

## PREVENTION OF DISABILITY IN LEPROSY-AFFECTED PERSONS

### -SUGGESTIONS FOR SOME STRATEGIES-

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1. *My friends and colleagues in the global efforts against leprosy, To begin with, I wish to record my sincere thanks to the international Leprosy Association, which has organized this African Leprosy Congress, for affording me this opportunity to place before you some of my ideas regarding disability prevention in leprosy affected persons. This is a rare privilege for a person like me who has never before addressed an African audience and I appreciate this very much. Eradication of small pox from the face of the earth and eliminating leprosy as a public health problem from most countries of the world are two of the great achievements of humankind in the field of health in the last one hundred years. However the problems faced by the millions of leprosy-affected persons have not diminished, leave alone disappeared, and it is time that we examine the issues involved in this conundrum and try to solve them.*

2. All cultures and societies all over the world have dreaded Leprosy since time immemorial. Three features of this disease were responsible for generating this attitude. 1) There was no remedy for the disease; 2) it posed a danger to normal healthy people as it appeared capable of spreading from one person to another; and, 3) to cap it all, leprosy-affected persons developed hideous deformities, stinking ulcers and crippling disabilities, making them objects of loathsome pity and fear.

3. These three features gave rise to three great problems regarding this disease. Its incurability presented the medical problem of how to treat the affected persons. Its infectiousness posed the problem in the sphere of public health. Its deforming and disabling potential, combined with the other two features of incurability and infectiousness, made the society to develop a highly negative attitude towards affected persons leading to their stigmatisation and excommunication from normal society, giving rise to great human problem.

4. But, that is all old story. The situation to-day is very different and leprosy is no more a medical problem as we now have very effective anti-leprosy drugs in rifampicin, ofloxacin, minocyclin, clofazimine and dapsone. Thanks to the concerted efforts of the WHO, International Federation of Anti-leprosy organizations (ILEP) and innumerable national and sub-national NGOs, organizations like the Sasakawa Medical Foundation and SIDA and the national governments all over the world, leprosy has been more or less eliminated as a public health problem from most countries of the world.

5. However, as I had mentioned earlier, the human problem of deformities, disablement, stigmatisation and debilitation of affected persons continues. That is because curing leprosy has made no difference to those who have developed impairments, deformities and disabilities already. And more patients are being added to those under risk of developing impairments and disabilities. It is time we addressed this issue now.

6. Before proceeding further, I would like to provide some clarifications about the terms used in this talk. 'Deformity' normally refers to changes in appearance that are noticeable to others; whereas 'disability' refers to difficulties experienced by the affected person in carrying out some specific tasks and activities.

7. However, in leprosy circles, the term 'deformity' originally covered 'disabilities' also. Now, 'disability' is being used to refer to both disabilities and deformities as well. In the WHO disability grading, grade 0 disability indicates that the part is not affected by leprosy, grade 1 disability indicates that the part is affected by leprosy, but no visible changes are present and grade 2 disability means that the part is affected and that visible changes are also present. This classification may have been useful to health administrators, but is not very helpful for the purpose of disability management.

8. However, the WHO has also developed concept of 'consequences of diseases and disorders', the ICIDH (international classification of impairment, disability and handicap) classification and its further elaborations, which have led to a better understanding of the disability problem and to better formulation of remedial and preventive measures to meet the adverse consequences of chronic disabling conditions.

9. A disease is seen as giving rise to impairments, disabilities and handicaps and these terms were clearly defined. Applying this concept to leprosy, I have suggested that the stage of 'handicap' may be further elaborated into handicap, debilitation and destitution.

10. The anatomical, physiological and psychological changes (losses, and abnormalities) consequent to diseases and disorders are referred to as "**Impairments**". Diseases and diagnoses are most often named after the resulting impairment, as for example in *pulmonary tuberculosis, carcinoma of the prostate, fracture neck of femur, or, mental retardation*.

11. Leprosy-affected persons develop most commonly impairments involving hands, feet, face and eyes and the nerve trunks that supply these body parts.

12. Leprosy-affected persons develop deformities for three different reasons:

- i) due to infection of the tissues with *M. leprae*;
- ii) due to muscle paralysis resulting from damage to motor nerves infected with lepra bacilli; and
- iii) due to tissue damage and scarring resulting from tissue loss consequent to infection of neglected injuries occurring in insensitive parts of the body.

These deformities are, accordingly, described as *specific, paralytic and anaesthetic* deformities. The first two kinds of deformities (specific and paralytic) are also called primary impairments as they are direct consequences of leprosy; and the anaesthetic deformities are called secondary impairments as they are consequences of primary impairments and are not due to leprosy per se.

13. It is interesting to note that specific impairments are seen most often in the face, paralytic deformities are found most commonly in hands and anaesthetic deformities are most frequently found in the feet.

14. impairments give rise to **disabilities**, which are limitations of activities involving the use of hands, feet and eyes.

15. Persistently disabled persons experience disadvantages in life, which severely restrict their active participation in normal social life. They are then said to be handicapped.

16. **Handicaps** thus experienced by leprosy-affected persons include lack of proper education, unemployment, mobility problems and difficulties in communication, impoverishment and loss of physical independence.

17. Persistently handicapped persons are progressively ignored and increasingly marginalized from the affairs of their families and society. Their social status progressively diminishes and they get increasingly isolated from their immediate society. This process of progressive estrangement from society has been called **dehabilitation**.

18. The culmination of the process of dehabilitation is ejection or emigration of affected persons from their homes and villages to settle in an alien colony of similarly dehabilitated persons, under conditions of anonymity, in large or metropolitan cities.

19. The end stage of such progressive deterioration in the life of the affected person is **destitution**.

20. The destitute is completely isolated from all society, is totally friendless, lacks food security and often has no shelter either to protect her or him from the elements. He may be dying by the roadside while world passes him by unconcerned.

21. Luckily, this dismal sequence of events is not inevitable as many people imagine, and to-day we have enough knowledge and over half a century of experience to arrest progressive disablement and restore the affected person to as near normal a state as possible, through a variety of appropriate interventions. This approach, to meet the needs of the individual patient, has not been given sufficient emphasis in leprosy programmes till recently as their efforts were mostly, if not wholly, directed towards breaking the chain of transmission of the disease by identifying and "curing" patients with anti-leprosy therapy.

22. Now that the bogey of leprosy as a public health problem has been more or less laid to rest, I would say that we need to meet the individual needs of leprosy-affected persons. A little reflection will show that while undertaking to treat a person for a disease one has the responsibility to prevent and treat its complications as well. In the context of leprosy, this means that treatment of leprosy entails:

- 1 . provision of antibacterial treatment to get rid of the infection
2. prevention of primary and secondary impairments
3. prevention of worsening of impairments
4. correction of existing impairments,
5. prevention of debilitation, and
6. rehabilitation where necessary.

Herein lies the importance of prevention of disabilities.

23. Africa is a vast continent with a great variety of nations, cultures and patterns of medical and health services, and it will not be correct to prescribe one rigid pattern of strategy for the entire continent. Further, I do not have personal experience of the conditions here. Therefore, it will be presumptuous on my part to prescribe strategies in detail for implementing a comprehensive programme as mentioned above. I shall, therefore, outline only the goals that we should strive to achieve and a broad approach that may serve as guide for local application. For this purpose, I am assuming a two-level health/medical service for a sub-national administrative unit like a district, namely (1) a higher (or more central) level medical facility having necessary expertise, and (2) a peripheral health post or clinic manned by medical auxiliaries. For purposes of prevention of disability, a third level of activities, namely the patients' homes, must also be included.

24. Two different kinds of tasks will need to be carried out at the first and second level of health/medical services. They are: 1) treat conditions treatable at that level and, 2) train personnel at the lower level for carrying out their tasks. The second or peripheral level medical workers will in their turn train affected persons to carry out the disability prevention activities in their home environment.

25. Luckily, in most cases of leprosy, impairments are mild to begin with, progress slowly and become severe only when the condition has been neglected. Thus, even when leprosy has appeared, major nerve trunks may not be affected for some time; even when some of them are affected they may not be damaged; even when they are damaged only part of the nerve may be affected: and even when the whole nerve is affected the condition may be reversible for quite some time. Such a slow progression of events provides us enough opportunities to arrest worsening of impairments and revert them.

26. Thus, prevention of impairments consequent to nerve damage involves prevention of nerves getting damaged permanently and irreversibly. From the point of disability prevention, besides treatment of leprosy and its complications, preventing permanent nerve damage is thus the most important task at the medical facility level. This task requires medical care of a high order that can be available only at higher-level medical facilities as at designated and other more advanced medical centres.

27. Therefore, at this level, we should attempt to achieve prevention of (both primary and secondary) impairments and consequent disabilities by diagnosing leprosy early and promptly providing multidrug therapy, before the disease has spread to the nerve trunks and before they are damaged irreversibly. Secondly, early recognition and prompt and adequate treatment of the chief complications of leprosy, viz., reactions and neuritis, is the other component of disability prevention

activity at this level. Because of its importance I have put "Nerve Care" as the special disability prevention activity at this level.

28. "Nerve care" has only one aim and that is to prevent permanent or irreversible damage to nerve trunks, thereby prevent the occurrence of paralytic and anaesthetic deformities by preventing insensitivity of hands, feet and eyes and permanent paralysis of muscles in these organs.

29. "Nerve care" involves two different activities. They are: 1) recognition and management of "clinical neuritis"; and 2) recognition and management of nerve damage or "Nerve Function Deficit" (NFD). it should be remembered that both may involve institution of steroid therapy.

30. it is well known that there is no leprosy without neuritis. Thus, every case of leprosy has 'neuritis', in the strict sense of the term that is, inflammatory involvement of peripheral neural elements. I have here used the term "Clinical neuritis" to distinguish the clinical condition warranting institution of nerve care from the "routine" involvement of neural elements in leprosy, where such nerve care is not indicated. "Clinical neuritis" is diagnosed when, on palpation, a nerve trunk is more than mildly tender (that is, tenderness grade of 2 and above) or when there is spontaneous nerve pain graded as more than mild (that is nerve pain grade 2 and above) or when both are present.

31. For this purpose, one may use a qualitative, but dependable, scale for categorizing nerve tenderness as no tenderness (grade 0), mild tenderness (Gr. 1), moderate tenderness (Gr. 2) and severe tenderness (Gr. 3), depending upon patient's reaction to nerve trunk palpation. Presence of nerve trunk tenderness of grade 2 or above will invite the diagnosis of "clinical neuritis" and warrant the institution of "Nerve Care" programme. "Nerve tenderness" is assessed as grade 2 when the patient indicates that palpation is painful even without our asking about it.

32. Likewise, we may use a dependable qualitative scale for nerve pain, again graded as no pain (Gr. 0), mild pain (Gr. 1), moderate pain (Gr. 2) and severe pain (Gr. 3). Here also, presence of nerve pain of grade 2 and above will invite the diagnosis of "clinical neuritis" warranting institution of "Nerve Care" programme. "Nerve pain" is assessed as grade 2 when patient complains of nerve pain even without our asking about it with a leading question.

33. In order to determine the line of treatment, the patient is assigned to one of four categories (A,B,C&D) based on the concomitant presence / absence of clinical neuritis and nerve function deficit (NFD): category A having no clinical neuritis and no NFD, category B having neuritis but no NFD, Category C having NFD but no neuritis and category D having both neuritis and NFD. The treatment programme is chalked out according to the category to which the patient belongs.

34. Category A patients (no neuritis, no NFD) have no problem; and if they are in the high risk group, they need to be trained to recognize neuritis and NFD and report without delay if they suspect the onset of these conditions.

35. Category B patients have neuritis, but no NFD as yet. They may develop nerve damage and so the aim of management here is to prevent such an event. Institution of a standard course of steroid therapy is needed and this needs to be supplemented with surgical nerve decompression if there is no significant improvement in neuritis in two to three weeks of steroid therapy. Earlier surgery is indicated if there is worsening of neuritis or onset of NFD even while under steroid cover.

36. Category C patients are those who show NFD without concomitant neuritis. If the NFD is considered to be irreversible (i. e., long standing), the patient requires palliative treatment for nerve paralysis, including training in disability prevention practices (DPP) and, where possible, reconstructive surgery. If NFD is of recent duration (i.e., duration of up to six months) and if the patient has already completed MDT before the onset of NFD, it is probably a case of late reversal reaction or relapse and is to be treated accordingly.

37. If NFD is of recent onset and the patient has not had anti-leprosy treatment, institute MDT and carefully follow the patient, monitoring nerve function at least once a month. In many cases, the nerve recovers with MDT. If no significant improvement is noticed after three months of MDT, institute a standard course of steroid therapy. The patient is followed up as before. Steroid therapy is tapered off if there is no improvement even after three months or when no further improvement occurs. Decompression of the nerve trunk is unlikely to be of much help in these cases, but may be offered.

38. If the patient develops NFD while under treatment with MDT, institute steroid therapy at the earliest opportunity, continue with it as long as there is improvement, and taper off when there is no further improvement. There is no convincing evidence to recommend surgical decompression of the nerve trunk in category C patients, having nerve function deficit without concomitant clinical neuritis.

39. Category D patients are those having NFD and concomitant clinical neuritis of the affected nerve. If NFD is of recent onset and so considered reversible, initiate steroid therapy. Start with high dosage (more than 40 mg daily) and bring it down to 30 mg daily in the course of two to four weeks. Maintain steroid dosage at that level for at least three months. If there is no improvement in NFD by then, taper off steroid dosage. Otherwise, continue with steroids at the maintenance dose as long as improvement lasts and then taper off the drug. Add surgical decompression when NFD does not improve or improvement reaches a plateau while under steroid therapy.

40. Steroid therapy and frequent monitoring of the progress is essential for saving nerves from destruction. This is supplemented with other supportive measures like splinting affected limbs, anti-inflammatory and analgesic physical therapy, as well as active / passive exercises for weak and paralysed muscles and joints. This is necessary to prevent stiffness of joints and atrophy of the muscles.

41. Where NFD is deemed irreversible, preventing nerve damage is no more the object of treatment. The goal in these cases will be to train the patient to live with his or her impairments and disabilities while maintaining a reasonably good quality of life. The patient will therefore need to be trained in

"disability prevention practices". In addition, one may still need to resort to steroid therapy for pain relief and surgical decompression for avoiding prolonged administration of steroid drugs. Where possible corrective surgery may also be offered.

42. The central or district medical / health facility has also the task of training the lower level staff in their tasks including training patients in disability prevention practices.

43. The peripheral clinic level personnel, who are most likely to be medical auxiliaries or paramedical staff, have three jobs to do. They are: (i) treat conditions (like not very complicated ulcers and mild reactions) treatable at this level, (ii) train patients and their well-wishers in appropriate disability prevention practices and, (iii) provide physical and moral support and help to patients in their efforts at disability prevention, including arranging for their obtaining protective footwear.

44. Disability prevention practices have two aims: (i) to avoid secondary impairments (like wounds, ulcers, skin cracks, joint stiffness and serious eye problems) to the extent possible and (ii) to recognize and manage them early so that they do not become severe and complicated requiring expert advice and intervention (which may or may not be available).

45. Disability prevention is to be practised by the affected persons in their homes and workplaces. Others can only help them and cannot do much more. In order to achieve disability prevention, the patient has to learn how impairments occur, how to avoid them, what to do if they occur despite one's efforts to prevent them getting worse and put into practice what one has learnt. Ultimately, this is the most crucial aspect of disability prevention in leprosy and the importance of home level practice of disability prevention cannot be overemphasized.

46. Leprosy-affected persons can save their hands and feet from mutilation and crippling deformities by diligently practising disability prevention, and escape stigmatisation and consequent debilitation. For the patients to continue to practise disability prevention for the rest of their lives it is essential that they understand this.

47. Disability prevention practices have four components. They are: Skin care, Wound care, Joint care and lastly Eye care practices.

48. The aim of skin care practices is to prevent breakdown of the insensitive skin of hands and feet. In order to achieve this the patient learns to use the anaesthetic hand without endangering the skin and thus avoid injuries, uses protective footwear to avoid injury to the insensitive soles of his feet, hydrates the dry anaesthetic skin of hands and feet and keeps it soft and supple thus preventing skin cracks. He also learns to inspect his hands and feet frequently to identify any injuries that may have occurred and get them healed at the earliest. These activities constitute skin care practices.

49. The aim of wound care practice is to get the "wound" healed at the earliest. In this context the term "wound" refers not only to wounds like cuts and traumatic loss of skin, but also to other conditions like ulcers and skin cracks in which the skin is breached. Recognize the wounds early and keep them clean and covered. Occlusive dressing using direct application of sticking plaster is very helpful for use in the field for this purpose. Lastly, the affected part should be rested (splinted if need be) to permit early healing. 'Rest' does not always mean bed rest; it refers to avoiding any physical or physiological stress on the wound that is likely to interfere with early healing.

50. When there is muscle paralysis, balance of forces around affected joints is affected and the joints are held in abnormal postures of deformity. They are never actively moved through their full range because of muscle paralysis. This leads to development of joint stiffness in the deformed position and that makes use of the affected part difficult and stressful. These adverse consequences are completely avoided by putting the joints through the full range of movements few times a day. Practice of oil massage and exercises achieves this and also helps to keep the skin soft and supple. Occasionally, splints may have to be used to prevent the joints going into a posture of deformity, especially during night time.

51. Lastly, eye care is practised to protect dry and insensitive eyes, which may also have weakness of eyelids, from drying up and from injuries. Simple measures like putting a drop of oil, consciously practicing periodic blinking and use of an eyeshade go a long way to save these eyes.

52. From what I have said so far, it should have become evident that prevention of disability and consequent debilitation is not a medical problem, because we know what to do. The problem is make this knowledge and the necessary techniques available to all those who need them. This is actually a management problem for health administrators and leprosy workers. The managerial task of providing MDT to all those who need anti-leprosy treatment has been successfully achieved, thanks to concerted and pointed efforts at a global level. I have no doubt that a similar time-bound effort can easily achieve disability prevention also.

53. In this connection, I want to make one point clear. And that is about deformity correction and disability improvement by reconstructive surgery. While surgery may greatly benefit the patient, we must also remember that a good proportion of affected persons are not suitable for such surgery, because of age and local complications like severe stiffness and mutilation of the part. Surgery cannot help them. Secondly, even among those who are likely to be helped by surgery, many are not willing for such surgery for a variety of reasons. Thirdly, reconstructive surgery is expensive and the needed surgical expertise is not generally available. Therefore, one will have to reconcile with the fact that while surgery may be good if we can have it, many patients will not be able to have the benefit of that kind of intervention.

54. Even while implementing a disability prevention programme, we must be realistic and keep our goal clear. It is not our aim to provide training in disability prevention. Our aim is to provide such training TO THOSE WHO ARE LIKELY TO BENEFIT FROM IT. Persons with very severe deformities and disabilities as well as those who are unwilling and uncooperative are not likely to benefit from such a programme, Therefore, for a disability prevention programme to be truly successful, we should select the beneficiaries. That will save a lot of wasted labour. Secondly, not all the four care practices need to be taught to all affected persons. Instead, they need to be trained

in only those practices that are relevant to them. Thus skin care is taught only to those have anaesthetic hands and feet, joint care to those with mobile deformities of hands and feet, wound care to those with "wounds" in their extremities and eye care to those with anaesthetic cornea and / or weakness of eyelids.

55. The other point to remember is that the programme should be realistic and flexible so that it may be successfully applied in any given locality depending upon the ground situation. In order to be successful, we should attempt to tap the local resources human and material, to the extent possible and involve the local community so that it gets interested in the success of the programme, develops a helpful attitude towards the efforts of affected persons at maintaining their independence and dignity.

56. It is a basic management principle that a complex problem is more easily solved if it is broken down to its various components, which are then solved piecemeal. The more easily solvable parts are solved first so that everybody sees the successes of their efforts and gets encouraged to proceed further. Making the local community have a stake in the programme ensures better co-operation from the community, which is very essential for the success of programmes like this one. Simultaneously, one also develops resources for the more difficult parts of the programme that could be implemented subsequently. I am convinced that prevention of deformity, disability and debilitation is achievable within a prescribed time frame if we use imaginative, flexible, and beneficiary-friendly programmes.

*57. Ladies and gentlemen, I thank you all for patiently giving me a hearing and the organizers for giving me this privilege of presenting my views to you all. May your glorious efforts to restore human dignity to the sufferers of leprosy who are one of the most wretched on the earth be crowned with resounding success! For, success in this area will make "elimination of leprosy " truly meaningful to the patients and to the society at large. Thank you.*