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EDITORIALS

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XIV LEPROSY CONGRESS STATE-OF-THE-ART LECTURE

We are pleased to have the opportunity of publishing the full texts of the State-of-the-Art Lectures presented at the XIV International Leprosy Congress in Orlando, Florida, U.S.A., 29 August–4 September, 1993. The first four of these lectures appeared in the March and June issues. Remaining lectures will appear in subsequent issues—RCH

Not by Chemotherapy Alone*

Pasteur's germ theory of diseases and Virchow's concept of cellular pathology were the two great discoveries of the last century that heralded the birth of modern medicine and laid its foundations. In that process they have also determined our view of diseases and their management. Thus, we have come to see diseases as unwanted changes that occur in certain cells and tissues caused by one or a few specific agents. Based on this viewpoint we have developed the framework "etiology-pathology-treatment" to deal with disease states. In this framework, "treatment" becomes the injunction to eliminate the causative agent.

Public health practice is also based on this medical perspective. Thus, we seek to prevent by producing changes in the body to resist or inactivate the causative agent (e.g., by immunization) or by producing changes in the environment to prevent contact with the causative agent (e.g., vector control). More recently, we have added a third kind of intervention, to produce changes in human behavior to minimize the operation of risk factors (e.g., low cholesterol diet, no smoking).

This approach and the practices on which it is based have yielded enormously beneficial results to mankind over the last 100 years and I need not detail them here. Nevertheless, in the recent years there has been an increasing realization that our traditional approach is not proving adequate to meet

* This State-of-the-Art Lecture was presented at the XIV International Leprosy Congress on 2 September 1993, Orlando, Florida, U.S.A.

a number of disease-related problems, particularly those associated with chronic and disabling disorders. It became evident that we needed a wider perspective than that provided by microscopic appearances and molecular configurations to meet those problems. The problem of leprosy comes under this category.

The problem of leprosy is not new. A Tamil poet of the classical Sangam age who lived in South India about 1800 years ago describes a scene in which a young woman complains to her girl friend: "As you had suggested, last night I went to the mango grove outside our village to meet my beloved. And what a trouble I had there! I had to leave the place in a hurry without meeting him. You know why? I could not stand the importunate advances of that wretched brahmin, with limbs mutilated by leprosy, who was thrown out of the village. I had to flee from him." This has been the problem of leprosy over the centuries, and it remains so even today.

Three-tier model

The consequences and repercussions of leprosy are better appreciated if we apply the three-tier model "impairment-disability-handicap" developed by rehabilitation scientists. Here, "impairment" refers to losses or abnormalities of body parts or functions; whereas "disability" refers to the difficulty or inability to carry out certain acts because of impairment. "Deformities" are visible impairments or visual consequences of hidden impairments. "Handicap" refers to the disadvantages experienced by affected persons in living in society because of which they are unable to play their normal roles and meet their normal societal obligations.

Leprosy gives rise to many kinds of impairments, both primary impairments resulting from the disease as well as secondary impairments which are consequences of primary impairments and not of the disease as such. The primary impairments of leprosy include involvement and damage to facial structures, involvement and damage to peripheral nerves, involvement and damage to ocular structures, and psychological disturbances consequent to the diagnosis of leprosy. Besides these primary impairments, unprotected use of anesthetic ex-

tremities and the neglect of paralytic deformities give rise to secondary impairments such as ulceration, contractures, shortening, mutilation, and skeletal disorganization. Secondary impairments such as corneal ulceration and secondary glaucoma may occur in the eyes.

These impairments give rise to a variety of disabilities. Although we have been using the term "disabilities" in the context of leprosy and a variety of disability gradings, including those suggested by the World Health Organization (WHO), we are in fact referring to impairments and deformities only. As far as I know, there have been few studies to ascertain the disabilities experienced by persons with leprosy-related impairments at home and at work. Hence, regarding the actual disabilities of leprosy patients we have very little factual information. Since the hands, feet and eyes are the organs affected we expect the resulting disabilities to involve manual dexterity, locomotion and vision.

The handicaps experienced by leprosy patients are many and varied and are related to mobility, education, employment, behavior, social integration, economic independence and physical independence. The severity of handicaps experienced by leprosy patients varies, depending on the level of prejudice against leprosy in the community as well as the availability and quality of medical and rehabilitative services.

Applying the three-tier model to leprosy, I found that the third tier, "handicap," needed to be expanded further into handicap, debilitation and destitution, thus giving us five tiers in all. While "handicap" refers to the disadvantages experienced in society by affected persons, "debilitation" refers to the process of marginalization and devaluation of persistently handicapped persons and the consequent loosening of social bonds that hold them and their families and the community together. "Dehabilitation" also refers to the end state of partial estrangement of affected persons when they opt out or get pushed out of their homes and communities to submerge themselves in the anonymity of urban multitude, or live in a colony where they are among their equals, or in a so-called "rehabilitation home" where they are segregated from society. With such existence

in an isolated social niche at the fringe of society, the process of debilitation is complete.

"Destitution," i.e., the state of total alienation from all society, is the final stage of this dismal story. The destitute are completely alone. The destitute "live" alone and die alone without anybody caring either way.

Aims of interventions

Health care activities may be viewed as interventions in the lives of persons with specific aims. The five-tier model shows that we can make six types of interventions in leprosy, each with a specific aim. The aims of these interventions are: 1) to prevent primary impairments, 2) to prevent secondary impairments, 3) to prevent permanent disabilities because of primary and secondary impairments, 4) to prevent handicaps and debilitation, 5) to prevent debilitation and destitution, and 6) to salvage the destitute.

The first aim of prevention of primary impairments is achieved by the timely detection of the disease and effective treatment of it with appropriate chemotherapy. The second aim of preventing secondary impairments is achieved by the affected persons taking proper care of their insensitive hands, feet and eyes which may also have muscle paralysis. The third aim of prevention of permanent disabilities is achieved by identifying the relevant impairments, such as neuritis, ulcers and injuries, at an early stage and treating them promptly. The fourth aim of preventing handicaps resulting from permanent disabilities is achievable by improving or abolishing the disability and making the patient able again. The fifth aim of the prevention of debilitation and destitution of affected persons is achieved by instituting measures to overcome their handicaps. The last aim of salvaging the destitute is achieved by providing them with shelter and sustenance as well as restoring human fellowship to them.

From the wider viewpoint provided by the five-tier model, we see that tackling the "leprosy problem," which means problems of leprosy-affected persons, requires a series of interventions of which chemotherapy is the first and foremost. Leprosy programs of different countries are achieving the first aim

of prevention of primary impairments by early case detection and effective treatment with multidrug therapy (MDT). But we must not forget that a substantial proportion of patients require other interventions besides chemotherapy in order to tackle their "leprosy problem."

Urgent need for other interventions

At the present juncture, it has become necessary and important to implement the other interventions on a priority basis. I say "present juncture" because widespread, intensive implementation of the MDT program has introduced a new dimension and a new need for urgency in the hitherto placid and rather sluggish world of leprosy and leprosy control.

The introduction of MDT has been the most notable advance in the therapy of leprosy since the introduction of sulfones in the late 1940s. Leprosy is cured now within 6 to 12 months in most cases and within 2 to 3 years in most of the remaining cases. This has encouraged leprosy workers, administrators, patients, and local communities to develop a positive and optimistic outlook toward leprosy, leading to improved case detection and greater regularity of attendance of patients.

Solutions devised for dealing with one problem generate new problems in their turn. This has been so with the MDT program also. Firstly, with the advent of MDT, contacts between the patient and the leprosy worker have become brief and hurried business encounters, the business being distribution of pills and capsules by one party and the collecting and consuming of them by the other. Secondly, once the treatment has been completed the affected persons' names are removed from the active register. They become subjects for surveillance, i.e., to be seen once a year for 2 to 5 years. As a rule, the surveillance work is not done with the same enthusiasm and diligence as the drug distribution. Thus, for all practical purposes, even the meager contact virtually ceases once MDT is completed.

This kind of benign neglect will not matter for those persons whose only problem is having the disease. But there is a sizeable minority, about 20%, who have already developed leprosy-related impairments and

disabilities. By the new definition, they are not "leprosy patients" since they do not need antileprosy treatment any more. Leprosy program personnel, especially those at the higher level, view the issue from the usual medical perspective and consider that by providing antileprosy chemotherapy they have done their job and any residual problem should be somebody else's responsibility. Other organizations catering to the needs of other handicapped and disabled are not technically or psychologically equipped to meet the needs of persons with leprosy-related impairments and disabilities. Thus, these persons with leprosy-related problems but not needing chemotherapy have nowhere to turn for help, and they are not equipped to cope with their problems on their own. This is the background in which we find that an increasing number of leprosy-affected persons are being discharged "cured," because of efficient implementation of the MDT program, and so an increasing number of persons with leprosy-related impairments and disabilities are being added to the general community outside the sphere of operation of the leprosy sector. This is the emerging problem following successful implementation of MDT on a large scale in India, which has the largest aggregate of leprosy-affected persons in the world. For example, in one district in South India in which the MDT program has been operating for the last 7 years, about 98% of the 2500 persons with leprosy-related disability problems have been cured of their disease and so fall outside the National Leprosy Programme, and they outnumber those receiving treatment for leprosy in the district.

Needs of persons with leprosy-related problems

What are the needs of persons with leprosy-related problems? First, they have the disease and that needs to be cured. Second, a proportion of them have some impairments (primary or secondary, or both) and consequent disabilities and deformities which may be handicapping them as well, although not too badly. They would like their disabilities and deformities abolished so that they may become as able and normal as others. Third, even if they were not se-

riously disabled or handicapped at present, their impairments, disabilities, deformities and handicaps will worsen in the future unless special measures are taken. They also may develop new impairments and disabilities over time, and that needs to be avoided. Last, a proportion of these persons are seriously handicapped and significantly debilitated, and some may even have become destitute. They need to be woven back into the fabric of normal society and the destitute need to be restored their humanity.

Thus, we find that leprosy-affected persons have four major needs: 1) to get their disease cured, 2) to be made able and normal-looking once again, 3) to prevent worsening of their impairments and the appearance of new impairments, and 4) to get their social status restored. These needs will be met by the interventions mentioned earlier. When we consider the matter, we find that the expertise, strategy and operational procedures required to meet these four needs are quite different, warranting four different programs, namely: 1) a "chemotherapy program" (providing the first level intervention) to get the disease cured; 2) a "re-ablement program" (providing the fourth level of intervention) to make affected persons able again; 3) a "disability prevention program" (providing the second and third levels of intervention) to prevent the occurrence of new impairments and worsening of impairments already present; and 4) a "rehabilitation program" (providing the fifth and sixth levels of intervention) to rehabilitate the severely handicapped and debilitated as well as to salvage those who are destitute.

I have already pointed out that the leprosy programs of most countries are chemotherapy programs, providing the first level intervention. There is no doubt that these programs have been very beneficial. Besides curing a large number of leprosy patients, they also have prevented the occurrence of primary impairments once the patient has been identified and treated at an early enough stage of the disease.

Before discussing the other three programs, I first wish to point out one obstacle, which is that many countries do not have a national policy regarding leprosy-related problems other than chemotherapy. Plan-

ners and managers of leprosy programs as well as the middle-level officials have been seeing the program solely from a public health point of view, which considers leprosy patients primarily as sources of infection and agents for the spread of the disease. Anything other than chemotherapy is, therefore, seen as an extraneous "rehabilitation" problem, outside the purview of the leprosy program. Because of this kind of rather limited perception, planners have not considered it necessary to incorporate measures for seriously tackling disability-related issues in their programs.

It is up to us to convince the planners and principal managers of leprosy programs, and through them their respective governments, that re-ablement, disability prevention and rehabilitation should not be thought of as fringe benefits or extravagant luxuries but as necessary components of treating persons with a chronic and disabling disease such as leprosy. Only then will we be able to develop policies and nationwide macro-level programs to achieve significant results at the global level in the same way as we have achieved in the chemotherapy of leprosy.

I must point out here that of late the situation shows some improvement. For example, the last WHO Expert Committee on Leprosy has, for the first time, acknowledged unambiguously in its report that the leprosy program is as much a medical treatment and patient-care program as it is a public health program. The Government of India is in the process of launching, as part of its National Leprosy Eradication Programme, measures to contain and correct disabilities and deformities and to rehabilitate debilitated leprosy-affected persons. I feel these are auguries of better things to come in the near future.

I shall now describe briefly the current situation regarding re-ablement, disability prevention and rehabilitation.

Re-ablement

The goal of "re-ablement" is to abolish disabilities and deformities and make affected persons able and normal-looking once again. We know from our experience over the last 40 years that this is possible through surgical and nonsurgical means. The responsibility for carrying out this program, therefore, rests with the medical sector.

It is a matter of historical fact that the technology and expertise of re-ablement has been developed almost exclusively in the leprosy sector, outside the mainstream of general medical academics and services. Even in the leprosy sector, these facilities have been available to only a limited extent and in only a few centers. Over the years, a large number of affected persons have availed themselves of the services of these centers. Nevertheless, we are now in an anomalous situation where even these few centers are underutilized while the number of persons with leprosy-related deformities and disabilities but not needing antileprosy chemotherapy is increasing all over the country, with no facility in their regions for making them able again.

I am afraid that by the time we eliminate leprosy, in another 10 or 15 years, few will be left in the field with the experience and expertise in re-ablement technology; whereas an enormous number of persons with leprosy-related disabilities and deformities will have been added to the existing pool of such persons. This is the situation regarding re-ablement of persons with leprosy-related disabilities.

Disability prevention

Prevention of the worsening of existing impairments and disabilities as well as the prevention of the occurrence of new impairments and disabilities are the goals of the disability prevention programs. Unlike "re-ablement," which is based on medical technology and services, disability prevention rests primarily on the efforts of the affected persons themselves, because it is only they who can protect their insensitive parts from injury, get any injury healed early, maintain their joints supple, and be on the look out for signs of onset or progress of nerve damage. All along we have been basing our efforts in this area on "health education," a not very powerful tool, and that, too, only half-heartedly, with predictably disappointing results. Leprosy workers have often felt helpless and frustrated in this situation. Since facilities for re-ablement are not likely to be available anywhere near the extent needed for a long time to come, an increasing number of leprosy-affected persons will necessarily have to live with their

problems, coping with them to the best of their ability.

Rehabilitation

I must clarify at the outset that I am using the term "rehabilitation" in the sense of restoring the value and social status of affected persons. Therefore, it is the persistently handicapped and the debilitated who will require rehabilitation. Even among the debilitated, I feel that we should concentrate our efforts on those who are still living with their families and in communities rather than on those living in colonies where they have managed to "rehabilitate" themselves, in a manner of speaking.

We do not have information regarding the number of persons who are debilitated but not yet displaced and so likely to need rehabilitation. Part of the difficulty is because debilitation is a slow and complex process. Furthermore, the handicaps of poverty and un(der)employment are ubiquitous in the countries in which leprosy is prevalent and it is not easy to determine if the deterioration in the economic status of affected persons was specifically due to leprosy-related causes. Thirdly, the political will to promote rehabilitation programs and people's participation in them also depends on the economic milieu; thriving communities will have greater inclination, resources and opportunities for rehabilitating their debilitated brethren, unlike declining communities, which is the case with many rural areas. We must not forget that in the matter of rehabilitation the ethos of the community is at least as important as the economic factor. We have all come across instances of severely crippled persons being well taken care of by their families and the local community, as well as instances of persons with hardly any deformity or disability being badly discriminated against just because they had leprosy. Lastly, there is the problem of jurisdiction—who is to provide the necessary funds and operate the services? The ministry of health, social welfare, labor? and so on. Although this is a resolvable bureaucratic problem, we know in practice that it can be very difficult to make officials from different departments and ministries work in a coordinated manner. Many a time a program is

held up or shelved on this score. This is the current situation.

The issues are this: Given this situation, a) How do we make re-ablement facilities accessible to all those who may need and desire them? b) How do we implement a viable disability prevention program on a large scale? c) What do we do to rehabilitate all those who need to be rehabilitated?

Suggested strategies

Re-ablement. Taking the first issue of extending re-ablement facilities to all those who need them, it is evident that with the present set-up it will not be possible to provide re-ablement services to most of those who need them. The only way to improve the situation is by large-scale transfer of re-ablement technology from the leprosy sector to the general medical services sector in a planned manner. In my opinion, in the present situation, the primary duty of those with expertise in this field is to exert their utmost to achieve this technology transfer. We have to convince the administrators in both the leprosy and general medical services sectors of the urgent need for such a technology transfer and work out appropriate actions. They may include traditional methods, such as prolonged in-service training and training courses. In addition, mobile training units may be set up to train identified surgeons in their own localities, limiting the training to certain essential surgical procedures. One may also consider training and employing surgeons or re-ablement teams on a contract basis to carry out a crash program of re-ablement in a given area. If such programs are carried out, I am sure that in about 5 years we can create a sufficiently large body of surgeons familiar with the necessary corrective procedures while, at the same time, clearing a big chunk of the backlog of patients needing re-ablement. A variety of learning materials, such as books, manuals and video cassettes, will be needed to carry out such a training program, and it is heartening to find that WHO is bringing out a manual on essential surgery in leprosy at district hospitals. Even more important than the preparation of learning materials is making them available widely and easily, if need be at subsidized prices. I do not see any other practicable way of

solving this problem. All of these measures call for increased funding.

Disability prevention. Coming to the second issue of large scale implementation of disability prevention, we must realize that "disability prevention" is the key activity without which neither re-ablement nor rehabilitation can be meaningfully carried out. Number-wise also, a maximum number of persons with leprosy-related impairments will require disability prevention, a proportion of them (about one third to one fourth, I suspect) will require re-ablement and a much smaller proportion (probably about 5% to 10%) would need rehabilitation.

The most important point to realize is that we in the leprosy sector can provide only periodic, occasional or one-time interventions relating to disability prevention, but the vulnerable parts of leprosy-affected persons require constant care. Such continuous and conscious care can be given only by the affected persons themselves. This means that, in order to achieve "disability prevention" on a large scale, the knowledge and technology of disability prevention will have to be transferred from the leprosy sector to the affected persons themselves.

Disability prevention requires leprosy-affected persons to learn new habits of living and working, and the discarding of many old habits that are harmful. They will need to carry out many everyday activities differently from others, and this may invite ridicule and even condemnation. Therefore, practicing disability prevention is not easy, and it requires understanding, encouragement and support from the family and the neighbors. In order to ensure that, it is necessary to elicit their cooperation and active participation by also inducting them into the process of technology transfer. With the right kind of inputs and approaches I am sure we can succeed in achieving this technology transfer, from the leprosy sector to affected persons, their family members and local community volunteers.

Such a technology transfer program will need to be a patient-oriented, participative, flexible, and interactive learning program involving affected persons, leprosy staff and others, such as family members and neighborhood volunteers, with leprosy staff playing a key role. Leprosy staff will function as

the catalysts, trainers and facilitators, and also provide moral and physical support such as aids and appliances to the affected persons and their communities in this venture.

This program also requires suitable learning material in sufficient numbers. In this connection I must bring to your notice two training packages (Nos. 17 and 18) brought out by WHO in their CBR Training package series. These exemplary training packages, dealing with the problem of loss of feeling in hands and feet, show how we can do this using simple language. The goal of this technology transfer is to make leprosy-affected persons not to be dependent on us, as far as possible, for solving their day-to-day problems of living with leprosy-related impairments.

We will need to take, in addition, three supportive actions: 1) train the staff of the leprosy sector in the technology of disability prevention and in the transfer of that technology; 2) improve the treatment capabilities of the leprosy sector, especially its peripheral units, so that treatable conditions, especially plantar ulcers, are effectively treated locally; and 3) create and strengthen back-up referral facilities so that problems requiring higher-level medical care can be dealt with and worsening of the disabilities prevented. In this connection I would like to bring to your attention the manual for leprosy field staff (to be brought out soon) by WHO on disability prevention in the field. Again, it is not enough to produce such manuals and training packages. They must be easily accessible to all those who would benefit from them. It is the duty of national governments to see that this happens.

We have started paying attention to this problem of disability prevention only recently, and we need the hindsight of experience to know if we are on the right track.

Rehabilitation. The third leprosy-related issue is rehabilitation. In this connection we must realize a) that rehabilitation is not the mere supply of certain goods and services; b) that rehabilitation is the device with which to provide social security to the handicapped and marginalized segments of society, particularly those with disabilities; and c) that just as debilitation is the process of the breaking down of bonds that held leprosy-affected persons and society together.

er, rehabilitation is the process of the re-establishment of those bonds.

Thus, rehabilitation is a much wider concept and process in which the local community has a crucial role to play. As mentioned earlier, the local communal ethos is a critical factor in determining debilitation and rehabilitation. Nevertheless, it will not be far wrong to say that economic dependency of the affected individual makes rehabilitation more difficult and that economic prosperity and independence make rehabilitation easier.

By and large, governments and nongovernmental organizations (NGOs) have three kinds of programs: development programs to improve the economy of a region, welfare programs to help the marginalized and handicapped segments of society, and rehabilitation programs for different categories of disabled persons.

To a large extent, particularly in rural areas, it should be possible to rehabilitate leprosy-affected persons under a community-based rehabilitation (CBR) program. Where such programs do not exist, leprosy can be used to introduce CBR and extend it to include other disabled persons. This will require training grass-root-level leprosy staff in the basics of CBR. In addition, leprosy-affected debilitated persons need to be helped along to benefit from the existing development, welfare and rehabilitation programs of governments and NGOs, by helping them in two crucial areas: infor-

mation about them and to gain entry into these programs. In short, I feel that leprosy program personnel need not run rehabilitation programs of their own, but they should keep rehabilitation of leprosy-affected persons as one of their major objectives and be able to function as facilitators and intermediaries to bring about economic rehabilitation of those persons in their jurisdiction. They must be equipped, and some effective administrative provision made for this purpose.

In conclusion, I have tried to put before you the view that the elimination of leprosy as a public health problem, a very laudable goal, is also a very limited goal from the wider perspective of the leprosy problem. What we ultimately want is elimination of leprosy as a human problem. This requires employment of other tools and technology besides chemotherapy, and I have attempted to identify them and indicate how they may be implemented. Once we convince the planners and administrators of the necessity for these programs and help them to develop policies and execute the programs, the elimination of leprosy will have become a meaningful reality.

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