

# The Stigma

Editorial

When I was just starting my dermatology practice about forty years ago, I remember assisting a couple that had brought into my office a young woman to be examined. She worked in their house as a baby sitter. When I saw the patient with a discrete diffuse infiltration on her face and several nodules on the arms and legs, I immediately understood that I was seeing a lepromatous leprosy? The satisfaction of having made the diagnosis was rapidly substituted by the panic for having to tell the couple what was on, that the young girl had leprosy, with all the implications of this finding, that it was a contagious disease and that it would be necessary to examine all the family periodically, that there was not a vaccine, and so on. I don't know how I managed to explain all these things but I will not forget the depression reflected on the face of the girl and the despair of her employers. The baby sitter became an in-patient in a leprosy colony and to soothe this narrative, I must say that the girl was cured, she did not present deformities, she married and had children without health problems.

As to the couple I continued to keep in touch with them and I know they and their children did not present leprosy.

So far I have often but made the diagnosis of that disease and in very similar as conditions as to the mentioned case but I have not seen the same despair related with the disease again. I am sure what happened that time is neither related with the treatment, because in that occasion sulphone already existed and it was believed to be an effective drug, nor with the fact that today I have more experience. I am convinced that the responsible for what is happening is the different designation for the disease, without prejudices and associations with curses, divine punishments and other things.

When Professor Rotherg began his fight to change the name leprosy which was considered an anti-educational name, most people agreed with his idea but others either remaining indifferent or were frankly against it because they believed that the changing of the name was of no benefit for disease control. Even some university professors prefer to pronounce the name leprosy in their classes and even in Congresses when the campaign to substitute the word leprosy by Hansen's disease was in its

acme in the entire country.

This fight was initiated in 1967 in São Paulo, and little by little it was getting positive results and almost ten years later other states were using the new terminology that was finally accepted in the National Conference on Hansen's held in Brasilia in March of 1976.

Some countries agreed with this proposition but others, mainly the non-endemic ones refused it. Some foreign authors accepted professor Rotherg's claims but considered that there were several reasons for the retention of the current terminology related with leprosy because they thought that it was better to make clear to the people that the Bible was misinterpreted, or that it was a semantic question only important to one region of the world, or that the word leprosy was very important because of its value for fund raising.

Rotherg says that leprosy is a disease, a somatic nucleus, involved by a psycho-social-somatic chain of legends, fantasies, superstitions and ignorance. I am convinced that today Hansen's is the somatic nucleus free of all prejudices.

There are, in our country, some places that insist on not surrendering, but they are just a few. Nowadays is difficult to hear the word leprosy, since the patients with Hansen's, the people in general, and even the physicians, when they use this word in any situation they expect to get the overall attention.

It became easier to deal with the disease today. During the diagnosis, when the patient asks - what disease do I have, doctor? The answer is - Hansen's.

After that, a new question - What is Hansen's? And the explanation is: a disease caused by a microbe that compromises the skin and the nerves and may sometimes be transmitted to other people. It is likely to hear a patient asking - Is Hansen's leprosy, doctor? The answer: Hansen's is one of the different forms of leprosy that existed in the past such as scabies, syphilis, psoriasis and others. Is it a problem to have such behavior?

It is a pity that never a formal assessment of this experience was done since it has succeeded for 35 years. Brazil got rid of leprosy much before other endemic countries. We have, of course, Hansen's but this has being eliminated by means of dealing with other diseases and

we managed to reduce its prevalence from 14/10.000 to 4/10.000. One day we will eradicate Hansen's and its many problems.

To day there is still a strong stigma related with leprosy in many endemic countries. Probably in those places several factors are important for maintenance of the stigma but it is possible that in some places the word leprosy has a particular role.

If there is a country that admits to have similar problem, it would be interesting for then to learn from experience to try to adapt it to their reality. In spite of Brazil being localized only in one region, it is the second

in the world in number of patients with hanseniasis and what the country achieved in that matter can not to be overlooked.

In the II Global Meeting for the Elimination of Hansen's, held in Brasilia last February, the commitment of showing Hansen's in a positive manner and to dissipate the fear and stigma caused by the disease were emphasized, and besides, the use of anti-educative pictures was discouraged. Therefore, fund raising campaigns based on anti-educative will suffer a drawback, and more ? ways to deal with the problem of stigma have to be used.

## REFERENCES

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