

## SOUTH AFRICAN LEPROSY LAWS AND CONTROL POLICY<sup>1</sup>

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Where such drastic and unique interference with individual liberty as the segregation of leprosy is practised on medical and public health grounds, it is but right that the subject should be reviewed periodically. Medical science is young and dynamic, and we have witnessed remarkable changes in outlook and concept of diseases. Leprosy control has been reviewed in the past with great benefit to both patients and community. Today we are exceptionally fortunate in witnessing the beginning of a new and revolutionary era in the management of this age-old and much misunderstood disease, and we sense a new hope and a change in outlook as a result of the acquisition of new and more successful drugs.

The subject is naturally considered with respect to: (a) the purely legal and administrative aspects, and (b) the medical and public health basis of legislation.

The legal and administrative aspects, one feels, are beyond the scope of a meeting of this nature. However, it should be noted that, whether accidentally or deliberately, direct leprosy legislation was left out of the Public Health Act No. 36 of 1919, although tuberculosis was thoroughly dealt with. The result is that leprosy is controlled today by a series of provincial ordinances some of which date back to the Leprosy Repression Act of 1884. These ordinances, with their amendments and regulations—more than 12 in number—spread over four provinces, are today administered by the central government. To a layman in these matters it seems that consolidation, as was actually contemplated in 1926 according to the Young Commission Report, would simplify matters considerably. This view is also shared by some of the people who actually administer this patchwork of legislation, in which it is said there are numerous loopholes.

The main reason for the introduction of this subject, however, is that specialist physicians in this branch of medicine may

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discuss the medical and scientific basis of the legislation and the policies based thereon. For some decades there has been a world-wide tendency toward relaxation of the rigid control of leprosy which has been practiced for many centuries, officially where possible and sometimes unofficially. Behind this trend is the overcoming of faulty traditional concepts of the disease and the realization of the low degree of communicability, as a result of accumulating field, laboratory and statistical evidence.

A review of leprosy control practice in other countries is illuminating. In Holland, where the disease is not endemic but where the influx from the West and East Indies dependencies cannot be negligible, no control whatsoever is exercised. J. J. van Loghem (2) states that, so feebly communicable is leprosy, dozens of patients are free to live normal lives; and it has been observed (1) that cases are treated in ordinary skin-disease clinics. In England it is difficult to find out how many cases there really are, because the disease is not notifiable. It is not endemic there, but it would seem that enough cases are imported from endemic areas to supply study groups for sulfone treatment.

In these countries compulsory segregation is not in force and no distinction is made between lepromatous and neural leprosy, and it is claimed that no autochthonous cases have occurred in them for many years. While one is not in agreement with such extreme laxity even though relatively few cases are involved, this practice in these two countries, whose empires include some of the worst endemic areas in the world, indicates that the disease is considered to be of very low communicability under those conditions. This attitude cannot be due to carelessness or ignorance, for these countries are advised by very able and experienced medical men.

In Norway (3), whose leprosy control regulations are considered to be a model for that type of population, only those patients whose circumstances are not suitable for domiciliary segregation or whose rights have been forfeited by abuse of privileges are segregated in institutions. This method of control has been exceptionally successful. From 2,850 in 1856 the number of cases has been reduced to 16, including a number of seamen who contracted the disease elsewhere. In 1913, about 125 of the 300 cases then there were not segregated. In that year South Africa had 190 European patients (5), all segregated; the figure today is 63. Thus in a comparable class of people

Norway has achieved better results by a less rigid policy of segregation.

The United States of America and the Union of South Africa are the only two countries in the world with endemic leprosy which could carry the expense of segregation of all leprosy cases. In one or two states in America leprosy patients are not segregated. Relaxation of rigid isolation is apparent in the granting of an annual period of leave from the federal leprosarium. New legislation has been drafted with presumably greater relaxation.

In countries like those of South America, and India and the Philippines, complete segregation cannot be practiced and, in general, the policy—where there is a definite policy—is to segregate only “open” cases, i.e., those with demonstrable bacilli, lepromatous and infectious neurals. In Cuba, noninfectious neurals are treated in ordinary dermatological clinics (4).

South Africa, as far as can be ascertained, is the only country in the world where all known leprosy patients are segregated, indiscriminately and completely, for at least one year. There is no doubt that the system applied at present in this country has had a beneficial effect on incidence, with due respect to other factors such as improved health organization and better living conditions. Due attention must also be paid to our unique mixed population, with extremes in the social scale living cheek by jowl. The legislation is workable, and from a governmental and public safety point of view the control is reasonably good.

There is an aspect of the matter, however, which is not always apparent from stacks of files neatly tied with red tape, namely, that of the individual patient, the unfortunate sufferer, who is isolated for the common good whether he is so inclined or not. I doubt if one could ever become indifferent to the mental pain and sufferings of people who are forcibly separated for long periods from their families, homes and interests.

As the surgeon inflicts pain in order to cure disease, so is it justifiable to inflict mental pain and suffering for the common good. But there is always the challenge: Are the premises sound? Morally, the onus is on the medical authorities to prove that a leprosy patient is a source of danger to his fellow human beings before taking the extreme step of compulsory segregation. That is specifically stated in the Leprosy Repression Act of 1884 (6), which empowers detention of persons suffering from leprosy *and likely to cause infection*. The Natal law of 1890 (7) explains that only cases of “infectious leprosy” are to be isolated. On the other hand, a confirmed diagnosis of leprosy, with no refer-

ence to infectivity, constitutes grounds for isolation under the Transvaal Leprosy Law of 1904 (8). Any relaxation of segregation based on the communicability of the disease is, therefore, partly a question of interpretation and policy and partly that of new legislation.

For the past 50 or more years the following concepts have stood the tests of scientific scrutiny:

1. *Mycobacterium leprae* is the sole cause of leprosy.
2. Infection can only occur by transmission of bacilli from a patient.
3. The degree of communicability of the disease as a whole is low. (In the opinion of many authorities this is lower than in tuberculosis. This is borne out by the remarkably low incidence of staff infections in leproseries as compared with tuberculosis institutions).
4. The degree of infectiousness of neural leprosy is very low.
5. Transmission is mainly determined by four factors:
  - (a) The susceptibility and condition of infectee.
  - (b) The infectiousness of the infector.
  - (c) The closeness of the contact.
  - (d) The period of contact.

It can safely be said that where no bacilli can be demonstrated, even by surgical procedures, no transmission can occur. This concept is a prominent feature in our present policy. It does not necessarily mean that no bacilli are present. The fact that *M. tuberculosis* is present in knee joints or lymph glands is no reason for isolation. The same applies to some forms of tertiary syphilis. Hence the emphasis on the availability of bacilli and the division into "open" and "closed" cases—a concept that could be used more widely in the institutional management of leprosy instead of the less accurate "lepromatous" and "neural" terminology, for neural cases can be "open."<sup>2</sup>

The crux of the whole matter is that a neural patient who has no available bacilli at one moment may have some at a later date. Fortunately, in South Africa this occurs only in a minority of cases, and then it is a matter not of days and weeks but of months or years. In neural cases available bacilli come mainly from limited sources, the nasal septum and—infrequently—the macules, and therefore they can be readily obtained and demonstrated.

<sup>2</sup> This distinction was made by the Leonard Wood Memorial Round Table Conference, held in Manila in 1931, when it set up a second, "administrative" classification of "open" and "closed" cases regardless of the clinical classification, and it has been used very extensively since then (see *Philippine J. Sci.* 44 (1931) 449-480).—EDITOR.

Of the neural patients admitted in the period of twenty-two years from 1916 to 1948, there remain 314 in the institution. Only 26 of these cases (8.3%) were positive on admission or just prior to admission. A larger number, 46 (14.6%) became positive after an average of 3.6 years in the institution, but they did not become lepromatous. That change occurred in 60 patients (19.1%) after an average stay of 8.8 years. A large majority, no less than 182 (57.9%), have never had positive nasal or skin smears; they have been in the institution for an average of 2.7 years. Thus more than one-half of the worst neural cases—i.e., those not fit for discharging, mainly on clinical grounds—never became infectious.

If the better class of neural case is considered, the proportion of infectious ones is smaller. Of the 134 cases discharged probationally in 1948, only 17 (12.7%) showed positive during their stay. That means that a full 87 per cent of them passed through the institution (average stay, 2.6 years) without ever being sources of available bacilli. During the last three years 533 neural cases were admitted, of which only 8 (1.5%) proved positive in nose or skin smears on admission.

The possibility of recrudescence is the reason for the prevalent system of surveillance. Six-monthly periods have not been found too long from an epidemiological point of view, and even though the system is not applied very efficiently it should be considered a prominent factor in the present degree of control. But it has been reinforced by high standards for discharge. It is contended that in cases which are suitable as regards intelligence and from the social and bacteriological points of view, these standards could be relaxed provided surveillance were increased and provided any breach of arrangement and regulations would be the signal for complete compulsory segregation. I do not think that there are many patients of suitable types who would not gladly submit to such an arrangement, with monthly or even more frequent examinations, if the restrictions on their liberty could be relaxed.

The examinations of cases under surveillance should be done by persons with special knowledge of the disease, or at leprosy institutions. The Norwegian idea of a medical inspector of leprosy has much to commend it. There is the moral issue that it is wrong that accidentally discovered cases should suffer segregation while the undiscovered ones remain at large. Active search for such cases would be a positive step forward, and



would raise the incidence of readily curable early cases. These would be the functions of the leprosy inspector.

The development of the sanatorium idea in leprosy work has much to commend it, and in my opinion it is an inevitable outcome which will derive great impetus from the dramatic changes now taking place in therapy. Voluntary use of specialized knowledge of the disease and its treatment at such sanatoria would be greatly encouraged. A newly discovered case would be thoroughly examined and detained for a suitable period, to be trained in the principles of infection control. Compulsory segregation, retained as a valuable weapon in leprosy control, would be kept in the background. But specialized treatment would be the inducement to stay.

No apology is offered for outlining a procedure which is applied in tuberculosis, when it is everywhere agreed that the latter is the more infectious of the two diseases. In tuberculosis, if ample accommodation were available, only open cases would be isolated. Tuberculous patients are certainly not transported in prison-like coaches attached to good trains, nor are they restricted from almost all means of livelihood after discharge. If leprosy were controlled as is tuberculosis, it would still be safely managed. Prejudice is a prominent reason why general hospitals do not accommodate leprosy patients, the treatment of which disease is less specialised than is that of tuberculosis. Other points arising from such development would be:

- (1) A possible decrease in the financial burden to the state.
- (2) The avoidance of superinfection, i.e., exposing relatively immune neurals to infection from lepromatous cases.
- (3) Increase in the number of early cases coming for treatment, and thus improvement of their chances of early arrest. That cases are still hiding or not consulting doctors because of fear of segregation is borne out by the beneficial effect of relaxation of permanent segregation in 1923.
- (4) The immense psychological effect as an aid to overcoming disease. The effect of sending the patients to Holiday Home<sup>3</sup> once a year already obvious.
- (5) The rate of absconding and hiding will be increased by the ease of administration and acquisition of the sulfones. This can be countered by the sanatorium idea.

To relax segregation and increase surveillance would require the effort of change. We cannot escape the fact that a great deal of conservatism today is influenced by an innate leprophobia. In lay people this is present in an unbelievably high degree, and it results in cruel practices of ostracism even among the more

<sup>3</sup> See news item, p. 338 of this issue.

intelligent people. Medical men themselves are not exempt from this influence of age-old literature. It is high time that the supposed leprosy of the Bible be separated in all minds from the leprosy of Danielssen and Boeck and Hansen and Looft and other modern workers, the ordinary infectious disease of low communicability which can be treated and often cured. If uninformed lay opinion militates against change it is our duty to educate that opinion.

From the *Lancet* of April 12, 1947, I quote a part of a leader:

"In this country the simple regulations of the domestic life of patients with this form of leprosy '(neural)' should be all that is necessary to remove the slight risk of their transmitting the infection to others." Sufferers are eager to cooperate fully in their treatment and in measures to prevent spread, but "there is no justification for indiscriminate segregation of all leprosy patients." Under the existing medieval attitude toward the disease it is virtually impossible to admit a known or suspected case of leprosy to any British hospital or other institution, except the small voluntary leprosarium maintained in the south of England. "This together with the needless stigma traditionally attaching to the disease renders the patients' plight indeed pitiful. Refused employment, ostracized by Society, and debarred from hospital facilities, he loses faith and hope which are essential for his recovery. All he asks for is a little more enlightened understanding."

#### SUMMARY

1. Leprosy legislation in the Union of South Africa consists of a series of antiquated provincial ordinances administered by the central government. These laws should be consolidated and brought up to date.

2. Leprosy control practices in other countries all indicate acceptance of the concept of the low communicability of the disease; they vary from no control whatsoever in England and Holland to segregation with periodic granting of leave in America.

3. South Africa stands alone in its policy of indiscriminate and complete segregation, and it is contended that in suitable cases concessions could be made provided increased surveillance were practised.

4. Morally the onus is upon the medical authorities to prove danger to the community before requiring segregation.

5. The psychological and social implications of total segregation are formidable, but not always apparent from stacks of files.

6. Advantages to be derived from less rigid segregation are, among others, decreased hiding of cases and early seeking of

treatment with increased chances of recovery under sulfone treatment.

7. Public opinion, if against such a change, should be educated systematically. Even in the minds of medical practitioners it is high time that the supposed leprosy of the Bible be clearly separated from the actual leprosy of today.

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6. [SOUTH AFRICA] Cape Province, Act No. 8 of 1884, Section 1.
7. [SOUTH AFRICA] Natal, Law 16, 1890, Section 4.
8. [SOUTH AFRICA] Transvaal, Ordinance No. 23, 1904, Section 11.

#### DISCUSSION OF THE SUBJECTS DEALT WITH IN THE PAPERS OF DRS. DAVISON AND WINTER

[This discussion, from the mimeographed report of the Pretoria Conference, has been much condensed and, to that end, considerably rearranged.—EDITOR.]

DR. J. J. DU PRÉ LE ROUX (*of East London*), stated that in 1756 there were few cases in South Africa, but that in 1833 leprosy had become such a problem that it led to the passing of the Contagious Disease Repression Act. The Leprosy Repression Act was passed in 1884. Only in 1923 did the present policy of discharging arrested cases become operative. Since then the duration of disease prior to admission has dropped from 10 to 2 years. He thought that the segregation policy had been relaxed as far as possible, that care must be taken not to discharge cases too soon. In the Cape the law is administered as written, i.e., only cases of active leprosy are segregated. He has personally seen many burnt-out cases and has not authorized their admission to institutions.

DR. J. H. LOOTS (*of Johannesburg*), held that the individual must conform to the general requirements of the community. Public opinion in South Africa demands segregation, and it is of benefit to the state and to the individual. Outside, a leprosy patient is shunned; in an institution he is a normal individual. Home segregation he is opposed to because, in his experience, the patients flagrantly disregard the regulations. The main trouble in South Africa is the number of undetected cases, and this could be remedied by education of both the physicians and the public.



DR. DAVISON said that, although the number of cases in the Transkei and in Pondoland had decreased by one-half in the last 20 years, there had been no such decrease in the Transvaal or in Natal. The number of Europeans under detention had dropped since 1913 from 190 to 60, and that of Cape Coloureds from 345 to 80.

With reference to Dr. Winter's paper he pointed out that in Holland there is no segregation but a high standard of civilization; the disease does not spread there. In Spain the estimated number of cases in 1932 was 800; in 1947 the known number was over 4,000, an effect of revolutions and wars and reduction in the standard of living. Norway once had the most stringent leprosy laws of any European country, which were relaxed only when they had gained control of the disease. The disease had spread under their previous partial segregation regulations, and it was segregation combined with the improved standard of living which had brought leprosy under control.

Neural leprosy has been compared to tuberculosis of joints and glands, but a closed case of bone tuberculosis or tertiary syphilis is never likely to become an open case. A very large proportion of closed neural leprosy do become open, unpredictably. The nasal septum is not the only possible portal of exit for bacilli.

The sanatorium idea the speaker regards with sympathy, that being what he believes the present institutions are developing into. The important factor of superinfection is their greatest fault. With regard to the plea for the individual who is isolated for the common good, it is imperative for his own good to be isolated and treated, for he cannot get proper treatment except in a leprosy institution. Dr. Winter's quotations from the *Lancet* apply to conditions in Britain, not as yet to those in South Africa.

DR. WINTER stressed the fact that he does not advocate relaxation of leprosy control. Effective control could be compatible with less rigid segregation, in suitable cases, by increasing surveillance. The relaxation of absolute and permanent segregation in the crucial year of 1923 has resulted in diminution in the number of cases. There is now a new era in leprosy work as a result of new treatment, and this has suggested a review of policy. Public opinion should only influence our policy to the extent of our being tactful. If public opinion militates against a change in policy which is based on scientific grounds, public opinion must be educated to a more rational attitude toward the disease.

The statement by Dr. Davison that leprosy in Norway was first controlled by complete segregation is not correct. Partial segregation has been in practice there since 1856, and the ratio of segregated to unsegregated has decreased steadily.

Referring to an inquiry by DR. B. D. WHITWORTH (*of Basutoland*), regarding evidence of infectivity of discharged cases, the reply was that there is no evidence. For the past 25 years unsanctioned field experiments on the infectivity of the disease have been carried out in South Africa. More than a dozen cases of all degrees of infectivity abscond every year, and lepromatous cases have been out on home segregation for many years. The bad effects of these experiments are not apparent. The necessary special conditions for the transmission of leprosy do not easily apply, especially where house and living conditions are of a suitably high standard.

In reply to another question by Dr. Whitworth, regarding infection of staff in institutions—i.e., if the organism remained viable for so long why

were there not more cases of infection?—it is impossible for a person living in an institution for leprosy or tuberculosis not to be exposed to bacilli. The difference between the incidence in staff infections in the two diseases is influenced by the probability that inhaled *M. leprae* do not cause infection. House conditions are a big factor in transmission. Another factor is that probably the majority of people are not susceptible to infection, or have so high an initial resistance that the attack is aborted.

DR. I. LE ROUX (*of the Westfort Institution*), stated that it was difficult to prove infectivity of neural leprosy from statistics only, as there are so many factors involved. With regard to the necessity of considering public opinion, in 1870 leprosy patients were found in village homes all over the country, but "public opinion was not alarmed" at their presence because a medical board had said it saw no reason why this condition should not exist, provided cases were under supervision by the district surgeon or magistrate. Ten years later a medical board—not public opinion—recommended that nothing short of absolute and indiscriminate segregation would ever stamp out "this very terrible and loathsome disease." Biblical accounts are mainly responsible for the public abhorrence of the disease; and it is for the medical profession to guide public opinion and not vice versa. Mentioning some of the unfortunate aspects of the legal situation, he said that it is not so much the law that has to be altered as the way in which it is being applied.

Discussing the psychosomatic influences, he said that the shock of transferring patients to institutions has a bad effect on them. The pathogenesis of most diseases cannot be explained completely without taking the mental influences into consideration. The psychological factor in the treatment of leprosy, especially in Europeans, cannot be easily over-stressed.

DR. M. PRATES (*of Laurencio Marques*), said the leprosy problem in rich South Africa is different from the conditions in the Portuguese, French and Belgian colonies. They have the difficulty of poor people with a high leprosy incidence. In Portuguese East Africa it is 4 per mille, which means 20,000 cases; and it is obvious that all these cases could not be isolated.

DR. H. VAN R. MOSTERT (*of Southern Rhodesia*), said in reference to conditions there that the outlook has changed markedly with a tendency to relax many of the restrictions previously considered necessary. The problem is how far can restrictions be modified and still safeguard the public health.

Certain propaganda from Carville in the United States, circulating chiefly among European patients, advocates almost complete disregard of the infectivity of leprosy and the abolition of all restrictions; and certain members of the public are being influenced to support this view. A century ago in the old Cape Colony this so-called "modern outlook" received support, was tried out, and had to be condemned. The Royal College of Physicians and Surgeons advised along similar lines in 1865, with disastrous consequences in many lands. Are we to fall into similar pitfalls today? It would not be logical.

A contrary policy, one of complete isolation, was instituted in South Africa with certain definite results in its favor. It would appear that the Union has now passed the peak period and that incidence is declining. It may be argued that the present system is too rigid, that the advent of the sulfones may change all this.

In Southern Rhodesia the position taken is somewhat different to that in the Union. In the former place 8,400 acres were set aside at Ngomahuru for the isolation of persons suffering from leprosy under the Public Health Act, until such time as they have recovered or are no longer of danger to the public health. A Ngomahuru Hospital Inquiry Commission, in 1946, advised that the provisions of that act are sufficient to deal adequately with leprosy and that the Leprosy Suppression Act of 12th September 1919 is unnecessary and might advantageously be repealed.

At Ngomahuru the personal liberty of the patients is not so restricted as in the South Africa leprosaria. The 800 native patients are encouraged to live as much as possible as they would at home, and they are housed in six well-separated villages or compounds, not enclosed by any barriers. The diet provided them is very liberal, and they are allowed to till the soil to their own advantage. Those who can work may carry on light duties for which they are paid, and there is a canteen where goods can be purchased at special rates. All this is conducive to contentment and encourages the patients to stay. It may be argued that the disadvantage of the system is that supervision is difficult, and that although the patients are relatively contented there is ample scope for desertion, illicit visiting, cohabitation among patients and other evasion of regulations. The European patients are similarly well cared for, normal visitors are encouraged, and with the permission of the medical superintendent the patients may leave the institution grounds for drives or picnics provided they do not come into contact with the general public. Under certain conditions they have been allowed to go home on "short leave" at Christmas and Easter.