

ON ETHICS AND SPECIFIC ANTI-HANSEN PURISM

EDITORIAL

One of the most curious objections to the medical usage of the modern and scientific-sounding term "Hansen's disease" is that "Dr. Hansen did not have the disease". But the fact that neither Dr. Parkinson nor Dr. Bright were victims of "their" diseases is conveniently ignored. As it is ignored that Dr. Recklinghausen never had skin tumors and that no malignant mammary "Paget's disease" ever developed on Dr. James Paget himself. It was never reported that Dr. Chagas had Chagas, that Dr. Duhring's skin was covered with blisters, that Dr. Hodgkin had any serious problem with his lymphatic glands, that neither Dr. Schonlein nor Dr. Henoch ever suffered from any of the lesions of the Schonlein-Henoch syndrome, that Dr. Addison had a pigmented, dog-like oral mucosa, that Dr. Hutchinson's teeth were notched or that Dr. Hebra scratched himself night and day.

As a matter of fact, there is no information that the hundreds of diseases and syndromes, from Abrami's to Ziehen-Oppenheim's, from Abercrombie's to Zellweger's were personal problems for those doctors.

The case of the derivatives is no less amusing. "Hansenoma"? a tumor of Dr. Hansen! "Hansenitis"? an inflammation of Dr. Hansen! "Hansenoid"? a resemblance to Dr. Hansen! "Gor forbib!" However, it never entered anybody's mind that "Schwannoma" is a tumor of Dr. Schwann's nerves, "Chagoma" a tumor on Dr.

Chagas's skin, "Littritis" an inflammation of Dr. Littré's urethral glands, "Skeneitis" an inflammation of the female urethral glands of Dr. Alexander Skene, "Cushingoid" a resemblance to Dr. Cushing, "Pagetoid" someone looking like Dr. Paget.

"Well, but these men were the discoverers of their diseases, tumors and inflammations" — is the inevitable rebuttal of the "anti-Hansen" purist. But did Dr. Leishman discover "Leishmaniasis", or did he suffer from it? Did Dr. Candid discover "Candidiasis" (an eponym which has replaced the old "Moniliasis")? Did Dr. Donovan discover "Donovanosis"?

Retorts the untiring "anti-Hansen" purist that "those men discovered the agents of the diseases, which appropriately were named *Leishmania*, *Candida*, *Donovania*, therefore the eponymics are all right." It seems that the terror, the horror, the loathsomeness and the stigma irremovably enchained to the pejorative "leprosy" should continue "per omnia saecula saeculorum", in or der not to disobey usually disobeyed lexical rules. What about a new genus *Hansenia* or, at least, a species *hansenii*, as suggested by Feldman, to honor Hansen and to provide a taxonomic basis for a new terminology? "Blasphemy! *Myco. leprae* is untouchable!"

Hybridism is another puristic taboo, although no one objects against "television", "automobile", "centimeter", "hypertension", "hemoglobin", "vasculi-

tis", "cellulitis", etc., etc. "Hanseniasis? Never! Never commit the horrendous crime of adding a Greek suffix to a non-Greek name!" The prohibition obviously does not apply to non-Norwegian doctors' names, so that there is absolutely nothing wrong with the hybrid eponyms "Donovanosis", "Leishmaniasis", "Brucellosis", "Pasteurellosis", "Shigellosis", "Listerellosis", "Pagetoid", etc., etc. Poor Hansen of Bergen! Forgotten for the bacillus, forgotten for the disease!

"Well, you win. Give us a non-hybrid, non-eponymic and internationally acceptable term and we will bury our "hanseniasis" — "Yes, we have a good one." And there comes the "pure" Greek pejorative, "the most negative of all medical terms" (Rolston & Chesteen), the word which Rev. George Appel qualifies as "obnoxious and unprintable" and that the new versions of the Bible are ridding themselves of.

MORE BASELESS ARGUMENTS

"Anti-Hansen" purism is not the single baseless argument to conserve a derogatory, defiling and disease-spreading "label of primary force". The viewpoint that stigma is a result of the physical aspects does not resist one second to the plain evidence that there is no ostracization in the worst deformities and disabilities of polio, whereas the maximum of terror and shame surrounds the smallest non-

annoying, but "leprous" skin patch or even the healthy skin of the distant relative of a "leper". *It is not the physical handicap, it is the "name" of the handicap.*

A third and totally false argument runs around the eventual "discovery" that "H.D." or "Hanseniasis" are the same old "leprosy", so that nothing is accomplished. What is not explained is why the stigmatizing "venereal" diseases have so rapidly and universally been changed to "sexually transmitted" — or why the "black" has replaced the pejorative "negro" in the American scene. Skin pigmentation certainly did not fade under the new name. It was not a question of "hiding and discovering" melanin, but of human concern. In the case of "leprosy", of public health as well.

The fact is that no convincing reason has yet appeared to conserve "that tragic name leprosy" (Lendrum), "opprobrious" (Feldman), "ugly" (Faget) and "unfit for human beings" (Gramberg).

Sorry, wrong statement. Two possibly valid arguments have shown up. "It does not hurt developed non-endemic Christian countries, so why bother with the Christians of the endemic and developing areas?" "It is a time-honored terrorizing nerve-shatterer and purse-opener word, essential to some charities. so why endanger fund-raising?"

Valid, perhaps. Ethical, never.

A. ROTBERG

WE DISAPPROVE OF FUND-RAISING BASED ON STIGMATIZATION

EDITORIAL

In an article published in "Leprosy Review" * one of the officers of the British Leprosy Relief Association ("LEPRA") explains that in order to raise funds in the United Kingdom, successfully competing against 77.000 local charities, and to go beyond the barrier represented by the nationalistic feelings of the British public ("Charity begins at home"), his "overseas" charity "must involve the potential donor in thought and in feeling of obligation... and the evocation of a reaction to the word "leprosy is an essential factor in stating the case". "Because of all the factors which frustrate the efforts of field workers, the word leprosy invites curiosity and attention and provides for a strategy in gaining support". "This seems a legitimate and harmless process". "In a similar way, pictorial representation of leprosy sufferers provides immediate information about the nature of the disease, but stressing the unaesthetic aspects of it, seems calculated to reinforce stigma".

In the summary, it is emphasized that "there is a case for retaining the substance of current terminology related to leprosy particularly because of its value to fund-raising".

* * *

International bodies and Congresses, reflecting world consensus, have repeatedly condemned sensationalism through pictures of patients, and many

authors and inquiries have stressed the even worse influence of the word "leprosy" itself.

The author of the article is well aware of the sensationalism and stigma attached to the instruments used to motivate the British public. The Brazilian name-changing appeal is "approached with profound humility and with acknowledgement that the deeply felt plea is for help with a local problem".

However, the idea of fund-raising predominates in the article, in spite of the social harm it causes. "Fundraisers, are, then, faced with a considerable dilemma. Do their efforts to provide funds for treatment and research perform a disservice to their medical colleagues, prolonging traditions...?" "It is a dilemma which cannot be resolved if the answer is affirmative, for a loss of income must affect the anti-leprosy work adversely". "We take it for granted that the more money we can provide, the greater will be the momentum of treatment and research programmes..." "Even against the background of implicit disapproval, we have to continue to rely on the dynamics of an appeal..."

Therefore, facing the dilemma, the choice is made: *fund-raising first, even with perpetuation of stigma and prolongation of traditions, and even against the background of implicit disapproval by the author's medical colleagues.*

(*) Stringer, T. A. Leprosy and "a disease called leprosy". **Lepr. Rev.**, 44:70-74. 1973.

We declare our choice: no money, if to raise it the infamous traditions of "leprosy" must be prolonged. We do disapprove all fund-raising activities based on perpetuation of stigma, ignorance and superstitions.

We consider that the *limited* amount of charity and research provided by the funds do not at all compensate for the *unlimited damage* to the morals and the social status of many millions of patients and families — who hide themselves for fear and shame, and in vast majority, do not seek the treatment provided by governments (or, *to a much minor degree, by charities*), and do not benefit, therefore, from any scientific advances.

We do not agree that this is a "legitimate and harmless process". Pictorial representation of the unaesthetic aspects may be so, as in "LEPRA" 's fund-raising campaigns it is restricted to Britain, were, fortunately, the "psycho-social-somatic" phenomenon of "leprosy" does not occur — although we are of the opinion that the British public also deserves the benefit of more sober and equilibrated notions about the disease. But the defense of *the shameful and ostracizing pejorative "leprosy" through an internationally circulated and influential magazine is illegitimate and tremendously harmful for all endemic regions where that pejorative or its translations are used.*

We are grateful to the "LEPRA" 's officer who, with his long and wide experience in the field, *gave* professional support to all those who accuse the terrorizing pejorative "leprosy" of being at least as emotion-loaded and nerve-shattering as the unaesthetic pictorial representation of patients — a

fact still ignored by the vast majority of his medical colleagues.

However, we hope that in the civilized era we live in, the "LEPRA" and other voluntary agencies will find ways of continuing their highly commendable work without contributing through horrifying pictures and words, to the permanence of stigma and of all the social and preventive problems it causes.

NOTE — This editorial is reprinted from "Hanseniasis, Abstracts and News" (7(1/2):6, 1976) and from "The Disease Hanseniasis" (1 (2) :173, 1977) in order to confirm the standing of "Hansenologia Internationalis" in the difficult fight against "stigmatizing charity", that is, the fund-raising activities by sensationalistic and stigmatizing words and pictures, which perpetuate the social problems of patients and their families, drive them into concealment, aggravate the disease and the endemic.

We beg the World Health Organization, the International Leprosy Association and the College of Hansenology of the Endemic Countries to program studies to assess : 1) the moral damages inflicted on patients and on their families by stigmatizing fund-raising activities and 2) the preventive problems caused by the same.

We beg our readers to make copies of this editorial and send them to local Ministries of Health or Public Health Services, as well as to charities which continue raising funds with the help of horrifying pictures and/or degrading terminology.

Thank you.