

# The Serious Latin-American Problems Caused by the Complex "Leprosy: The Word, The Disease" and an Appeal for World Co-operation\*

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Two Brazilian Congresses of Hygiene (in 1968 and 1970) agreed that a substitute name for "leprosy" would have psychological advantages in health education, facilitating preventive measures and alleviating the stigma. Accordingly, 3 state health services, the chairs of dermatology and many of neurology and preventive medicine of 27 medical schools in Brazil have already adopted the educational formula "hanseniasis, formerly called leprosy", aiming at a gradual elimination of the stigmatizing term leprosy. The complex "leprosy: the word and the disease" is also a problem for other countries of Latin America: education on "leprosy" there was a failure, as recognized by the Guadalajara (Mexico) Seminar of the Pan-American Health Organization (1968). The complex affects also the Gulf States of the United States of America, Portugal, Spain and Italy. Many specialists of Asia, Africa, the Western Pacific and Eastern Europe are already not insisting on conserving in our language a stigmatizing form which in any case does not belong to theirs. Many Europeans and Americans, whose countries do not suffer from an active endemic, are aware of the damage the word is causing to millions in our areas. The solution is relatively easy and consists simply in extending to the root "*lepra*" the international condemnation of the pejorative "leper". Usual objections against this extension are presented and rebutted.

The Seminar on the Prophylaxis of Leprosy (Hanseniasis) of the 18th Brazilian Congress of Hygiene (S. Paulo, 1970) considered that changing the term "leprosy" and its derivatives "would be constructive as a psychological step towards health education, facilitating the measures indicated for the control of the endemic and contributing to eliminating the social stigma hanging over the patients and their families".

This strengthened a conclusion of the 17th Brazilian Congress of Hygiene (Bahia, 1968) on these same lines. Previously, the dermatological societies of the Brazilian states of Minas Gerais and Rio Grande do Sul had given support to a new educational technique adopted in 1967 by the Secretary of Health of the State of S. Paulo, based on the provisional formula "hanseniasis, formerly leprosy", aiming at the gradual obsolescence of the ancient term. To date, two more state health services (Espírito Santo and Amazonas), the chairs of dermatology of 27 Brazilian medical schools and the departments of neurology and preventive medicine of

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some of these, adopted the formula and are gradually discarding the word "leprosy". The Seminar on Prophylaxis of Hanseniasis of the Brazilian state of Parana also recommended a new terminology.

It is not surprising that these recommendations and deliberations were taken in a country where the words "*lepra*" and "*leproso*" (leper) are commonly used as terms of insult; where in 1965 the *Nomenclatura Dermatologica* substituted "*Morbus Hansen*" for "leprosy", a substitution that should, according to Rabello (1955), "mark all the difference between a disease so often benign and curable and the fearful Biblical leprosy"; where Souza (1940) considered the term "*lepra*" a common cause for suicide and crime, Letayf (1955) "a trauma that disintegrates the patient", and Diniz (1965) "a nightmare, a terrible shock"; where standard dictionaries give as synonyms for "leprosy" . . . filth, abhorrence, defilement, vileness, viciousness, etc.: and from where 62 out of 65 specialists responded favourably to a questionnaire (Rotberg, 1969) referring to the elimination of the word from the medical literature. Lacaz (1970) advocates the substitution of "hanseniasis" for "leprosy" in all dictionaries, and Becker (1971), who prefers "hansenosis", writes that "leprosy" is a "vague name associated with mediaeval darkness and millenary maledictions and superstitions".

#### Education Unsuccessful Against "Leprosy", an Anti-educative and Stigmatizing "Label of Primary Force"

The alternative, which was to continue educating and teaching on "leprosy", was discarded as it has been proven useless up to now, except in some very limited areas (as the "leprosy" personnel themselves). The educational techniques that had been employed with more or less success in the past to enlighten the public about tuberculosis, venereal and other diseases, have failed almost completely where leprosy is concerned, and this difference is not difficult to explain. Whereas the public's attitude to health education about these diseases varies from indifference to all degrees of acceptance, sometimes even to sympathy and co-operation, "leprosy" constitutes a remarkable exception.

The word provokes an immediate and uncontrollable rejection: it is described as "horrifying" by itself. "*Lepra*" and "*leproso*" bring to mind immediately all the false notions and superstitions that have plagued the disease for centuries in this country (Brazil). They are used and abused by writers, journalists, reporters, actors, radio and TV personnel when it is necessary to emphasize what they consider the worst defects of persons and organizations, football teams, industrial products, political movements, and even animals. Huge front-page headlines announce that there are "LEPERS IN THE STREETS!" and that "HIPPIES SPREAD LEPROSY!" (Fig. 1a, b). Young children learn very early the insulting force of the words "*lepra*" and "*leproso*", made stronger at the reading age and in their first contacts with religious texts. As is known, "leprosy" figures in the Old and New Testaments as something vile and degrading, whose victims had to be banished "outside the camp"; or as an incurable disease that only the miraculous powers of Christ could cure. As though this were not enough, every year, at Easter time, the cinema provides for the biggest audiences the superstitious and stigmatizing fantasies of "Ben Hur". European and American fiction best-sellers in which "leprosy" and "leper" are the most degrading epithets are widely read and aggravate the situation.

In short, "leprosy" is, in Brazil, an anti-educative and stigmatizing "label of



Fig. 1. Two examples of the powerful and permanent anti-education in Brazil. (a) *Lepers in the streets of the city! 350 patients frequent cinemas and restaurants.* (b) *“Hippies” spread leprosy! A threat to all countries of the world.*

primary force" that ostracizes and causes immense suffering to patients and contacts, blocks any attempts to enlighten the public at any level, and hinders seriously the development of the prophylactic and social programmes, which are based on early diagnosis and treatment, leading to integration and acceptance by society.

### The Adoption of the Provisional Formula "Hanseniasis", formerly named "Leprosy" and the First Favourable Results

Unable to compete against such odds, the "working group" of the extinct "Leprosy Department"\* discussed and accepted the idea of a substitute name. The substitution was to be for the patients a well-grounded measure and a good omen for co-operation, as they have long campaigned publicly for just such a step in this country (appealing later to the Madrid Congress, 1953) and in the United States of America (appealing to the Havana Congress, 1948, as well as frequently through the magazine, *The Star*, published by the patients of Carville, Louisiana). Furthermore, a substitution had already been internationally recommended by the Conference of Manila (1931), ratified by the International Congresses of Havana (1948) and Madrid (1953), namely, that of "leprosy patient" for "leper"; but this did not, unfortunately, have any practical effect, most probably because of the permanence of the root "lepra" and of its derivatives "leprotic", "leproma", "leprous", etc. The modification of the word "leprosy" itself was a recommendation made by a significant group of the Pan-American Health Organization's Seminar on Administrative Methods for Leprosy Control Programmes (Guadalajara, Mexico, 1968).

Many substitute terms were studied, but finally those derived from the name of Hansen were preferred. In spite of the inconvenience of eponyms, they have in their favour the fact that the terms "Hansen's disease" and "hansenosis", as well as being acceptable to the patients, have already acquired some degree of scientific acceptance, both international and regional, for they figure in the Brazilian *Nomenclatura Dermatologica* and are often employed by Brazilian and foreign authors in medical articles and text-books. As the *Mycobacterium leprae* is also known alternatively as "Hansen's bacillus", it was thought that "*hanseniasis*" (as in leishmaniasis, psoriasis, elephantiasis) was a good choice. As it is pronounced in Portuguese (hansen-ee-ah-se) it is more euphonic than "hansenosis" and, in spite of some lexicographic defects, it was preferred by a majority of physicians and patients consulted. A whole set of substitutes was coined later with the help of hansenologists of other countries and the São Paulo State Council of Health.

The next problem was how to carry through the new educational techniques. Although some of the more enthusiastic advisers preferred to drop the word "leprosy" at once, the majority were of the opinion that this could be highly inconvenient as it would be a source of confusion, some of the results being socially and psychologically dangerous to the patients themselves. It was decided, then, that the programme should begin with a "transitional phase" when both words would be used together as synonyms. "Hanseniasis, formerly leprosy" was the educational formula adopted, based on the proven techniques of national administrative authorities when implanting new values and names for money

\* Comprising Souza Campos, Souza Lima, Martins de Barros and Rotberg.

currencies. "Hanseniasis", it was explained, became the new name of a curable and mildly contagious disease, which used to be called "leprosy" when there was no treatment and patients were isolated, etc. The aim is to make the term "leprosy" gradually obsolete with the minimum possible embarrassment, but the date when it can be finally discarded is unpredictable. It could take some years, in the absence of international co-operation for this regional measure.

Even though the old name has not been completely eliminated the results, so far, may be called "good". Dermatologists, general practitioners, patients, and contacts are now more co-operative with health authorities who demonstrate concern for their emotional and social problems. It is now possible to give lectures on "hanseniasis, formerly leprosy", in a more informative and scientific way, different from the superstitious atmosphere usually aroused by naming the topic "leprosy". Integration within general public health services has been facilitated. Medical students accept "hanseniasis" as "a disease like any other", and wonder that we are still using the term "leprosy". Our reasons for keeping it in this "transitional phase" have to be explained repeatedly.

#### **Latin America, the Major Victim of the Complex "Leprosy": the Word and the Disease**

Obviously, the word "leprosy" can do harm only where it exists, so excluding Asia, Africa, the Western Pacific and Eastern Europe; or where there is an active endemic and a large number of patients and families to be branded by it—that excludes most of the United States of America, Canada, the United Kingdom and France. In Russia, the word "leprosy", used occasionally, does not there have any shameful meaning; the regional stigmatizing and ostracizing word "*prokaza*" is never used in scientific writings (Torsuev, personal communication). Brazil remains as the largest and most populated area where the word "leprosy" stigmatizes, affects patients and contacts emotionally, blocks education, and hinders prophylactic programmes; but other countries of the Americas could be included as shareholders in this serious "semantic-prophylactic" problem—the complex "leprosy: the word, the disease".

When the Seminar of Guadalajara admitted that health education programmes about "leprosy" were unsuccessful, a group of 18 Latin Americans (including one Brazilian), representing almost half the participants, attributed the lack of success to the use of the word "leprosy", and "recommended a study for its possible modification". In Argentina, Quiroga (1968) spoke of the "malignity that seems to accompany the word leprosy", and the inquiries of Mangiaterra (1970), a teacher of educational sciences, demonstrated the stigma attached to the word. She writes: "'Leprosy' and 'leper' have a tremendously negative emotional charge that originates from the time when the patient was just a God-stricken, undesirable, horrifying, dirty, repulsive and marginal thing. No evidence can change those unfavourable feelings about these prejudiced terms. 'Leprosy' is incorporated in children's language with 'linguistic precedence'. They use it in a pejorative sense, with all the magical meaning that this word bears and before they know what it means; when they learn the truth, it is too late, and even long and costly educational campaigns will do nothing more than reduce, sometimes, the intensity of the prejudice."

Personal correspondence from Latin American countries\* is further evidence of the problems caused by the word leprosy. Also, at a recent Ibero-Latin American Congress of Dermatology (Caracas, Venezuela, 1971) and on the trip back to Brazil, through Colombia, Peru, Bolivia and Paraguay, I was able to confirm directly with colleagues and lay people the seriousness of the problem. This fact is not denied by any author in Latin America, although some of these still believe in the possibilities of education, or in the technique of using “leprosy” so often and frankly as to “wear it out” of its pejorative connotation.

Other less endemic areas are also victims of the word “leprosy”, such as the Gulf States of America, Portugal, and the Latin countries of the Mediterranean. This is confirmed by the persistent campaign by the patients of Carville, Louisiana, favouring the adoption of the substitute “Hansen’s disease”; by a recent study of the School of Social Welfare of Louisiana State University (Chesteen and Rolston); by Portuguese articles like those of Moura (1968) and Fonseca (1970), the latter suggesting the word “hansenia” (like “diphtheria”); and by personal correspondence.†

### The Co-operation of Countries not Affected by the Complex “Leprosy: the Word and the Disease” Would be Welcome

Latin American countries and other areas victimized by the complex “leprosy: the word and the disease” might eventually follow the three Brazilian states and 27 medical schools whose health services and dermatological clinics have already adopted “hanseniasis”. Peru seems to be the first in line with “hansenosis”, which was recommended to its Ministry of Health by a National Seminar held at Pucallpa in 1971; and the dermatological department of a Buenos Aires general hospital has recently accepted the word “hanseniasis”.

However, even a unanimous Latin American agreement to cancel the word “leprosy” as a medical term would have to face serious difficulties ahead. Medical text-books and periodicals from Europe and the United States circulate widely in the region and enjoy considerable authority. It would not be easy to consolidate a new non-stigmatizing terminology if it had to compete with the continued use of “leprosy”, “leprotic”, “*lèpre*” in English and French writings, aggravated by the use of the banned word “leper”, fortunately rare now in medical English but still quite frequent in French (“*lépreux*”, corresponding to the ultrastigmatizing insult “*leproso*” of the Portuguese and Spanish languages).

Therefore, a European and American decision to adopt any agreed substitute term would certainly be greatly appreciated by the large number of patients and their contacts who live in the area stretching from the Gulf States to Argentina, and by those authorities who find it impossible to enlighten their public about “leprosy” and accept it as “a disease like any other”. It would also convince some still reluctant Latin Americans who, although aware of the problems caused by

\* Argentina (Ambrosetti; Balaña; Bergel; Borda; Casala; Grinspan; Jonquieres; Kaminsky; Kriner; Lucena; Mangiaterra; Manzi; Marzetti; Nudemberg (B); Pecoraro; Pierini (L); Pomposiello; Tello). Colombia (Londoño; Muñoz Rivas). Costa Rica (Elizondo Salazar). Mexico (Saúl). Nicaragua (Esquivel). Panamá (Escartin; Tapia). Paraguay (Medina Garcia; Schmidt). Peru (Neyra Ramirez). Venezuela (Convit; Scannone).

† Portugal (Barbosa Leitão; Basto; Cruz Sobral; Esteves; Farrajota Ramos; Fraga Azevedo; Gomes Nicolau; Martins Barbosa; Menezes Ferreira; Norton Brandão; Novais Rebelo; Poiars Baptista). Italy (Baccaredda-Boy).

the word, are of the opinion that any change must have some kind of international support.

This U.S.-European co-operation could be postulated. Authors in these continents have protested in the past against the medical use of "leprosy": an "ugly name" (Faget, 1947); "a tragic name", "a curtain of terror" (Lendrum, 1945, 1952); a "shame for the patient and his whole family" (Lichtwardt, 1948); an "odious name, synonymous with something vile" (Burgess); "ignominious" (Feldman, 1953); a "horror based on a confusion of ideas" (Gramberg, 1960); a name that has to be changed "very urgently" (Swellingrebel, 1960); "a word that does carry a conditioned adverse connotation" (Rolston, 1968). Out of 44 specialists of these regions, 17 have responded favourably to a questionnaire (Rotberg, 1969) suggesting "hanseniasis", and personal correspondence\* also points towards the possibility of co-operation. Mallac (1971) considers our terminological changes as "a long-awaited move to alleviate and eventually clear, *inter alia*, the complex background of hanseniasis", and writes that "we, as medical men, owe humanely, morally and professionally such a breakthrough to the millions of hansenians in other parts of the world who, to use the words of a well-known hansenologist, are the victims of an acid-fast bacillus made more virulent by ignorance, prejudice and fear".

Names for diseases have changed for less important reasons. "Moniliasis" became "candidiasis" naturally, just to accompany the new name of the causal fungus. The current trend to substitute "exceptionals" for "mentally-retarded", as well as "convulsive syndrome" for "epilepsy", has the same humanitarian background and is not facing any serious reaction. The public in our areas should not be led to imagine, as many seem to be in Latin America, that changes in terminology are only acceptable when they are important to the more developed countries. This is a most unfounded suspicion, as it is known that the banishment of the insulting word "leper" was the recommendation of three international meetings, none of them held in Latin America or under Latin American leadership or influence.

Unfortunately, that well-intentioned banishment did not have any practical effect in Latin America, as the accepted terms "*doente de lepra*" or "*enfermo de lepra*" are employed only by an insignificant minority. "*Leproso*" (leper) continues as the general stigmatizing term, demoralizing patients and blocking their co-operation with health services. Therefore, the desired international next step would be the recommendation of a substitute name for the disease itself, to be used together with "leprosy" for some time, in order to establish synonymy and prevent misunderstandings. A "transitional phase", normal in all terminological changes—medical, monetary, industrial and administrative—should be short, and should cause fewer difficulties than when a whole system of classification of forms of the disease was substituted, 19 years ago.

Colleagues in Eastern Europe, Asia, Africa and the Western Pacific areas, also free from the complex "leprosy: the word and the disease", could co-operate. The Graeco-latin root "*lepra*" and its derivatives are not part of their languages, and they are probably not going to object to the banishment of that root on the same

\* Denmark (Möller-Christensen). England (Allen, Corcos, Currant, Jopling). France (Basset, Buu-Hoi, Duperrat, Grupper, Languillon). Holland (Gramberg). Switzerland (Gilbert, Mallac). U.S.A. (Buker, Canizares, Feldman, Gass, Goldie, Johansen, Kwittken, Reiss). USSR (Shubin, Torsuev).

grounds that Latin Americans would not oppose the substitution of *kusht*, *dudzam*, and other designations for the disease, if regional health authorities decided that such substitutions were necessary. "Mongolism", a term that is unfair and depreciative to the people of a large area of the world, is now being called "Down's syndrome", with support of non-mongolic people who understand their emotional and social problems.

There is no doubt that this Latin American problem is being understood by the public of the Eastern world. When the Japanese Leprosy Associations decided to discuss and to put to a vote the above-cited questionnaire about substituting "hanseniasis" (or other) for "leprosy", 3 members accepted the change and 30 did not, but "saw no objection to the use of 'hanseniasis' as a common term, while keeping 'leprosy' in the scientific language". It is evident that our Japanese colleagues were aware of our specific problems and willing to co-operate. From Dr Nishimura's letter reporting the meeting it is not clear whether or not they were considering "hanseniasis" as a common term for Japan itself, as a substitute for the local name of the disease.

Personal correspondence from those regions,\* accepting the new term "hanseniasis", or sympathetic with the change,† is further evidence that support for Latin America health and social measures may be awaited from regions where the Romance languages are not spoken. It must be recalled that Manila, Philippines (1931), was the location of the International Conference that first recommended the substitution of "leprosy case" for "leper".

### Objections and Rebuttals

The main objections to a terminological change are based on the somewhat contradictory assumptions that (1) the fear of "leprosy" is caused by its deformities and disabilities, not by its name; (2) that the fear of the name can be erased by education; (3) that any substitute name will sooner or later acquire the perjorative overtones of "leprosy"; (4) that eponyms are not the best substitutes; (5) that the names of earlier writers, not only Hansen's, should be considered for eponyms; (6) that the name "leprosy" is not a problem for the vast majority of patients in Asia, Africa, and the Western Pacific; (7) that an efficient form of treatment of the disease is the real solution; and (8) that the experience of Hawaii in changing the name "leprosy" to "Hansen's disease" was unsuccessful.

(1) I understand, from what I read, that patients of the East and Far East fear far more becoming deformed and crippled than they fear regional labels for the disease, but this is certainly not true in Brazil and other Latin American countries, where the word "leprosy" is a "psycho-social disease" by itself, usually much more feared than the physical ailment. People would rather be victims of the worst handicaps and deformities caused by poliomyelitis (or other neural conditions), leishmaniasis, pemphigus, accidents, etc., than to bear a small involuted skin lesion or a simple flexure of the left little finger under the shameful and ostracizing diagnosis "leprosy". All prophylactic programmes based on early diagnosis and treatment are prone to fail, as there is no prevention without

\* Arabia (Thoms). Ethiopia (Greppi). India (Garst, Khoshoo, Lahari, Patrick, Rutgers). Israel (Sagher, Sheskin). Japan (Ito, M.; Mayama, A.; Ross, H.; Takashima, S.). Malaysia (Chelliah). Thailand (Ettinger).

† India (Nimbkar).



co-operation, and no co-operation while that stigmatizing word is used. There are no “early cases of stigma”.

(2) Education about “leprosy” was unsuccessful in the Americas, according to the Seminar of Guadalajara in 1968, and not a single fact has occurred since to modify that gloomy conclusion.

(3) The worst of substitutes would have a chance of success in renewed educational programmes, but “leprosy” never would. “Leprosy” is a millenary invincible “label of primary force” whose terrifying powers are increasing continuously, through all media of communication. “Lunar lepers to be isolated by double-thick glass plates when they return”, is how the international press reported the first landing on the moon. The most sophisticated technological achievement of Man thus destroyed, in one single day, years of hard and patient work trying to enlighten the public about “leprosy”. Would “lunar hansenians” have the same sensationalistic impact? Not even a freshman in journalism would employ such a “cold” word. It is unbelievable that any future dictionary will apply to an agreed substitute the same connotation used now in connection with “leprosy” and “leper”.

(4) and (5) As stated before (Rotberg, 1969), “hanseniasis” is a suggestion that happened to be satisfactory to many, including Rabello (1970) who substituted it for the former “*Morbus Hansen*” in the Brazilian *Nomenclature Dermatologica*. The Journal of the American Medical Association (1970, 211, 2023), although not accepting the change “at the moment”, asked if “someone could not suggest ‘fracastoriosis’”. But eponyms are not necessary. The School of Social Welfare of Louisiana State University, in a recent study of rehabilitation in the United States of America which concluded that the name “leprosy” is harmful for the patient, employed the terms “bacterial neurodermatitis” and “Hansen’s disease”. “Mycobacteriosis” might be the solution if tuberculosis and others are excluded by general agreement. The final objective is to banish “leprosy”, not to implant “hanseniasis”.

(6) If the word “leprosy” is a problem for a continent of 300 million people, an estimated 4 million contacts and 800,000 patients, most of them non-diagnosed or hiding from the stigma, it is a problem for the small world we live in. As stated above, the rest of the world, not directly interested, could, and is expected to, co-operate by the simple measure of extending to the root “*lepra*” the condemnation already existing of the word “leper”.

(7) While we wait for more efficient drugs—which may take some years—patients must not be scared away by the extremely high cost of our present treatment: social ostracism and economic collapse. For our precarious sulphones, we ask them first to register as “leprosy patients” (in practice “lepers”), then we complain that they do not show up and that the endemic spreads. It is very unlikely that they will even be interested in a future “magic bullet” at such high cost—the “leprosy stigma”.

(8) I have no way of knowing exactly what happened in Hawaii, but it is certain that there is not the slightest resemblance between the social, racial, cultural, religious and epidemiological conditions of Brazil and that State. In any case, the official change there in 1949 proves that the word “leprosy” was troubling Hawaiians too. But, we ask, was everybody co-operating, as necessary, to implant and consolidate the new term “Hansen’s disease”? A search of the literature points in a different direction, suggesting the existence of a determined opposition by at least one influential author (Skinsnes. 1966).

Did the Hawaiian authorities institute a "transitional phase" and did they strive enough to educate on a formula similar to "Hansen's disease, formerly called leprosy" to prevent confusion? One thing I am certain of: if the word "leprosy" circulates among the heavily infected racial groups of Hawaii with the same pejorative overtones attached to it in Latin America and the Gulf States of the United States of America, its reintroduction is not at all helping Hawaiian educational programmes but, on the contrary, aggravating stigma and hindering prevention.

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