Role of leprosy related research & training institutions in management and prevention of disabilities and rehabilitation

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INTRODUCTION

Due to the complexity of leprosy as a disease, its infectiousness, its potential disfigurement and its long presence in the history of medicine, it has been historically a disease confined to hospitals or closed institutions devoted to treat awkward diseases. This was especially true in the end of the 19th century when the isolation of patients in these institutions was regarded as a great advance from public health point of view.

However, outstanding modifications in the management of leprosy as a disease has occurred in a very short period of time, that is, from the introduction of Dapsone as the first really effective treatment for leprosy and the introduction of the MDT regimen recommended by WHO, not to mention the important improvements in the microbiological and immunological knowledge of the disease, has elapsed not more than 40 years - this is really a very short period taking into consideration leprosy as a biblical disease.

With the rapid implementation of the WHO recommended MDT regimen, the prevalence of leprosy has dropped dramatically, the goal of elimination of the disease as a public health problem by the year 2000 has been accepted worldwide by health workers and program managers and, most important, the envisage of leprosy as a curable disease had a tremendous effect in the management of the disease both for patients and health team. However, two points remain unsolved to some extent:

- the stigma
- the disabling potential of leprosy

MDT, STIGMA & NERVE DAMAGE

People feared leprosy because it was an infectious and incurable disease. The treatment was for life and physical disability an almost certain outcome of the disease.

MDT had an important role in changing this picture. The curability of leprosy with MDT and the impact it provoked in the change of this picture is enormous. Not only the curability but also the improvements of the quality of patient care that is part of MDT as a strategy to control the disease. Additionally, effective early case detection has drastically decreased the number of those old, supple lepromatous cases. There are also some indications that, presently, bacteriological index of new most cases does not exceed average 2 +. The probable reasons for voluntary early report of patients for treatment is the widespread notion that leprosy is indeed a curable disease, that the treatment is short and that segregation is no longer necessary. In other words, MDT, as a philosophy of care has been of outstanding importance in reducing stigma.

The disabling potential of leprosy is closely related to nerve damage which, by its turn, is closely related to the immune status of

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the patient facing M. *leprae.* In this regard, reactions are the most important contributors to nerve damage.

MDT has also contributed to the prevention of disabilities. Some reports refer that the number of reactions has dropped after introduction of the WHO recommended regimen and it is clear that early detection, adequate treatment and improvement of the patient care (mainly by early recognition and effective treatment of reactions) has contributed to an overall reduction on the incidence of disabilities. In this regard, WHO estimates that between one and two million cases with disabilities have been prevented since the introduction of MDT[3].

NERVE DAMAGE — A CONTINUING CHALLENGE

Although MDT has effectively contributed to a variety of improvements in the control of leprosy, nerve damage still is a continuing threat to managers of control programs and a challenge to health personnel and researchers. The best approach to prevent nerve damage, and thus prevent disabilities, is still early detection and adequate treatment. However, it is clear that a number of patients will need some sort of actions to prevent disabilities, to prevent its worsening or some rehabilitation measure. This group would be constituted of:

– new cases already detected with some disability;

– treated cases that will develop disabilities during treatment of short after treatment, and

- backlog cases who have already established disabilities

Figures are not quite clear regarding the magnitude of these groups (Virmond, 1995)[2]. However, some available could bring some light to the problem:

It is estimated that averages 12.5% of newly detected cases shows WHO grade 2 at the moment of diagnosis. This figure varies a lot depending mainly on the quality of services in a given area.

It is supposed that there is a low rate of development of disabilities during WHO-MDT treatment or later. Rao[1] in 1994 report 0.2% in a group of 2054 cases. Results from a non-published study held in Brazil following 155 newly detected cases showed no patients at all developing disabilities or worsening of disabilities.

The backlog cases that may need some sort of action for prevention of disability or rehabilitation is still under need for a better epidemiological evaluation. However, WHO (1996)' estimates that presently there are 1.878.600 individuals presenting disabilities due to past or present leprosy.

The information presented so far has the aim to call the attention to the fact that disability is still an existing problem, the prevalence of deformities is relevant and that this is the time to give POD and Rehabilitation actions the appropriated importance and priority.

THE FUTURE ROLE OF R&T INSTITUTIONS

There is a widespread fear that Research & Training institution will reduce its activities or even they will be closed with the attainment of the goal of eliminating leprosy as a public health problem. This is not justifiable because, more than ever, R&T institutions will have continue to play an important role in the years to come. With the continuing acceptance of horizontalization, of integration of leprosy control in the general health services, R&T institution will act as island of excellence, as a reservoir of knowledge on leprosy science. In this regard, the following roles will be of priority in such institutions:

– to maintain alive the available knowledge on leprosy produced so far

- to act as reference centers for specially difficult cases

– to develop research to in order to look for solutions to many problems still unsolved and those still to came

Its is reasonable to understand that district, province or state level units or hospital

OPDs treating leprosy patients in an integrated base has no personnel nor available time to cope with specific activities of special training and improvement of leprosy knowledge, since they are involved in treating and controlling other conditions besides leprosy. This is even more true with the reduction of leprosy prevalence due to the introduction of WHO recommendation of 12 month fixed dose for MB cases and the use of newer drug regimens which will make leprosy curable even more quickly than now. In short, leprosy will be regarded in general health services as a normal disease among other - not as a special condition in need of special arrangements to deal with. In some places or regions, leprosy could even become a rare condition.

These are the reasons to R&T institutions take over and strengthen their role as reservoir of the leprological knowledge.

These are the places to provide general health services workers continuing training in order to adequately cope with a reduced but still present prevalence in the years beyond 2000.

These are the places where specialized and differentiated expertise in clinical leprosy should be available to clarify doubts of peripheral units and, in some instances, to admit for screening, diagnose and treatment of unusual severe conditions of leprosy.

One should remind that M. *leprae* is still a non-cultivable microorganism although being the very first bacteria to be identified as the causative agent of a human disease. In brief, it is most likely that leprosy will be eliminated and many intriguing questions will be still unanswered before elimination. Of course, most of these questions will probably not help in the elimination of leprosy if answers are at hand after elimination. However, they will be of utmost importance for the new and highly controversial goal to come: the eradication of leprosy. In this regard, R&T institutions should be strengthened and supported to play a vital role as centers of research to look for solutions of many still existing problems. Among priorities for research, three issues must be mentioned:

- Nerve damage - a top priority
- Reliable and cost-effective methods for detection of subclinical infection
- New drug regimens

R&T INSTITUTIONS AND POD

This is not the place to mention basic points on POD & rehabilitation, which have been extensively discussed in congresses, meetings and publications. However, some points should be remarked in relation to the interface among R&T institutions, POD and rehabilitation.

- POD activities are integrated part of patient care activities and thus should be performed at the patient level, that is, in the health unit and/or community.

- The available technology for POD is considered adequate to fulfil it needs.

- The challenge of POD is how to make the available technology effective and not what to do.

R&T institutions plays also an important role in the issue of POD, as follows:

1 - Training of the basic health system personnel should be provided by the staff of R&T institutions. If integration of leprosy in basic health services is an important strategy to achieve the goal of elimination, the successful integration necessitates training of the staff in those services. This is particularly important to POD activities. In this regard, despite training in general techniques and approaches to POD, early detection and monitoring of neuritis is a special issue to be addressed in these courses. Furthermore, training does not necessarily must be held in the institution compound. Its is recognized that training for POD is more effective than conventional courses held in institutions. In this case, staff members with adequate expertise should move to the health unit to provide local training.

2 - As research & training institutions, these places should implement training course on Health System Research (HSR) as proposed by WHO and act as supervisor centers for HRS

projects particularly on POD needs.

3 - Clinical and epidemiological research should be designed and conducted by R&T institutions. Some priorities could include:

– modification of presently available test to detect nerve damage in order to make them more reliable and simple to field use.

– development of entirely new tests for reliable and quantitative assessment of nerve damage.

– development and testing of more effective footwear and new shoe modifications for plantar ulcer prevention.

- development of new modifications for daily-life work and household use.

– design of new approaches to make POD more effective, that is, to make patients accept, understand and effectively incorporate POD actions in their day-life. In this regard, the transfer of technology is essential as well as the way to do this transfer.

- epidemiological studies to better quantify the burden of leprosy-related disability in order to allow manager to set reliable targets for actions.

- epidemiological studies on the relations between leprosy reactions and disabilities.

– clinical studies on new approaches in the therapeutics of leprosy reactions.

R&T institutions and rehabilitation

If POD activities have been long ago incorporated in basic care of leprosy patients, rehabilitation has remained a typical institutional activity. Just to mention a few: Carville, Karigiri, Kumbakonam, Chingelput, Bombay, Bauru, ALERT, Dakar, Ching mai, etc. For this reason it would be obvious to mention that rehabilitation, basically physical rehabilitation, is a must to leprosy related R&T institutions. This is reasonably since historically rehabilitation of leprosy was initiated and developed in these institutions in a time where admission of leprosy patients in a general hospital was unthinkable. However, the concept that rehabilitation, being a complex health action, should be integrated into the general health services of this sort precedes the present concept of integration of leprosy control activities into the basic health services. In the other hand, although the continuing effort of some institutions to develop this concept by means of training of staffs of general hospitals and the marketing of the integration of leprosy rehabilitation during all sort of non-leprosy related medical meetings (Plastic Surgery meetings, orthopedics congresses, etc.), the present picture is not rewarding. Due mainly to stigma, a fear of increased workload for the general hospital staff and the poor conditions of general health services in most endemic countries, leprosy patients have poor acceptance by these services.

In this regard, some roles for R&T in the near future are as follows:

1 - Similarly to clinical leprosy, R&T institutions should function as reservoirs of leprosy rehabilitation knowledge.

2 - The institutions should strengthen their activities of training on physical rehabilitation and related sciences which should be supported by governmental agencies and NGO"s. Similarly to POD, staff members should be available to train surgeons at their own hospitals, besides regular courses held at the institution.

3 - These institutions should be active centers for diffusion of rehabilitation, being responsible for the marketing of the rehabilitation cause.

4 - Research on all aspects of rehabilitation should be encouraged, including:

– new strategies to decrease stigma towards leprosy in the community

– the role of nerve decompression in the treatment of neuritis, prevention of deformities and prevention of worsening of deformities.

– new approaches to nasal reconstruction in leprosy

- new techniques to improve cosmetic appearance of face and hands affected by leprosy.

- role of microsurgical flaps in treating difficult plantar ulcers

- effective management of the arthropaty of Charcot and other bone and joint conditions.

- pathogenesis and new approaches to the treatment of leg ulcers.

If POD is a typical peripheral activity, rehabilitation may be an activity based in the R&T institution if infrastructure do exist in the institution. Main reason for this statement is that, despite all effort in the last 50 years, the top skills on rehabilitation are mostly restricted to leprosy related R&T institutions. The transfer of this technology, although desirable and insistently pursued, has not quantitatively been achieved in regard to the present load of correctable or amenable disabilities in leprosy.

CONCLUSION

As a conclusion, in the field of POD and rehabilitation, R&T institutions should be regarded as specialized units responsible to maintain and further develop knowledge. However, no matter the complexity of actions developed in these institutions, they should bear in mind that their most relevant role is to be ready to provide the control program in the field with adequate answers to their needs to achieve an effective control of leprosy as a public health problem, before and beyond the year 2000.

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