

HANSENOLOGIA INTERNATIONALIS

(Hansen. 1nt)

Brazil officially admits the insufficiency of conventional policies to control hanseniasis and adopts new measures based on removal of the cultural barriers of "leprosy"

EDITORIAL

There is no efficient method as yet to control the hanseniasis endemic. There is no known vector to destroy, nor vaccine or serum to immunize the healthy population. Everything depends on therapy — and therapy is not a very useful tool in preventive medicine.

Sulfones and other drugs might, however, help in preventive work if a great majority of patients and contacts appeared for treatment and examinations. Unfortunately, just the opposite occurs: the *great* majority is neither treated nor examined.

Therefore, prospects to control hanseniasis with our present drugs are the worst possible on account of an *almost unbelievable situation still occurring at this end of the XX Century*: instead of queuing up for Government-supplied free medicines — as in all other diseases — patients hide themselves and their ailments, from doctors, from their community, from their friends, even, sometimes, from their own families.

Why should they not? To stretch their arms to accept a package of

sulfones, they must be prepared to be rejected "leprosy-patients", that is, in practice, "lepers" and outcasts — and be resigned to lose all of their friends, their jobs, and their status in society. His whole family group would panick, be ashamed and ostracized. "*Civil Death*" is as inevitable today as it was in the Middle Ages.

That is exactly where we stand — inexpensive and easily produced sulfones, useful to some degree, especially in early cases, pile up on our shelves — *for we ask the most exorbitant and prohibitive price ever charged for a drug: social degradation and economic collapse.* (1)

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Let us forget prevention for a while: "leprosy" is still a serious médico-social problem which throws millions into the inferno of the worst psychological and social tortures, nurtured with the most antique superstitions, the most ingrained stigma and the most incurable ignorance. It is not necessary for a patient to be physically handicapped or look like an advanced "leonin" or "anto-

(1) Rotberg, A. The exorbitant and prohibitive price of sulfones: social degradation and economic collapse. Hans. abst. news 3:299-302, 1972.

nin". A small tuberculoid patch in his buttock will do the job of making of him an outcast "leper" and a mentally perturbed person. A man paralysed from his waist down by a bullet, or by the polio virus, may become a Presidential candidate, or a President, of a great nation; whereas a flexure of his left finger — if it is "leprosy" — will shut all doors to him, even those of a general hospital, if he dares to try to enter to take care of his bronchitis or heart trouble.

It is not the skin lesion, it is not the handicap, it is the "leprous" etiology that counts. The "diagnosis of leprosy" is the worst "iatrogenic" psycho-social disease ever inflicted on the patients and on mankind. (2)

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For more than nine years our periodicals of the Institute of Health of the Public Health Service of S. Paulo have been calling the attention of the world a) to this unique "psycho-social-somatic phenomenon" called "leprosy", much more serious for its psycho-social aspects than for its somatic component; b) to the impossibility of controlling the disease and/or to prevent the development of that somatic component, if the "iatrogenic" psycho-social factor of "leprosy" is not taken care of, and c) to the impossibility of taking care of this psycho-social factor of the "phenomenon leprosy" prior to the banishment of a sensationalistic, opprobrious and stigmatizing terminology, which chains the physical disease to millenia of prejudice and defilement.

And for more than nine years we were forced to refute groundless rebuttals until we read in an influential periodical of international circulation *the appalling statements that we are right — but that our social and cultural*

problems are not important enough for the world; and that, in spite of the psycho-social and preventive difficulties that the word "leprosy" determines, it must be conserved, especially because it is an "essential factor" in raising funds for a charity.

The fact, now abundantly confirmed, is that, *while it is attempted to make of "leprosy" a "disease like any other" and to educate the public with a counter-educational pejorative, all efforts are being lost and all financial resources of the country — as a matter of fact of all endemic countries — are being exhausted without even scratching the steel-armour of an ancient monster freely and abundantly fed by all sensationalistic media of modern "mass misinformation".*

Patients and contacts continue as terrified by the prospect of social rejection as they were by "compulsory segregation" — if not more. Abolishment of segregation did not accomplish the expected miracle of making them crowd our integrated health centers. We still have to "find" them as meticulously as in the "bad old times", instead of having them "finding us", as is the general rule in medicine. They are the iceberg whose visible peak, in Brazil, is formed by 140.000 "officially registered cases", but whose total mass only God knows, between a half and a full million, according to some estimates. *No prophylaxis will ever work while the "submersed" do not show up, and very few patients will show up to be rewarded with a "leprous" medal.*

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These were some of the topics of medico-social interest discussed, first at a preparatory meeting of hansenologists and public health workers of the Brazilian Ministry of Health, of

(2) W. Belda, who considers the "diagnosis of leprosy" a "iatrogenic disease", is writing an article about the matter.

the National Division of Sanitary Dermatology and of the Public Health Service of the State of S. Paulo, at the Hospital "Lauro de Souza Lima" (Bauru. Feb. 1976), and, a month latter, at a National Conference to Assess the Policies of Hanseniasis Control, attended by participants from the whole country (Brasilia, March 1976).

The conclusions and recommendations acknowledged: a) the insufficiency of internationally recommended policies to control the disease in Brazil; b) the overwhelming importance of the social problem; c) the need of a continuous fight against stigma and misinformation, and even against charities which reinforce stigma in order to raise funds for their empty coffers (and their often obsolete organizations) ; d) the importance of a new, sane, educational and scientific terminology to sever the disease's ties with an opprobrious past, to make education and rehabilitation work and to frustrate sensationalism of all kind; e) the priority of prevention of physical inabilities in *all* possible patients — over the highly sophisticated and expensive surgical techniques for a selected *few*; f) the importance of family planning when teratogenic drugs and reactions or aggravations due to pregnancy, childbirth and puerperium are considered; g) the urgency to give an end to out-dated "leprosaria", "asylums" and "colonies" and of transforming them into general or dermatological hospitals; h) the help which could be given by a team of private practitioners in close cooperation with public health authorities; i) the special problem of the Amazonic area.

Obviously, the principle of integration with public health centers was maintained and the importance of research, instruction, training, nursing, physical and social rehabilitation emphasized.

Is Brazil *going* to make it? It won't be easy, of course, but there is no other way ahead. Opening the Conference, Minister Almeida Machado was very clear and very conscious of the difficulties.

"It is very probable that a new cold and objective appraisal would lead us to conclusions which might shock medieval prejudices, and force us to disturbing options, if we wish to keep in peace with science, with our conscience, with our duty toward the people". "We must discuss, study and propose the innovations recommended by scientific progress". "It is possible that our conclusions will lead us to grievous fights". "Still more grievous would be omission by timidity." "The endemic grows under the shade of timidity of those who know and the superstitious terror of those who do not know".

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Are our new plans going to be supported by other endemic countries with similar medico-social problems? We certainly hope so, and we have reasons to believe it will not take too long. The social troubles of "leprosy" have always been a tremendous worry for anybody with a minimum of information on what is going on in endemic areas, but never a "call for action" was as strident as in the last few years.

"Unfortunately after seventeen years of mass campaigns we realize that the control of leprosy still evades us. *We are now beginning to realize the difference between theory and practice.* That we are dealing with human beings whose fear is not only of the disease but also of social stigma and economic loss, and that theoretical advantages of continuous and long term

New Brazilian anti-hansenic policies

treatment may often be subordinated to the immediate needs of hiding the disease. *All efforts at the control of leprosy are doomed to failure unless the significance of stigma and the associated social and economic factors are given due consideration.* It must also be appreciated that the achievement of the necessary psychological changes in a disease like leprosy, is a much more subtle and formidable task than the technical problems of treatment. *The social scientist has probably a greater role to play than a doctor.* Yet if we look in the past, the social scientist has hardly been brought into any of our leprosy programmes. What is required is a change in attitude toward this disease not only on the part of the patient or the public but more important of the medical profession. No amount of preaching about the curability of the disease, the decreased danger of infection and the feasibility of rehabilitation can have any impact on the patient or the public so long as the medical profession itself maintains its distance from leprosy, and refuses to treat it like any other disease. *What is required is not a mere intensification of the efforts of the past two decades, but a new look at all aspects of the disease both medical and social.* We require a fundamental change in attitude towards this disease by all concerned, that is the leprosy workers, the medical profession, the patients and the lay public. Once such a change is obtained the detailed mechanisms of control

should not prove an insuperable task." (3) (Emphasis added).

"The need for changing priorities is well expressed in a recent World Health Organization publication." Health services are too often tied down by definitions of 'environmental health factors' which underline biological and physical factors as opposed to social and economic aspects; the latter entailing changes in human relationships. The conventional structure of many health services at all levels, be they national, regional, or local, are still geared to deal almost exclusively with bio-physical hazards and nuisances. *Little time has been found up to now to deal with psycho-social and psycho-economic factors which influence the life and health of people.*" (4) (Dr. Davey's italics). So it is with the leprosy patient. When planning his welfare, it is all too easy to think of him as the pawn in the game, who will fit into a pattern of play without question. He is in fact a person, who will make his own choices whatever we plan, and it *behoves us to study his real situation, and devise ways of helping him* which preserve his personal dignity and relationships, at the same time as attacking in the community the infection from which he is suffering." (3) (Emphasis added).

"A stifling smog of ignorance, fear, myth, and superstition surrounds the problem of leprosy, often diminishing the chances for early diagnosis and effective treatment. Furthermore, existing pre-

(3) Antla, N. H. A change in attitude. *Lepr. in India* 46:121-129, 1974.

(4) Levi. WHO Features, May 1974, n.e 30, apud Davey, T. F.

(5) Davey, T. F. Realism in leprosy control. *Lepr. Rev.* 45:197-200, 1974. (Editorial)

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judices are apt to exert a strong influence on the patient's own view of himself and his role in society, and to sharply reduce his chances for recovery. A leprosy patient is often unable to build up a self-identity that will reestablish his feelings of self-respect and integrity." (6) (Emphasis added)

A 15-years-old decree on control of "leprosy" was revoked by President Geisel and Minister Machado and a new bill was signed in record time, incorporating all social, medical and linguistic measures recommended by the seven working groups and the plenary session of the Conference — except those which depend on other Ministries, or which have to pass through the Congress.

The hansenological periodicals of our Institute of Health will be pleased to inform the world about the development of the new Brazilian programs and to receive comments and *suggestions* which will be referred to our health authorities and help them to achieve their goals.

To liberate a disease from a millenary stigma is not an easy task, but Brazil accepted it and does not intend to give up before trying hard. Never before was an international concert against a "medico-social phenomenon" so necessary and never was the world's understanding and cooperation with a national project so important.

We are certain that Brazil deserves that.

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(6) Hasselblad, O. W. Aspectos psicosociales de la lepra. Bol. Ofic. Sanit. Panamer., 78(5):422-429, 1975.