

THE BRAZILIAN PHASE III OF PREVENTION OF HANSENIASIS *

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Phase I in the prevention of hanseniasis (a half-century of compulsory isolation of patients), and Phase II (thirty years of case finding, ambulatory treatment, integration and education on "lepra" and attempts at social rehabilitation of "leprosy patients") have failed. The endemic and the stigma are rising in most developing countries, social rejection of patients and contacts continue, ignorance and counter-education prevail everywhere. Phase III is inaugurated in Brazil with the frank admission that "lepra is not a disease like any other," but rather an exceptional "psycho-social-somatic phenomenon" to be handled in an exceptional way.

In 1976, a completely new program for the prophylaxis of hanseniasis was inaugurated by the Brazilian Ministry of Health, which was to be in accordance with the recommendations of the "National Conference to Assess the Policies of Hanseniasis Control" (Brasilia, March 1976) and with an eight-year-old satisfactory experience in the Brazilian state of S. Paulo. This new program is practically an official admission that the two previous phases have failed to control the endemic in the country. It is based on the

concepts that: (1) The worst of the patients and their contacts suffering is not physical but social and psychological; (2) The removal of the psychosocial factors, besides solving the greater part of the patients' problems, ends their hiding and opens the way to medical measures essential to preventing the aggravation of the physical disease and of the endemic; (3) The psychosocial cultural factor is intimately and inextricably bound to the term "lepra," a "label of primary force" whose ancient and continuously reinforced stigmatizing and degrading connotations by all communication media will never be erased by any amount of educational effort.

In fact, the term "leprosy" was compared to a "curtain of terror" and considered "a more serious barrier to sound medical care than any difficulty in diagnosis or treatment." Its psychological and social malignancy was demonstrated in two recent American inquiries, which concluded that "leprosy" is "the most negative of all medical terms, hindering the patient's social rehabilitations,"² and causing them "continued psychic pain and trauma."³ Previous inquiries in Brazil and Argentina have accused that

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term of being a "disintegrator of the patient's personality,"⁴ a "label overloaded with negative emotions, penetrating the infantile mind with 'linguistic precedence' and blocking any and all future attempts at education." B⁶

The Council of the X International Leprosy Congress at Bergen, 1973, recognized the problems caused by the use of the word "leprosy" ("lepra," "lèpre," "Iebbra") in some countries, which were declared "free to choose any other convenient term." *

The Failure of Phase I

Compulsory isolation of patients, recommended by the International Leprosy Congress (Berlin, 1897), characterized Phase I. It was based on the assumption that Hansen's Isolation Law of 1885 had determined the decline of the Norwegian endemic (only 162 new cases in the 1891-1895 quinquennium), but overlooked the fact that the sharpest fall (1,040 new cases in 1861-1865, 376 in 1881-1885) had begun 20 years before the law, and soon after the institution of Health Committees, in 1857.

Hansen's law, mild and only partially isolationist, was enacted only to reinforce the action of those Committees on the worst cases, but apparently became a sort of scientific anchorage to chronic irrational public fear. It was the scientific legitimization of ancient "segregation" and the starting point of drastic and generalized isolationist measures. Enormous "colonies" or "leprosaria" were built in many countries (35 in Brazil alone). Hundreds of thousands of homes were destroyed, causing innumerable personal and socioeconomic problems.

However, subsequent signs of a declining endemic appeared nowhere. "Leprosaria" were finally declared not only useless but even noxious as they resulted in:

"a. The hiding of numerous patients afraid of being isolated. (This makes it impossible to observe and control those with whom the patient associates.) b. High cost for the public treasury, resulting in the dissipation of funds that might be used better in the development of more rational and efficient methods for fighting leprosy. c. Disintegration and stigmatization of the family make its social readjustment more difficult. d. Unfair discrimination against this category of patients who are then regarded as outcasts, which makes it impossible to reintegrate them into society. e. Perpetuation of popular prejudices".⁷

The Failure of Phase II

Out-patient treatment at integrated health centers was initiated in the late forties and characterized Phase II. It was based on too much optimism concerning the therapeutic and preventive action of sulfones and the possibility of administering these "inexpensive" drugs to large masses of patients, now relieved from the fear of segregation. Case finding would be easier. Patients and contacts would leave their hideouts. "Leprosy" was declared a "disease like any other," to be treated at integrated public health centers and general hospitals. The former "leprosaria" would be reserved for special circumstances. Enlightenment of the public would prepare the way to destigmatization of the disease, to social rehabilitation of the patients, and to the acceptance of all those innovations.

(*) The Workshop on "Human Aspects in the Treatment of Leprosy Patients" of the XI International Leprosy Congress (Mexico City, Nov. 1978) stated that "the word leprosy is to be used with caution since it tends to have a socio-historical, in addition to a medical connotation."

Three decades have passed and no favorable changes have been noticed anywhere in regard to the social stigma of "leprosy," in the ignorance of the public, in the trend of the endemic. Patients and contacts, rejected by health centers, by general hospitals and by society, continue hiding; the minority, found by painstaking "case finding" techniques, soon become defaulters, and rarely receive adequate treatment. Widespread ignorance, due to "mass misinformation," and devastating sensationalism through all modern communication media, are worse than ever.

"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 prejudices 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".⁸

As was to be expected, the endemic flourishes.

"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 of social stigma and economic loss, and that theoretical advantages of continuous and long term treatment may often be subordinated to the immediate needs of hiding the disease".⁹

"Time has not changed much the image of the disease. On the contrary, the literature of different epochs only contributed to aggravate popular

prejudice. So, the word leprosy became a synonym for impurity and filth".¹⁰

"In spite of widening knowledge over the whole field of leprosy studies, of the immense practical efforts of the last 25 years, and in spite of the increased facilities for the growing number of patients under treatment the situation is bleak. (1) There is growing evidence and concern that leprosy is not being contained. Treatment and control programmes have not reduced the prevalence of leprosy in the world and most countries are far from any real control of the disease; (2) Approximately 80% of sufferers from leprosy still receive no medical care at all; (3) Where treatment is available, it is often made ineffective by a combination of : a) irregular attendance; b) a high rate of drop-out; c) continuing social prejudice and pressures against the disease".¹¹

Similar statements have appeared in practically all endemic countries, and are confirmed by the World Health Organization which reported, in 1976, that "strong prejudice against leprosy" prevails in the world.¹² Phase II has failed to control the endemic and to relieve stigma.

Phase III and the Priority of the Psycho-social Problem

The Brazilian Phase III is based on the frank admissions that:

1. "leprosy" is not and will never be "a disease like the others," but, rather an exceptional "psychosocial-somatic phenomenon" which has to be handled in an exceptional way—not by doctors alone but principally by sociologists, educators, psychologists, anthropologists, lexicologists and experts in mass communication¹³;

2. stigma and its psychological consequences are as feared as the old segregation, and sulfones are not that

"inexpensive" if "social degradation and economic collapse" are added to their cost.¹⁴

In other countries, conditions were found to be the same.

"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 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".⁹

"The conventional structure of many health services at all levels, be they national, regional or local, are still geared to deal almost exclusively with biophysical 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".¹⁵

"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 behooves 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".¹⁶

The Purposes and Techniques of Phase III

By removing the social stigma and the problems psychologically related, which often lead to psychopathy, 17, 18 most of the problems of the disease will be solved, as only a relatively small fraction of patients are victims of seriously deforming and debilitating conditions. *This is the new angle from which the whole question is seen in Phase III.*

Furthermore, most physical and epidemiologic consequences of the disease are expected to be averted, as soon as patients really feel that their disease is "like the others," and that they—and their contacts—may seek examination and treatment totally fearless of social ostracism. Only when early "service finding" and "doctor finding" occur in massive proportions, as in other diseases, and replace the peculiar and painstaking "leprosy case finding" will the disease begin to be clinically and epidemiologically controlled.¹⁹

Proven by the failure of Phase II and by the inquiries cited, this cannot be achieved with the term "lepra" or equivalent appellations. In Brazil, a new name was found necessary to gradually disentangle the physical disease from the enormously heavy load of stigma and disgrace carried by a term whose pejorative connotations are being constantly reinforced by all mass communication media. *Neither Brazil nor any other developing endemic country will ever have the means to resist such massive daily counter-education.*

As international organizations have not yet substituted a better terminology, the eponymic "hanseniasis" pre-

viously tested with reasonable success in São Paulo ²⁰ and other Brazilian states, was nationally adopted. * Extensive educational programs with the new word are being prepared. Basic teaching on "hanseniasis" will be included in health courses at all levels, beginning with primary schools. **

Measures to eliminate the "leprosa-ria" of Phase I are already under way. Under the new names of "Hospitals of Sanitary Dermatology" or "Tropical Pathology," some are already admitting patients of pemphigus, leishmaniasis, etc. In exchange, general hospitals are accepting hanseniasis out-patients and beginning to admit a few into infirmaries for intercurrent diseases. Interest in hansenology is augmenting among medical and paramedical professionals and students, and teaching is being intensified.

Sensationalism with the word "lepra," obviously not yet eliminated, will be combatted by all possible means. Charities pose a very difficult problem, as they often resort to sensationalism with the words "lepra" or "leproso," and with stigmatizing photographs, in order to raise funds. It is hoped that most of the charitable agencies will understand the new program and cooperate in destigmatization and prevention. A few have already voluntarily substituted the word "hanseniasis" in their names.

Bodies made up of private medical practitioners are being prepared to take care of patients and contacts still fearful of the ancient stigma and shy of public agencies. Drugs will be dispensed to those doctors, free of charge. Emphasis is being given to simple techniques to prevent disabilities, to be executed at all integrated public health

centers. Contraceptives and family planning instructions will be given to avert the effects of thalidomide therapy, of pregnancy and puerperium.

BCG will be extensively administered in conjunction with phthisiologists, and intensively reinforced in hansenic foci. Although no major preventive effect is to be expected in the immunologically "Anergic Margin" of the population, an artificial anticipation of the Mitsuda reactivity in the "N-Factor" bearers ("natural reactors") might be clinically important. ²¹⁻²³

International Cooperation— Both Directions

The problems of other western endemic countries are similar to Brazil's. Many have suffered the tragedies of Phase I, all are passing Phase II, none has had, so far, any reason to be optimistic about the increase of education concerning "lepra," or on the fall of any of the epidemiologic indexes. In other endemic non-Christian countries, the words "leprosy" or "lepra" may cause less trouble, but all of their local equivalents are more or less noxious. The Brazilian Phase III might be considered as a reasonable substitute for former ineffective policies. A system of information exchange between endemic countries might be implanted, for mutual advantages.

On the other hand, Brazil and other developing Latin American countries interested in the new program, would most certainly appreciate the cooperation of colleagues in the developed English and French speaking non endemic Christian countries, where the words "leprosy," "lèpre," "lepers" and "lepreux" do not hurt their own coun-

(*) In 1975, the U.S. Public Health Service adopted the older eponym "Hansen's disease." The government of Portugal also replaced "lepra" with "doença de Hansen," in 1977.

(**) Since this article was published in "International Journal of Dermatology", the governments of Italy, Bolivia, Jamaica and Trinidad and Tobago have also officially replaced the term "leprosy" with "Hansen's disease". (Author's note)

trymen and do not cause any social and preventive problems.

It is understandably more pressing to look for lexicologic solutions when one's own country is directly affected. In the American scene, for instance, the word "black" is replacing "negro." In the medical field, the new term "sexually transmitted" is being internationally recommended to replace the ancient and stigmatizing "venereal" diseases. There are no more "Invaliden" in Holland, only "Gehandikaptten."

The "lepers" or "leprosy patients" of the endemic countries have the same human rights to less opprobrious appellations. In a civilized and ever-shrinking world, it is reasonable to hope for terminological changes for the benefit of underprivileged developing nations.

The destigmatizing and preventive programs of Brazil — and other countries which might adopt similar measures — would certainly acquire a new impulse everytime an English or French-speaking author substitutes "hanseniasis," "hansenosis," "Hansen's disease" or "maladie de Hansen" for the demoralizing "leprosy" or "lèpre", whose connotations in Latin — American dictionaries are those of "filth," "vice," "loathsomeness," "foulness" — or worse.

"If dermatologists even of the older generations have abandoned "monilia-sis" almost overnight in favor of "candidiasis" to accompany a change in mycological nomenclature, "leprosy" could disappear also, for much more important reasons."²⁰

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