

Editorial

NERVE INVOLVEMENT IN LEPROSY. PREVENTION AND MANAGEMENT OF DEFORMITIES: NEED FOR A PARADIGM-SHIFT

WHY IS IT NECESSARY OR ESSENTIAL TO TALK OF PREVENTION OF DEFORMITIES?

We no more talk about leprosy control or about multidrug therapy (MDT) because these are well established, in concept, organization and operation. About deformity, disability and rehabilitation we have now started talking more and more, but neither with the same clarity, nor do we have an equally efficient action plan which has been accepted by the leaders.

We agree that leprosy is feared because of the deformities and disabilities. We have always talked of the incidence of deformity as an index of success of our control programmes. We even talk of early diagnosis and treatment as a means of deformity prevention. But in practice we find that deformities do occur in spite of early detection and treatment with chemotherapy. Deformities do develop after a patient is declared cured. We agree that whatever may be the diminishing incidence of deformities at entry, nothing would justify our neglect of Grade 1 of deformity, i.e. loss of sensation. Yet we do not have figures of WHO Grade 1 deformity, i.e. loss of sensation. We know that unless cared for with a sense of responsibility, loss of sensation leads to later deformities. These deformities, of course, occur but do not find a place either in the WHO or ILEP or National statistics. Seeing these uncared deformities leaves the patient and society dissatisfied in spite of the specialist telling them that leprosy is controlled. And that, 'leprosy soon will not be a public health problem' becomes a meaningless statement.

WHAT IS HAPPENING AND WHY?

Why is so little being done to intervene actively for disability prevention (POD) and prevention of worsening of deformity (POWD) while so much has been and is being done indirectly through control of leprosy by early and effective treatment?

We could have, but did not anticipate such a situation as exists today. In many areas of the world today there is a rapid diminution in the number of patients under treatment and at the same time an increasing cumulative number of patients with deformity and disability, an ever increasing number of unemployed because of deformity. We never looked beyond the objective of diminishing the number of active cases of the disease in the community. So many of us were shocked last year at the statement that, in a few years leprosy will not be a public health problem. What constituted a public health problem was fully defined. Why were we shocked instead of being delighted? There were

possibly two reasons, one the recognition that a lot of work needs to be done for the prevention of deformities, of their worsening and for rehabilitation. The second reason is the fear that the flow of finances from the public may reduce substantially. Finances have up to now always been asked for a wider social benefit, to get rid of the great load of infection in society. Research up to now was mainly justified to achieve similar objectives. The structural concept, the model successfully used for action against leprosy, including fund-raising, has been a specific kind of epidemiological model, the objective being fight against infection. And it has worked. But now this model will not do.

And we, the workers, policy makers, fund-raisers did not prepare strategies, conceptual structures, paradigm for what could have been seen if we had tried to foresee. A new approach is needed.

And this is the difficulty. And change in a mind-set, a paradigm-shift, a change of approach is often a dynamic, slow and a painful process. A change of approach, to be effective has to take place at the top, in the policy makers, fund-raisers, and leaders. Then only can it percolate down. The other way is an increased demand from the public or public authority brought by a recognition that something different, something better indeed needs to be done.

IS THERE THEN SUCH A RADICAL CHANGE IN CONCEPT REQUIRED?

Table 1 shows the great difference in nature and management of disease and of disability and deformity.

This has to happen and soon enough. Otherwise, for the general public and for the patient who is disabled, eradication or control of leprosy, even when achieved by the WHO definition, will remain meaningless.

This shift in the conceptual structure has to be achieved not only by the medical persons but also their associates, namely the public and the patient and the families in all the geographical areas where leprosy work is already going on. Some examples are given in Table 2 to show what is required to know how a change of slogan would indicate a fundamental change of approach.

The phase 'care after cure', may be more appropriately rephrased as 'care with

Table 1. Differences in management

Disease	Deformity/disability
Medical problem	medical and human problem
Mass programme	individual programme
Time bound	life-long
Early diagnosis & treatment done by SET * and demands drug delivery by an active medical team and an obedient patient	early diagnosis & treatment demands early detection and drugs, measures that need active cooperation and understanding of both patient and medical persons
Evaluation: Yes or no	graded evaluation essential
On the patients part the need is of	
Acquiescence and compliance	Active responsible collaboration

A major change in the conceptual structure, is needed. For some time we, indeed, need both conceptual structures. An integration of the two paradigms is even more difficult psychologically because this requires not only a change of perception but flexibility.

* (SET, survey, education and treatment).

Table 2. Change in approach

Methodology		
Care after cure	becomes	care during treatment: POD care with respect
POWD by instruction	becomes	transfer of skills
Ulcer dressings by PM	changes	into self-care & POWD
Giving of footwear	changes	into the patient wanting footwear
Health talks and education	becomes	health learning by patients and it spreads to other patients
Medical team's dictate	becomes	a collaborative effort

PM, paramedical; POWD, prevention of worsening of deformity.

respect' or 'care during treatment'. This care, of course, starts together with drug therapy and extends to care after stopping chemotherapy. The care procedure, like a daily bath, naturally is going to be a life-long affair and thus becomes a primary responsibility of the patient and his near ones including the medical advisor.

We have not defined how to execute 'early' and 'effective' detection and treatment as it would apply to deformities and disabilities. There are two reasons, one reason for the difficulty is because of the differences in the nature and management of the two problems, one control of the disease and the second is control of deformities and disabilities.

Disease control, as in the case of say smallpox, is a mass programme where the patient is a passive participant. He is 'given' a drug or a vaccine, and he just has to be compliant and obedient enough to 'take' it. The medical persons are the active agents, who plan and execute even to the extent of putting the tablets in the patients mouth. The indices for success relate to bacterial positivity, prevalence and incidence of disease and reduction of disability rate/incidence AT ENTRY POINT, which is a one-time statistic.

What is considered as worth recording and compiling is obvious deformation and not anaesthesia, even when everyone knows that it inevitably, unless 'cared for', leads to secondary impairments—plantar ulcers, wounds and infections and deformities and morbidity.

Disability control, on the other hand, is an individual's problem, liability and responsibility and needs his active participation, whether it be in wearing proper footwear or in taking precautions to avoid injuries to the anaesthetic hand or foot or to ask for surgical correction.

The second reason is that up to now we have used very crude methods for describing signs and symptoms of early nerve involvement. For example, we say and record that there is either sensory loss or none, deformity or no deformity. While disability has not even been defined and hence not recorded. Here 'early' has only a temporal meaning, time oriented. We can indeed have methods to record these parameters in a graded way where we can see and record improvement or worsening, e.g. by use of various nylon filaments for sensory testing.

Let me repeat why, even when there is no lack of humanness, of knowledge, of methodology, so little is being done for prevention and correction of deformities and for rehabilitation.

The most important reason is the nonrecognition of the differences in management techniques, methodology and philosophy needed for deformity prevention as compared with the control programme. Moreover instead of an exclusive vertical approach, an increasing wider or global approach is needed to bring out not only the disease but the deformities and disabilities in the mainstream of health sciences.

HOW IS THIS CHANGE OF APPROACH TO OCCUR?

The easiest is pressure by peer groups, by the leaders and by holders of the purse-strings. The first forces change of thinking, the other of practice. With the need to counteract the effects of the statement, 'Leprosy will cease to be a public health problem pretty soon', the financiers and fund-raisers have to change their approach and this could be a successful way. Instead of an appeal on behalf of a mass of leprosy patients and the society of which they form a part, it would be an appeal on behalf of individuals for whom the society has to contribute instead of the other way round.

For this we need information, for ourselves, for the leprosy workers, the authorities and the general public. We need factual data which, as we should know, does not exist, is not available for it has never been asked for by either the policymakers or governments or the public at large. Information like: What is the load of deformity in the community? How many of them are disabled? What kind of assistance do they need? What is the prevalence of loss of sensation amongst known leprosy patients? What is the natural 'progress' of such a condition? How many persons develop nerve involvement, disability and deformity AFTER starting MDT, etc has to be made available.

I find it amazing that everyone still continues to say disability, disability index, disability grading when what is meant is primarily a grading of a complex formed of impairment of sensory loss and deformities of different parts of the body. Thus THE MEANING OF THE TERM DISABILITY REMAINS UNDEFINED. We have to define and grade disability.

The basic concept, the philosophy is restoration of self-dignity and responsibility to the patient and then to motivate him to learn how he can take care of himself. The rest, 'how' of it, are details.

First comes recognition and then putting it into action, first is change of perspective, then a change of approach while planning and finally putting it into action. We, the medical people have already the knowledge and technology to work out the details of such a programme. But without first achieving the change of perspective, of approach, any number of pamphlets, articles and books published and distributed is not going to have much practical impact. They, like the excellent book by Srinivasan published by WHO,¹ and those by Jean Watson on POD,^{2,3} will adorn the bookcases, mute witnesses of our inadequacy to put into practice what we write and read and talk about.

Let us then work aiming at restoration of self-dignity and responsibility to the patient and then to motivate him/her to learn methods of self-care. We have to forget our paternal role, of how wonderful we are and assume the true role of more fortunate, but still caring friends.

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