

Portraying a Positive Image of Persons (Previously) Affected by Leprosy

TO THE EDITOR:

In recent years a world-wide realization has been growing of the important role of language and terminology in social stigma against people with many chronic condi-

tions. People with impairments or disabilities were labelled for life as the "disabled" or the "handicapped." People who were suffering from AIDS were called "AIDS patients" until their death. Strong appeals, particularly from the affected people them-

selves, have led to changes in terminology. The "disabled" are now called "people with disability" or "differently abled people." The blind and deaf, in a dignified way, are called "visually handicapped" and "hearing impaired," respectively. Instead of speaking of "AIDS patients," many publications now talk about "people with AIDS."

In leprosy the situation has been very similar. It is possible that the social stigma against those affected by leprosy has been even stronger than against people suffering from other chronic conditions. The word "leper" has become almost synonymous with "outcast." In a quest to restore dignity to those who have had leprosy, the affected people themselves, as well as many leprosy workers, have started to call for a change in the language used in the field of leprosy. Particularly instrumental in this is the organization IDEA (the International Association for Integration, Dignity and Economic Advancement).

During the 2nd International Conference on the Elimination of Leprosy, a major discussion was held on this topic. Many people who themselves had been affected by leprosy were present. There was a strong feeling that if someone who has (had) leprosy is always being labelled as a "leprosy patient" or even just as a "patient," it will have negative consequences for that person. Given the social stigma against leprosy, this label wrongly gives the impression that an affected person will always remain a patient and, thus, is never really cured.

From a rehabilitation point of view it would be very desirable to change positively the terminology used in this field. The attitude conveyed by the behavior of the health worker toward patients is also very important in this context.

Based on these and other similar discussions, we would like to make the following recommendations:

1. The use of the word "patient" should be context-dependent. It is only appropriate in a medical context of a health worker-patient relationship.

2. The preferred term to use when referring to an affected person, when his/her association with leprosy needs mentioning, is a "person affected by leprosy."

3. In situations where the relation with leprosy is irrelevant, e.g., in many rehabili-

tation situations, a description such as a "person with disability," or simply "person" or "affected person" would be preferable.

4. Recommendations for a change of terminology should be prepared for a wide range of uses, including the media, health training materials, legal documents and medical/technical papers and publications.

5. The importance of health workers acting out a positive attitude toward leprosy patients should be emphasized whenever possible. Training to this extent should be included in leprosy courses, particularly those for general health workers.

6. Appropriate education should be given to all persons on or after multidrug therapy (MDT) regarding their noninfectiousness. Too many affected people are still unsure, even after MDT, whether or not they can still pass on the disease to others. This may strongly influence their social relationships and lead to (self-)isolation. All community education should also include the message that a patient is no longer contagious as soon as (s)he starts to take MDT.

It is encouraging to see that in several organizations the term "person affected by leprosy" has been readily accepted. Unfortunately, however, people have started abbreviating this term to "PAL." They have now started speaking about "PALs" when referring to people affected by leprosy. This practice is undesirable for two reasons: First, the word "pal" is a very colloquial word for "friend," while it is often used in situations where the use of the word "friend(s)" would be inappropriate. The second is the major reason for not using the abbreviation "pal": The use of a special word like "pal" is essentially the same as using the word "leper." The use of a special term will label people as different from other people, which is exactly what we want to avoid! We don't go around or write about people with tuberculosis or malaria as "pals," so why should we do this to people affected by leprosy?

What we are trying to achieve is that the language and terminology used to describe people who have (had) leprosy is as much normalized as possible. If we abbreviate "person affected by leprosy" to "pal," we will be using this word all the time. If we use the "full form," we can be flexible: one time talking about "the affected person,"

another time “the leprosy-affected person,” or just “the person.”

We would therefore like to make a strong appeal to anyone working in the field of leprosy, or anyone otherwise needing to talk or write about leprosy-affected people: For the sake of the dignity of the persons affected by leprosy, please do not use the word “pal.”

It is also important to realize that English is not the main language in most leprosy-endemic countries. It is therefore essential to initiate a discussion in all endemic countries about nonstigmatizing terms that would be appropriate in the different languages spoken. In Nepal this discussion has led to agreement to use the term “kustha prabhavit byekti” as the Nepali equivalent for “person affected by leprosy.”

We hope that our concerted efforts at introducing and using positive language in relation to people affected by leprosy will

help to raise their dignity and will slowly push back the age-old stigma attached to the disease.

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Reprint requests to Dr. van Brakel. This letter first appeared in the *ilep Flash Special Edition*, 1998.