

HANSENOLOGIA INTERNATIONALIS

(Hansen. Int)

The "technically impossible education on leprosy", plus a warning to the endemic world

EDITORIAL

As a result of the 11th International Leprosy Congress (Mexico City, 1978) it has become imperative for us to repeat once again, the principal reasons why "education on leprosy is a technical impossibility" and a "dangerous myth" (6).

- a) "Leprosy" is an ugly word, a used and abused synonym for "uncleanness", "filth", "decay", "abomination", "corruption" and "foulness". There is absolutely no method for cleaning up that word from these outrageous connotations. The medical use of the word "leprosy" has not contributed at all to give status to it but, on the contrary, it tainted the disease and its bearers — the "leprosy patients", in practice the "lepers" — with the most insulting and degrading of the epithets. *Consult any psychologist in your country.*
- b) The word "leprosy" is an unbreakable yoke with a millenary past of fear, ignorance, superstition and persecution. There is absolutely no technical method of dissociating the word "leprosy" from this most ingrained history of stigmatization. *Consult any historian in your country.*

- c) "Leprosy" is a "hot and spicy" word, a favorite of sensationalists, the safest verbal weapon to terrorize and horrify mankind.

Governments have no powers of counteracting not even one fraction of a millionth of this overwhelming attack via all mass communication media. "Superman", who asked to be cremated so that his "Leprosy of Krypton" should not spread, is at least one hundred million times more effective than any of the so-called educational cartoons. "Papillon" and his "leprosy finger" which fell off and "was thrown into the fire" — have at least one hundred million times more readers — the hundreds of millions of moviegoers excluded — than the authors of the so-called educational leaflets. "Cabaret" and Liza Minelli's "leprosy nose" which could "fall off" have at least one hundred million times more viewers than the nice girl of these so-called educational slides who guarantees that patients' noses do not behave that badly. Shakespeare with his "leperous poisons", and the universal literary crowd up to the earliest and latest Nobel prize winners — Saul Bellow included ("the fatal disorder of worldliness, this Western plague, this mental leprosy") will certainly not be neutral-

ized by the well-meaning writers of the so-called educational pamphlets.

"Time" magazine with its "experimental leper" — the armadillo — has certainly more readers than the "anti-leper" recommendation of the Manila Conference, buried in the early thirties. Hundreds of millions of mammoth front-page headlines about the "extra-cautionary measures" to protect the world against Armstrong, Aldrin & Collins, the "lunar lepers" newly arrived from the first trip to the moon, never have read and never will read the odd small print item in the most hidden part of the inside pages about the "low contagiousity of leprosy" — if it were ever published.

This colossal counter-education, *specific for "leprosy"*, will never be overcome. Consult any professional in mass communication, and ask whether anybody in the field of industry, commerce, advertising and politics would ever commit such dreadful blunders.

A WARNING, ONE MOTIVE AND TWO OBJECTIVES

The *WARNING* is that *endemic countries should immediately stop exhausting their coffers and overburdening their personnel with the infeasible task of "gathering grapes from thorns."*

)0(

The *MOTIVE* of this warning is the recent statement of the "Workshop on Human Aspects in the Treatment of Leprosy Patients" of the 11th International Leprosy Congress (Mexico City, 1978) that "the stigma attached to leprosy can only be overcome by a continuous programme of health education at all levels, and for all target audiences."

This is a mere repetition of what has been stated and recommended by countless local, regional and international Congresses, Conferences, Meetings and Seminars in the past fifty years, with the appalling — and predictable — result that leprostigma is worse than ever, due to the explosive expansion of sensationalism and "mass misinformation media". There is not a single country to report that "education on leprosy" (or on any other local stigmatizing equivalent) has ever enlightened the public and diminished by one millimeter the rejection of the "leprosy patient" — and the most absolutely justified hiding of the "leper". One cannot count on the cooperation of the "humiliated and offended". (7)

The "Workshop" should be congratulated on having, at last, recognized that "the word 'leprosy' is to be used with caution, since it tends to have a socio-historical, in addition to a medical connotation." It is the first time that an International Congress publicly admits that the term "leprosy" is not altogether strictly "scientific", and that it shares with its companion pejorative "leper" the terrific burden of social rejection and historical stigma and opprobrium.

Unfortunately, the solution of the "Workshop" was not to discard at once the horrifying and noxious term — as has recently happened with the "venereal", which became "sexually transmissible" overnight — and as is happening with the "deaf" in New York (1) and with the "neurotics", wiped out from the diagnostic manual of the American Psychiatric Association — but only to "use the word 'leprosy' with caution and to "communicate to the patient the shock of the first diagnosis with kindness."

"Kindness" and "leprosy" are incompatible and mutually excluding words. Real "kindness" is to banish forever from the medical nomenclature — what has been clearly demonstrated by extensive inquiries as the "most negative of all medical terms" (Rolston & Chesteen, 5) the "word which carries prejudice" (Mangiaterra, 3) the "disintegrator of the patient's personality" (Letayf, 2) the "continued psychic pain and trauma" (Pearson, 4).

)0(

a) The principal OBJECTIVE of this warning is to convince developing endemic countries to avert the inevitable defeat in the unequal fight against leprostigma, and to evade with substitute scientific non-degrading appellations for the disease, as has been done many times in other areas of medicine. That decision might be combatted by a few charitable organizations in these countries, which depend on the money raised by the terror of "leprosy" and stigma — but there is no other alternative. A three month extremely costly edu-

cational campaign of the former S. Paulo "Leprosy Department" (1967) was destroyed in a single day by a single sensationalistic and fallacious headline, "Lepers in the City's Streets !" They should take advantage of our sorrowful example and should never repeat our tragic mistake. *Leprostitigma is invincible.*

b) From past experience, recently reinforced from what was seen, heard and felt at the Mexico Congress, we must recognize that our viewpoints are usually not taken into consideration and that, therefore, new useless attempts to "educate with counter-educational pejoratives" and with stigmatizing "labels of primary force" will go on in most countries. When they fail again, and again — as they always have in the past, with no exception, and as they most certainly will, in the future — remember that we have done Our best to avoid it and that our conscience is clear. This is our second and least important objective.

A. ROTBERG

REFERENCES

1. GOFFMAN, E. Stigma. Notes on the management of spoiled identity. Englewood Cliffs, N.J., Prentice Hall Inc., 1963.
2. LETAYF, S. Recherche sur la mentalité des malades de la lèpre. *Rev. Psicol. Norm. Patol.*, 1 :3-59, 1955.
3. MANGIATERRA, M. "Leprosy" is a term which carries prejudice. In: INTERNATIONAL LEPROSY CONGRESS, 11th, Mexico, 1978. Report.
4. PEARSON, E. A. Leprosy or Hansen's disease: a study of semantic conflict. *Hansen: res. not./abs. news*, 5(1) :5-13, 1974.
5. ROLSTON, R. H. & CHESTEEN, H. E. The identification of psychosocial factors related to the rehabilitation of leprosy patients Baton Rouge L., School Soc. Welfare Louisiana State Univ., 1970.
6. ROTBERG, A. Education on leprosy is a dangerous myth. *Int. J. Leprosy*, 40:79-80, 1972 (Correspondence).
7. ROTBERG, A. The exorbitant and prohibitive cost of sulfones: social degradation and economic collapse. *Hansen: res. not./abs. news*, 3:299-302, 1972.