fear and a Religious Fear.

(*a*) *Primitive Fear.* According to RYRIE leprosy is the foremost example of a group of blemishing diseases which evoke the guilt complex in the sufferer and in the observer. FRAZER cites many examples of belief among primitive peoples of leprosy or other blemishing diseases affecting those guilty of violating certain taboos. How guilt is evoked in the observer is less clear but the complex nature of taboo discussed by FREUD would seem to make this possible. Perhaps related is dread of a 'living death' (associated with taboo on the dead) fear of disfigurement, and revulsion towards the unaesthetic.

(*b*) *Rational Fear.* That is fear of contagion. The Laws of Moses provide a rational basis for fear of the disease as they are sanitary laws, not superstitious taboos. Nevertheless because they occur amid sacred writings they assume Divine significance and can contribute to the Religious fear. It must be mentioned however that fear of contagion may not have been as important in the past as it is today. Leprosy has frequently been considered an hereditary disease and there are accounts which suggest that infection was not feared in parts of Britain (MACARTHUR) and Scandinavia (RICHARDS). A further example is the Chinese proverb quoted by MAXWELL 'Sleep with a leper but do not be a neighbour across the street to a man with itch (scabies)'.

(*c*) *Religious Fear.* Fear of divine punishment increases the primitive fear. In China and Japan, and India, and many other parts of the world leprosy is considered a punishment inflicted on the guilty by the gods. The mistaken identification of the Old Testament disease *zaraath* with leprosy today has added to this fear as there are examples of *zaraath* being punishment for sin (Numbers 12: 9–14; 2 Kings 5: 1–27; 2 Kings 15: 5; 2 Chronicles 26: 17–21, 23).

It is apparent that history and translation problems have contributed to the fear of leprosy. Identifying historical diseases with those today presents difficult historical, semantic and diagnostic problems as the ancients frequently omitted to record obvious features. According to DHARMENDRA the earliest accurate description of leprosy is to be found in the Sanskrit Sushruta Samhita (600 B.C.). Suggestions that earlier descriptions occur in Chinese and Egyptian literature have been discredited by LOWE. Aretaeus of Cappadocia (A.D. 100) wrote a detailed account of lepromatous leprosy. SCOTT quotes later accounts from Chinese (seventh century), Japanese (eighth century) and Mediaeval European literature.

Translation problems. In Leviticus (Chapters 13 and 14) there are diagnostic criteria of a condition termed *zaraath* in Hebrew. Three possibilities exist as to the nature of *zaraath*.

(i) It is modern leprosy, an assumption made in most translations and by earlier authors on the history of leprosy (quoted in *Leprosy and the Bible*).

(ii) It represents a group of blemishing diseases including leprosy (CHAUSSINAND).

(iii) It bears no relation to modern leprosy (COCHRANE, LENDRUM, LIE TAS). Not only are the lesions different from those of leprosy but there is no mention of cutaneous anaesthesia. LENDRUM suggests that *zaraath* is not a disease but a state of ceremonial uncleanliness (comparable to the state of the 'untouchables' in Hindu society) as it can be shared by inanimate objects such as garments (Leviticus 13: 47) and house walls (Leviticus 14: 33–47).

When the Hebrew scriptures were translated into Greek (in the Septuagint 200 B.C.) there was the problem of translating the typically Hebrew idea into the Greek where it did not exist. *Lepra* was used for *zaraath* as it had been used for a skin condition in Hippocratic writing (400 B.C.) where it originally meant 'something which peels off' (MACARTHUR). *Lepra* in Greek medicine was used for scaling skin diseases such as psoriasis but never to leprosy which was called *elephantiasis*. It is under the title *elephantiasis graecorum* that historical descriptions of leprosy are to be found even as recently as 1847 when Danielssen and Boeck published their work which founded modern leprology. The Greek *lepra* became *leprosus* in the Vulgate, Jecrome's Latin translation of the Bible about A.D. 400. In the translation of Isaiah 53: 4 foretelling Christ's suffering the Hebrew *naga* (stricken) was rendered, in keeping with ancient usage, *leprosus* which became *leprous* in John Wyclif's English translation (fourteenth century). This resulted in the belief that Christ died a 'leper' (MACARTHUR). The word *leprosy*, subsequently used in the plural by Pliny and Macaulay, according to INNES included syphilis, scabies, dermatophytosis, psoriasis, bubonic plague and destitution so that a beggar could be called a 'leper', the word also used for the disease

itself in some manuscripts. *Leprosy* and *leprous* were also used for diseases of animals and plants. The examples cited by MACARTHUR are ' . . . the cankred mangenesse called Leprossie' and 'Myst and fog . . . make graine leprous'.

It is tradition that Job had leprosy though LIE believes that he suffered with scabies crustosa. The disease suffered by Lazarus (whose name means without help) was identified as *lepra* by the Church Fathers though this is described as *ulceribus plenus* similar to the name given to Job's disease in the Vulgate. It is very unlikely therefore that the Hebrew *zaraath*, the *lepra* of Hippocrates, the diseases of Job and Lazarus or the many conditions included in the mediaeval meaning of the word bear any relation to modern leprosy. LENDRUM points out that it is only since Armauer Hansen described the causative organism in 1874 that the word has its present official meaning.

The Reaction of Society to the Sufferer

This has been ambivalent. The commoner reaction has been ostracization. The methods vary from an African one of simply driving him into the bush to die to the more complex but no less effective measures of Religious and Civic legislation evident in Hebrew, Chinese, Indian and European history depriving him of his home, his citizenship, his freedom, and all but depriving him of his life; frequently this too was taken. In China sufferers have been burnt alive if rich, and buried alive if poor (MAXWELL) and shot (KELLERSBURGER) and in Mexico they have been burnt as sacrifices (FRAZER). It is likely that guilt motivates this attitude, certainly one of the ways of dealing with guilt is projection of the guilt onto a scapegoat. For centuries sufferers from leprosy have been scapegoats for society but in this role have not differed from the many other scapegoats in history, witches, Jews or any other religious, political or racial groups. It may be significant that the stigma of leprosy is greatest in the more sophisticated forms of society. Certainly some of the most pathetic examples of the stigma come from the United States. In India similarly the stigma is strongest in the higher stratum of society (SURTY).

Less commonly sufferers from leprosy have been shown great compassion, as from the Franciscans and other religious orders when leprosy was endemic in Europe in the Middle Ages. Undoubtedly most was zealous Christian service partly based, perhaps, on the mistaken belief that Christ died a 'leper' but RYRIE suggests that contributary was an over compensation for guilt. The dread of the disease and the over-compensation is well recorded in GOUDGE's life of St. Francis of Assisi. A similar over-compensation may have contributed in motivating Father Damien (whose great work and sacrifice is well recorded by FARROW) and other workers

since (RYRIE.) Motives founded on compensation for guilt or gaining personal merit (exemplified in the Mohammedan or Hindu obligation to almsgiving) rather than improving the lot of the sufferer are incompatible however with the modern scientific approach aimed at eradicating leprosy.

The Psychological Reactions of the sufferer to his disease

Leprosy is a severe and prolonged mental stress but there are no specific changes. At the onset the patient shares with society a confused horror of the disease and reacts with strong feelings of guilt which may drive him to suicide. The suicides occurring in Carville, U.S.A., have received great publicity suggesting they are a common occurrence which they are not. In Japan KAMIYA claims that the suicide rate among leprosy patients is no higher than among the general population.

Isolation is traditional in the management of leprosy patients and this can have profound psychological effects. LOWINGER claims that 10% of leprosy patients at Carville develop psychosis against approximately 1.25% in the normal American population. A similar incidence was found in England by JOPLING who points out that he has not found psychosis in outpatients. KAMIYA, however, found the incidence of psychosis similar to that in the normal Japanese population. Schizophrenia was the commonest functional psychosis in Carville. It is doubtful whether there exists a true organic psychosis in leprosy as there is no histological evidence of brain involvement though KAMIYA describes delirious states and amentia like pictures occurring in some cases of acute exacerbation of leprosy. Sulphones have long been accused of causing psychosis but it is likely that they can now be exonerated. It is likely that those patients developing psychosis possessed a constitutional predisposition to psychosis though the psychosis frequently improves with treatment of the leprosy. Leprosy naturally occurs occasionally in mental patients but according to VERMA it does not change the mental picture. Overt psychoneurosis is not often found in psychiatric studies. LOWINGER suggests the reason for this is fear of psychiatric referal, the unavailability of psychotherapy, the reduction of anxiety by work assignments and religion (PEDLEY) and general medical management.

In the absence of clinical mental illness leprosy nevertheless produces profound mental changes. Group Rorschach tests on hospitalised patients in Japan (KAMIYA), Molokai (LORD) and Africa (PEIFFER) show the typical effects of hospitalisation, immaturity, withdrawal, narrowed mental horizons and a reduced capacity of thinking in line with community thought. The Need Inventory revealed to KAMIYA a clear picture of over-compensation; the needs of autonomy, aggression, achievement, affiliation, nurturance and understanding appeared significantly stronger than in the control

normal group. KAMIYA also found that the Rosenzweig Picture Frustration test revealed repression and resignation (which increased in institutionalised patients as age, period of residency and degree of physical disability increased) in both hospital patients and out-patients who in addition showed guilt feelings and a reduced power of self assertion. Boredom, a sense of the futility of life and lack of future aims and hopes were also common in institutionalised patients who may be classified, according to KAMIYA into two types: the resigned and the aggressive. LOWINGER describes the atmosphere at Carville as suspicious and depressed and paranoid tendencies are evident in autobiographies of leprosy patients such as MARTIN. The above tests have also shown disturbances of body imagery and LORD cites the example that leprosy patients may fail to notice the absence of the nose in a drawing of a face. It is interesting to speculate with LOWINGER that leprosy may precipitate psychosis in susceptible individuals because of disturbance of body imagery resulting from auto-amputation and seeing deformities in others, and from social and psychological isolation (from blindness and cutaneous anaesthesia), both features of schizophrenia. The degree of withdrawal attained by the patient may be considerable even in the absence of psychosis that the patient cannot or will not return to society outside their institution and this is becoming a major problem in Culion Sanatorium (LARA and TIONG) and elsewhere.

This is not to suggest that all leprosy patients are so affected to the degree described and rather than being struck with the observed changes one is impressed (as pointed out by LORD) by the relatively healthy overall picture suggesting a certain flexibility and adaptation of the human personality under conditions of rather extreme long-standing physical and environmental stresses. Much of the mental suffering described can be prevented by a rehabilitation policy starting on the day of diagnosis. Further, mental rehabilitation must precede and thus determine the degree of physical rehabilitation.

Modern Management

Rehabilitation. 'By rehabilitation is meant the physical and mental restoration, as far as possible, of all treated patients to normal activity, so that they may be able to resume their place in the home, society and industry. To achieve this, treatment of their physical disability is obviously a necessity, but it must be accompanied by the education of the patient, his family and the public so that not only can he take his normal place, but society will also accept him and assist in his complete rehabilitation' (World Health Organisation). It is estimated that more than 25% of all leprosy patients have some disability, mostly paralysis and injuries to anaesthetic limbs, many requiring physical rehabilitation. This is aimed at preventing deformity by methods pioneered by BRAND and easily explained to

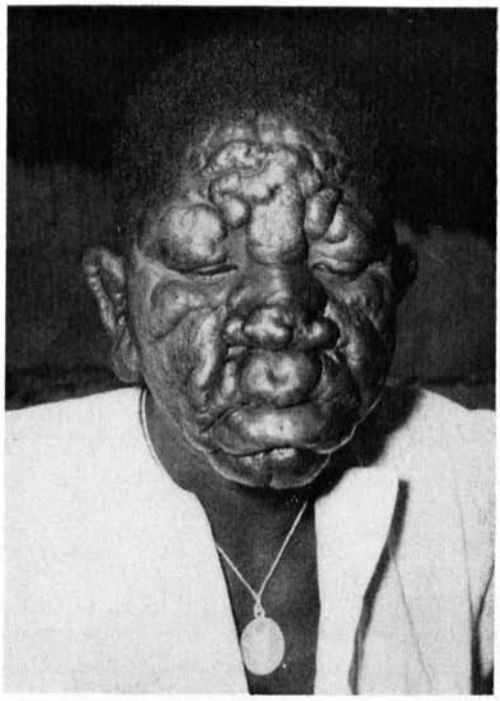
the patient, enabling him to earn his living. These principles of rehabilitation are of great importance in the surgery of leprosy.

The Surgery of Leprosy. For the small percentage of patients to whom it is available surgery has much to offer because of the residual disfigurement and disability after cessation of active disease. Eyebrow alopecia, a collapsed nose, lagophthalmos and the claw hand all indicate active disease evoking fear and guilt in the mind of a superstitious and ignorant public. Surgical correction of these stigmata not only increases the patient's self confidence but also make his future employment more likely. Orthopaedic operations designed to correct physical disability are based on the fact that only certain nerves are affected by the disease (BRAND). Tendons from normal muscles can be transformed to perform the actions of those paralysed. The success of these operations depends on physiotherapy: oil massage, wax baths, splints, exercises are methods used in the preoperative preparation of the patient and the re-education of muscles after tendon transplantation.

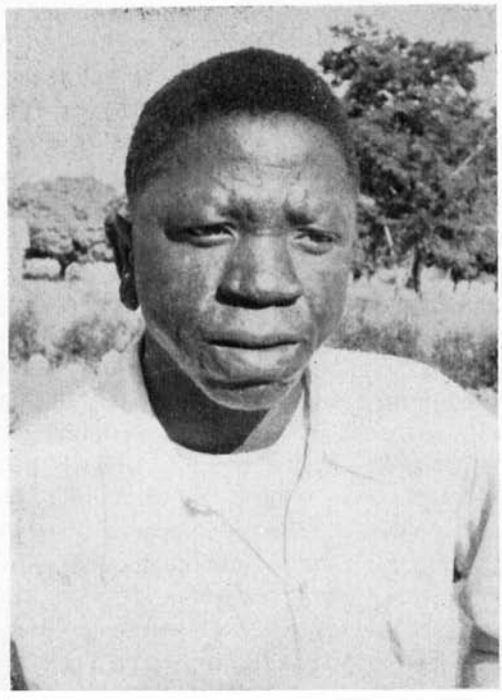
Of greater importance because of its wider application and prophylaxis is the chemotherapy of leprosy.

Chemotherapy. Although chaulmoogra oil was after many years treatment able to render a patient bacteriologically negative it was the introduction of the sulphones twenty years ago that caused the present revolution in the treatment of leprosy.

The Sulphones. Chemically related to the sulphonamides the sulphones are derivatives of Diamino Diphenyl Sulphonic Acid (DDS), an incomplete antimetabolite (BROWNE (a)). Full treatment in must be continued (JOPLING (b)) for two years or until all signs of activity have disappeared for eighteen months in tuberculoid and indeterminate forms, and for more than two years after all sgns of activity have disappeared in lepromatous and dimorphous leprosy, the treatment lasting as long as ten years in some lepromatous patients. A few fail to respond, others relapse after apparent cure and in others resistance develops and others manifest toxic actions, anaemia, nausea, iritis dermatitis and hepatitis. For these reasons sulphones are not ideal and other compounds are being tried in the search for a drug which will cure leprosy in a few months and so prevent deformities developing. Sulphones possess one advantage over all subsequent drugs in that they are cheap and can be used in mass schemes aimed at eradicating leprosy from endemic areas. Mass schemes today operate from a central institution where the most infectious and debilitated patients can be treated and where drug trials, research and surgery can be done. Ambulatory patients are supplied with sulphones from dispensaries and itinerant leprosy workers who search for new cases and educate the public about leprosy, important because it is estimated that not more than 20% of all leprosy patients are receiving treatment of any kind.



An advanced lepromatous patient from Sikonge leprosarium Tanganyika, before treatment.



The same patient, showing dramatic improvement after four years' treatment.

Thanks and acknowledgement to the Mission to Lepers for permission to reproduce these photographs.—AUTHOR.

The results of such schemes, conducted for only two decades, are to be seen already. In Eastern Nigeria the incidence of leprosy is declining steadily at the rate of 15% per annum (BROWNE (b)).

Other drugs. These include Diphenylthiourea (Ciba 1906), Thiosemicarbazone (Conteben Bayer) Diethyldithiolisophthalate (Etisul I.C.I.) B663 (Geigy), Vadrine (Geistlich), Methimazole Cycloserine, Isonicotinic Acid Hydrazide, Sulphamethoxypyridine, Macrocyclon and Etoxid. Not one of these compounds has had the same popularity as sulphones because of toxicity, early development of resistance, expense, or relative ineffectiveness. Some such as Diphenylthiourea and Diethyldithiolisophthalate are initially more effective that sulphones in reducing the bacterial index but resistance soon develops, nevertheless they can be useful in conjunction with sulphones. Thiosemicarbazone, Diphenylthiourea, and Vadrine may be used as alternatives to sulphone therapy when resistance or hypersensitivity have developed to the latter. The literature related to these substances and their effectiveness in treating leprosy is to be found in past numbers of *Leprosy Review*.

The importance of carefully planned clinical trial of new compounds cannot be over emphasised. Clinical trials of antileprotic agents need to be based on the general principles outlined by BRADFORD HILL. Difficulties inherent in planning any clinical trial (CROMBIE), those of individual susceptibility, choosing dosage, side effects, presentation and assessment of the significance of the results, are also to be found in the trial of an antileprotic. These difficulties can be largely overcome as exemplified in the careful trial of Macrocyclon by WATERS in which a comparison was made between the effectiveness of Macrocyclon plus sulphone and sulphone alone (control group). No difference was found so that this one trial has given clear information which obviates the need for future trial of the drug, thus saving time, manpower and expense.

Clinical trials need not be very long today. Assessment can be made on the rate of decrease of Ridley's Bacterial index, and comparison with that of a control group receiving sulphones. Now that WATERS and REES have defined the changes in the morphology of *M. leprae* in patients under treatment it is possible by estimating the rate of fall in the proportion of non-granular (viable) organisms to assess the effectiveness of a drug in a period of a few months only. A further result of their work is that patients formerly considered infective by the Bacterial Index may in fact, if the proportion of viable organisms is low, be considered non-infective and may be treated as such.

It is interesting that more attention is now being taken to the reaction of the body to invasion by *M. leprae*. It is known from the work of WATERS and REES that the dead (granular) organisms are eliminated only slowly from the body. A search is in progress now for

compounds which will accelerate the disposal of dead organisms and it was partly for its surface active properties thought to be useful in this respect that Macrocyclon was tried. Similarly utilisation of biological reactions such as the Epithelioid Cell Reaction (Pseudo-reaction de Souza Lima) is suggested by HIRAKO and SAKURAI. The TECHNICAL COMMITTEE ON PATHOLOGY AND EXPERIMENTAL TRANSMISSION in the recent Congress suggest that an Histological Index (comprising not only the concentration of Acid Fast Bacilli but also the area of cellular infiltration) to be a better assessment of the disease process than the Bacterial Index.

The discovery of the ideal antileprotic agent must await studies on the metabolism and immunology of *M. leprae* made possible by its culture.

Mycobacterium leprae.

This is the first specific micro-organism to have been associated with a human disease.

Culture. Culture on media which support growth of other Mycobacteria has failed repeatedly. Growth of *M. leprae* occurs according to BROWNE (a) on tissue cultures of Schwann Cells. Consistent growth in the footpads of mice is claimed by SHEPARD. Hitherto all such work has been complicated by the growth of contaminant, and largely unknown mycobacteria. The problems posed by *M. leprae* have stimulated interest and research on other mycobacteria and much has been learnt by analogy with *M. leprae murium* and *M. tuberculosis*.

Immunology. In other diseases methods of inducing active passive immunity have been devised soon after the discovery of the causative organism. Little success has attended such attempts in leprosy probably because it is now known that *M. leprae* belongs to a group of mycobacteria which lack surface antigens, circulating antibodies forming only to the antigenic products of the dead organism. Until recently the immunology of leprosy was largely concerned with the use and interpretation of the lepromin reaction. Assuming that the allergic response determines the form of the disease then conversion of lepromin reaction from negative to positive using Baccille Calmette Guerin (BCG) should be advantageous. Trials have cast doubt on the effectiveness of BCG as a prophylactic in leprosy and it may be that it is rather the form of the disease that determines the allergic response, making the lepromin reaction less relevant. Attempts are being made by SHEPARD to make a combined prophylactic containing *M. leprae* and BCG. Finally, it is not entirely surprising that auto-antibodies have been found in leprosy (BONOMO). The fact that they are thyroglobulin antibodies and their relation to thyroid metabolism in leprosy must await further evidence as must the whole question of thyroid metabolism in leprosy.

Epidemiology. The exact mode of transmission of *M. leprae* is unknown. Although many modes including insect vectors have been suggested, prolonged intimate contact has been the official teaching. However, the few patients who have contracted leprosy after apparently casual contact have raised the possibility that individual susceptibility to the organism is important. The incidence of conjugal transmission suggests that less than 10% of the population are susceptible. SPICKETT provides evidence that individual susceptibility and the form of the disease are genetically determined by a single irregularly dominant gene. HSUEN and others find that the incidence of leprosy is high in Blood Group O and low in Blood Group B. A pressing need therefore is for a test which will identify susceptible individuals.

The Future.

The problems caused by leprosy are not unique but rather represent a convergence of the undesirable features of many diseases. There are diseases which are more disfiguring, more disabling, and more debilitating; which are less effectively treated than leprosy and which are associated with a social stigma. Solution of the problems depends on future developments in other fields and the solution will undoubtedly contribute to other fields in medicine. The study of leprosy needs increasing contributions from anatomy, physiology, pharmacology, pathology, radiology, surgery, medicine and psychology. Improvement in the treatment of leprosy awaits easier culturing of *M. leprae* and a clearer understanding of the pathogenesis of leprosy based on histological observations, such as those of WEDDELL, when integrated with known clinical and epidemiological facts.

As the disease is better understood and treated more effectively so there is hope that the stigma of leprosy will disappear. The stigma will be lost in history when public and patient understand that leprosy is a disease like any other but unlike many is eminently curable. Euphemism alone will not eradicate the stigma though measures such as avoidance of the term 'leper' and substituting Hansen's disease instead of 'leprosy' can contribute greatly to the peace of mind of existing patients. In this respect it is worth recalling the name suggested by Dr. Ross Innes for leprosy: Mycobacterial Neuropathic Dermatosis (M.N.D. for short). This has the advantage of being completely free from any emotional connotation while exactly defining the nature of the disease in line with present trends in medical nomenclature.

Correction of the attitude of society towards the leprosy patient does not depend only on education. More fundamentally it depends, with correction of the attitude towards all who cannot, or will not contribute and conform to an established pattern of society, upon 'a

belief in the individual worth and dignity of every human being' (CARSTAIRS). To be counted in a recent census was thus a source of great comfort for a leprosy patient in Nigeria. Christian Missions and organisations have pioneered leprosy work stressing the worth of the patient to his Creator and his fellowman and this must be believed by public and patient.

A special interest in leprosy is necessary until it ceases to be considered an affliction apart from other diseases and until patients are managed under the usual health and social services. This interest is more than charity aimed at relieving present sufferings: it is a vision of a thrilling venture aimed at preventing suffering in future generations of mankind.

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