

## HANSENOLOGIA INTERNATIONALIS

(Hansen. Int.)

### Phase III of hanseniasis control commences in Brazil

EDITORIAL

The new program for the control of Hanseniasis organized by the Brazilian Ministry of Health and reported in past numbers of the hansenological magazines of the "Instituto de Saúde" (Institute of Health) of S. Paulo, Brazil (Hansen. Int., 1:106-110, 1976; Hansen: abs. news, 7:324, 337, 1976; D. Hansen, 1:136-146, 1977) and of the Divisão Nacional de Dermatologia Sanitária (Bol. Div. Nac. Derm. Sanit., 35:9-23, 1976) may justly be considered Phase III of the fight against hanseniasis in modern times.

*Phase I, Compulsory isolation*, as was recommended by the International Leprosy Congress (Berlin, 1897) was based on Hansen's "Isolation Law" (1885), which was credited with having caused the decline of the endemic in Norway. In fact, the decline clearly commenced about twenty years before the law, and about 7 years after the institution of "Health Committees". Hansen only intended to reinforce the educational work of the Committees, by isolating the more advanced patients, who did not or could not cooperate.

It seems that a chronically and intensely fearful and prejudiced world took the recommendation as a legitimation of a segregationist past, and as a suggestion, that, if Hansen's mild measures worked, "less mild" ones would work

even faster. Harsh regulations appeared in many countries, leading to one of the largest "man-hunting seasons" in history.

The Brazilian law n° 610 of 1949, which has been revoked, was typical. It forced the isolation of all cases of "lepromatous leprosy", of all "non-lepromatous" but "probably contagious", and of *all* other "non-lepromatous" who "might represent a threat to public health". Thirty-five "leprosaria" were built in the country for the purpose.

However, neither Brazil nor any other isolationist country became a second Norway. The endemic expanded as seriously as in countries where patients were never arrested and imprisoned. Compulsory isolation was finally condemned, as was to be expected by anybody who had carefully studied the Norwegian events.

*Phase II — Treatment of out-patients in integrated services* began in the fifties with an over-optimistic view of the value of sulfones and of the possibility of dispensing them to masses of new patients, recently relieved from the fear of isolation. Patients would be socially rehabilitated. The public would be enlightened and rejection would come to an end. "Leprosy, a disease like any other" would be admitted into general hospitals. The old "leprosaria" were now

accused as the cause of most evils. A seminar held during this phase concluded that they resulted in: "a) The hiding of numerous patients who are 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 better used in the development of more rational and efficient methods for fighting leprosy. c) Disintegration and stigmatization of the family, making 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." "Leprosaria" should be reserved for special situation and adapted for research, training of personnel and rehabilitation.

Almost 30 years have passed and, in most countries, the disease continues to be fought with the methods and concepts of Phase II, although not even the feeblest signs of a declining endemic and of a declining stigma have appeared anywhere. In some places segregation goes on, due either to ancient laws or to community pressures. "Leprosaria" have not changed much, and the "segregationist spirit" is as alive as ever. Patients continue to be rejected by general hospitals, by health centers, by society. Education does not work. Ignorance, terror and superstitions prevail. Contacts hide themselves. Fearful and ostracized patients do not show up (or soon become defaulters, if they ever do). *Only a small fraction of the small fraction who dares appear in the open, receives adequate treatment.* No prevention should be expected under those conditions.

Phase II has certainly been less tragic than Phase I; but its results have been equally negative.

## THE PRIORITY OF PSYCHOSOCIAL PROBLEMS

*Phase III starts in Brazil with a completely new concept and with the plain admission that "leprosy?" is not and will never be "a disease like any other", but, on the contrary, an exceptional "psycho-social-somatic phenomenon" to be handled in an exceptional way.* It is not a common physical disease to be taken care of by common medical and preventive measures alone, but a "somatic nucleus" encircled by an enormously heavy "psycho-social chain" of legends, fantasies, superstitions and ignorance, leading to grave psychological problems and absolute social rejection — a "chain" growing heavier every day by overwhelming "mass-misinformation", sensationalism, religious texts and sermons, literature, press, radio, cinema, theater, TV and "stigmatizing charity".

*Human suffering is vastly more attached to this "psycho-social-chain" than to the "somatic nucleus". Hence, destigmatization will correspond to the end of the problems of the large majority not yet affected by the worst deformities and disabilities.*

*Furthermore, this "psycho-social chain" blocks now and will always block the way to the application of all medical measures (adequate examination of contacts and patients, early treatment, prevention of disabilities) and to control the endemic — by present or future methods.*

*Therefore, liberating the "nucleus" — the disease — from the "chain" — the stigma — is in Phase III the fundamental "sine qua non" step. How to manage it is the controversial problem.*

The aim of the classic educational techniques of Phase II was to inform the public about the scientific advances about the disease, in order to confer "medical status" to the term "leprosy" and deprive it of all its emotional and stigmatizing connotations.

As it can be easily understood, this was considered an impossible task in Brazil in face of the powerful national and international sensationalistic counter-education continuously nurturing a millenary and firmly grounded stigma. *All resources of the country — as a matter of fact, of any endemic country — would be wasted before removing a single microgram of the "leprous chain".*

The alternative adopted was to leave the "chain" as it is, and pull out the physical disease under another name. "Leprosy", the cultural phenomenon would remain untouched — but it would not touch the disease "Hanseniasis".

There is no originality in this procedure. To discard demoralized names and look for better appellations in order to improve the "image" of anything, from objects to abstractions, is an age-old, approved, normal technique constantly applied in all fields of human activities. In medicine, one of the latest examples is that of the New York League for the hard of hearing, adopting a new term to replace "deafness", as the word "deaf", has acquired unpleasant overtones in the U.S. In Holland, "Gehandicapten" is the new word for the "Invaliden". *There is no reason why developing countries should not also be able to introduce similar terminological changes. (\*)*

The single originality found was the antagonism that the terminological revision provoked in most specialized centers. This could be expected from some voluntary agencies to which the emotion-loaded word "leprosy" is essential for fund raising, and to which any new "cold" scientific term would correspond to financial losses. However no valid reason has appeared yet to justify other criticisms. The most common of all — that stigma depends on deformities and disabilities — is easily refuted: anybody with a minimum of experience in the

endemic areas knows the difference between disabilities "by leprosy" and other disabilities, and is perfectly aware of the stigma caused by a single non-deforming and non-disabling macular lesion — if it is "leprous".

#### OTHER CONVENTIONAL AND NON-CONVENTIONAL MEASURES

The transformation of the fearful "leproseria" of Phase I into integrated dermatological or tropical diseases hospitals is on the way in Brazil. Teaching is being intensified and covenants with medical schools are in progress. Emphasis is being given to prevention of physical disabilities by simple techniques in all health centers. BCG will be extensively applied, in conjunction with tisiological services and intensively reinforced in hansenic foci. The risks of pregnancy, puerperium and thalidomide therapy will be abolished by ample contraceptive instructions and facilities. Bodies of private dermatologists and general practitioners are being organized to take care of patients and contacts who might prefer not to be treated at public agencies. Anti-hansenic drugs will be handed over to those cooperating doctors, free of charge.

Case-finding, treatment, integration with public health services, physical rehabilitation, training of personnel and other principles and measures of Phase II are not only conserved but being adapted for the increased work expected to parallel the vanishing of stigma.

#### PHASE III APPROVED IN THE PRELIMINARY, TESTS

In the state of S. Paulo, Phase III has proven its validity since its initiation in 1967. In spite of it having been limited to a single area of the country, and of the continuous emotional load of "leprosy", the first signs of *terra firma* began

(\*) The stigmatizing term «venereal diseases» is being substituted internationally by sexually transmissible diseases.

to appear. The interest of the medical profession was augmented, teaching and research in the Universities was intensified, Congresses, Seminars and Symposia multiplied. The educators' work was eased, as they were no longer under obligation to recuperate an irrecoverable word, a counter-educational "label of primary force".

"Hanseniasis patients" began to be accepted with less reservations in integrated health centers, although it was no secret that they were the same ancient and feared "leprosy patients". On the other hand, a few non-hansenic cases were admitted into a "hanseniasis hospital" — the first step toward its transformation into a "hospital of sanitary dermatology". Last, but not least, many patients intimated that they were psychologically alleviated and less fearful of the world.

As the indications of success became known, other states adopted similar methods. The Phase III, which expanded now to the rest of the country, includes new measures recommended by the National Conference on Hanseniasis, in Brasilia, March 1976. It is obvious that this expansion will consolidate previous gains and foster new advances in the fight against the endemics of hanseniasis and the stigma of "leprosy".

#### A FRANK TALK BETWEEN ENDEMIC COUNTRIES

We dare suggest that services and colleagues of other endemic countries meditate on the recommendations of Phase I, cancelled after half-century of useless tragedies and waste of resources; and on those of Phase II, approaching their 30th year which is taking us nowhere —

*while resources continue to be wasted in useless attempts to educate about "leprosy" or any equivalent degrading term.*

Some of the measures of Phase III might deserve their attention and careful study. In other Latin-American countries and English or French speaking endemic areas of Christian background, conditions are similar to ours. There might be differences in Africa, Asia and the Western Pacific. However, nowhere can "leprosy", or any of its local equivalents, be declared innocent of causing serious social and mental problems — usually worse than the physical disease itself, and certainly leading to the aggravation of this physical disease and of the endemic.

To liberate "Hanseniasis" or "Hansen's Disease", a physical condition, from millenia of leprostigma and defamation — a cultural phenomenon — is not at all easy. An exchange of information between Brazil and other countries eventually adopting similar policies would surely contribute to hasten the process.

International bodies and persons of good will of non-endemic areas might be interested in cooperating in this tremendous effort. Or, perhaps, these problems and solutions could be discussed at a College of Hansenology of Endemic Countries, in organization. Phase III might then become general

In any case, if we have to "walk alone", and if Phase III must continue "Brazilian", *we will be counting on their understanding and benevolent attention to the development of our new psycho - social medical-preventive programs.*