

Social Rehabilitation and Surgery in Leprosy

Dinkar D. Palande¹Marcos Virmond²

ABSTRACT

The image of leprosy in the community causes a reduction in the socioeconomic status of the affected and the family. The prevalence of disability is on the increase and because of neglect, the severity of established disability is also increasing. In fact, untreated disability worsens and leads to debilitation and send negative messages to the community. We know how to negate, lessen or control disability but full application of this knowledge has not yet become a part of leprosy control programs or, if present, still it has a low priority fact, untreated disability worsens and leads to debilitation and send negative messages to the community. On the other hand a rehabilitated person is a force for positive behaviour. Early disability correction prevents debilitation. Correction of disability sends positive messages and together with transfer of information, education and counseling restore socioeconomic status. Surgery is aimed at optimum correction of deformity and disability and consists of reconstructive surgery, cosmetic surgery, ulcer surgery and salvage surgery. Very little evidence-based information is available on the impact of surgery in the rehabilitation of leprosy affected persons. LEPRO had sponsored one study on impact of surgery in Sonepur district of Orissa by National Institute of Social Sciences in 1998 wherein 140 individuals who had 226 operations between 1994 and 1997 were studied, in the majority of persons the income before disease, which was very much reduced during the disease and hospitalization, was regained after surgery. In others it was in the process of being regained. The acceptance by the community also increased after surgery. Before the disease non-acceptance by the family was more than by the community.

Uniterms: Rehabilitation, social, leprosy, surgery

INTRODUCTION

Leprosy as a social problem

Leprosy is a communicable disease caused by a mycobacteria (*Mycobacterium leprae*), which was identified in 1873 by Harnaer Hansen. It is one of the oldest diseases recognized as such by populations. An effective treatment was made available in 1940. However, the real cure of leprosy has been achieved with the introduction of multi- drug regimens as recommended by the World Health Organization in the late 1980. Although with marked features of a skin disease, leprosy is mainly a disease of the peripheral nerve system leading, if not early diagnosed and properly treated, to loss of sensation in the skin and muscular paralysis. The problems affect mainly the face, upper and lower limb. The consequence can be physical deformities and disablement and this is the reason why leprosy is considered a public health problem in endemic countries. Another serious consequence of deformity disabilities and disablement is the stigma that accompanies leprosy since biblical times and is still present in many communities in various grades.

The present position

Well-planned and intensive application of the multi-drug therapy has drastically reduced the prevalence and this knowledge is also reducing the social effects of this disease.

But, for the public, for the affected, and for the patient-oriented, Leprosy is not really cured as long as its morbidity due to disabilities', continues. The prevalence of disability is on the increase. Because of neglect, the severity of established disability is also increasing. We know how to negate, lessen or control disability. Full application of this knowledge has not yet become a part of anti-Leprosy programs, still it has a low priority. We need a planned approach and a higher priority for morbidity control and rehabilitation.

There have been definite advances. There is better understanding, planning and good publications. There are newer concepts of rehabilitation and recognition of the need of

¹MS-LEPRO — India, Pondicherry, India —27 Advocate
Chunnathambi street — Kurichikuppan — Pondicherry — 12 India
605012

²M.D. PhD - Instituto Lauro de Souza Lima — Caixa Postal 3021 —
CEP 17034-971 — fone: 014-2215900 — fax: 014-2215865 e-
[mail: mvirmond@ils.br](mailto:mvirmond@ils.br)

³The word disability used in this article includes deformity.

a separate and well-staffed socioeconomic rehabilitation departments. The prevention of disability by early detection is now accepted, but is likely to suffer because of the expected low priority after integration.

Lack of Information

There is an amazing and disturbing lack of information on disability its prevalence, severity, its consequences on the person's physical, psychological and socio-economic health and the impact of its treatment. This inadequacy reduces the efficiency of planning and budgeting.

The relationship between Disability and Rehabilitation

The image of leprosy in the community causes a reduction in the socioeconomic status of the affected and the family. The range varies in different regions from 6 to 25% (KOPPERTY, 1995; GOPAL, 1997). This effect is increased many folds, up to ten times by the presence of disability - 6 to 60% (KOPERTY, 1995) Untreated disability worsens and leads to debilitation and send negative messages to the community. Together with ignorance about the disease this is the main cause of stigma and isolation.

Early disability correction prevents debilitation. Correction of disability sends positive messages and together with transfer of information, education and counseling restore socioeconomic status. In this context, the slogan "Leprosy is curable" is then more acceptable. Unfortunately, this is not happening in a large extent

Main constraints for that are:

1. The sheer **size** of the problem, nearly 2 million cases of disabled due to leprosy in the world today, seems to daunt the leaders to attempt its solution.
2. There is a lack of Will and of firm Commitment, both at the management and field levels.
3. There is also a lack of information at most levels of management and of the concerned persons (affected, family, supporters.) The result of a lack of information is inadequate planning, and budgeting as also a low demand for disability control and treatment.

The Size of the Problem of Disability

The prevalence of established disability ranges from a low of 3.55% to 97% as reported by Srinivasan (2000). In 2001, in India, the prevalence of disability in Orissa was 14% of total cases, while in Raipur Block it was 25% (SANJEEV SHUKLA, 2002). In Urban area, a recent study of 1105 cases registered from 1993 to 1997 in Gwalior, India (SRIVASTAV, 2002), showed the prevalence of disabled to be 32%, of which 42% were women, and 70% of the disability cases were in persons above 40 years age. Only 20% of the

disabled were considered suitable for surgery.

The importance of physical rehabilitation

The physical rehabilitation of affected patients can be done by non-surgical and surgical methods.

All disabled can be functionally helped by non-surgical measures that compensate to a variable extent for the disability Surgery restores form and function in selected cases while in others it can improve function appredably.

Social Acceptance by family and Community

In a study reported by Gopal (1997), 79% of patients experienced rejection by family while 25% of these were without deformity.

Visible sign of the disease is a known trigger for negative Community behaviour. On the other hand a rehabilitated person is a force for positive behaviour.

Economic Instability

In 1991 Gopal reported that 35% of patients and their families face socioeconomic problems. This figure comes down to 22% after intensive work. In children and students correction of deformity is a method of preventive rehabilitation. The relationship between economic instability and social acceptance needs to be better investigated. Some statistics from Lepra India Projects in India, in 2001, shows that out of nearly 100,000 total recorded cases till December 2001 the deformity prevalence was 9.53%. Economic consequences were seen in 44% and psychosocial in only 9%. These figures show a trend, the actual prevalence varies from region to region and from time to time.

Socioeconomic Rehabilitation

Socioeconomic rehabilitation, through different interventions, helps to restore social status by enhancing motivation, giving information and training. In this regard, Community participation and financial help is essential.

Methods of Morbidity Control

The following methods of Morbidity Control have been found to give good results. This statement is either evidence based or subjective from the affected person's point of view.

1. Early detection and treatment of the disease diminishes deformity
2. Early detection and treatment of nerve involvement prevents deformity.
3. Established deformity can be corrected by surgery
4. Or can be compensated by non-surgical measures.
5. Transfer of information on how to use a limb — hand or foot — with loss of sensation involves special

techniques that are a part of physical therapy and health education in leprosy. This work in Leprosy has proved that Learning Techniques can indeed succeed in using an anaesthetic hand or foot without any injuries. This training is mandatory for all persons with sensory loss.

6. When the paralytic deformity is mobile, surgery restores form and function to an optimum. In case of fixed deformity, surgery can improve the function.
7. The non-surgical measures are physical therapy, splints, adaptive devices and use of protective, easily moldable, material. These measures improve function and prevent worsening of form and function.
8. Early detection and treatment of pre-ulcer conditions, like signs of inflammation, prevent ulceration due to internal injury and infections. Additional measures for long-term prevention are a change of life-style, walking with short steps, and use of proper footwear.
9. Early detection and treatment of ulcers, use of weight-relieving podiatric devices and appropriate footwear prevent recurrence of ulcer.
10. Ulcer Treatment The main principles are conversion of a complicated to a simple ulcer and treatment of a simple ulcer by protection at home.

If these are available methods, a question that arises is: Why are we not using or even planning to establish and use all these methods everywhere? May be that the task is too big, that they do not fit in our mind-set and in our today's concepts and priorities of leprosy work. However, we *must* accept *this challenge*.

Rehabilitation - recent advances.

The demand for rehabilitation services will increase as evidence accrues for their effectiveness. Today it is easy to argue for the provision of a well-organised, coordinated, multidisciplinary rehabilitation service based on a problem-oriented approach.

The general acceptance of the revised ICIDH, International Classification of Impairment, Disability and Handicap by the WHO is a great advance. The Classification (now called I.C.F. —International Classification of Function) is mainly conceptual and needs to be translated in practical terms. The advantages of this model, well described by Wade et al. (2000) are:

1. First there is a *change in emphasis* from the medically biased to the personal. The psychological, social, and physical context has been expanded. Some of the major terms have been changed to reflect the need for more neutral and subject oriented terminology: "disability" has now become "activity" and "handicap" has become "participation." This facilitates a change in the mind-set of all of us.

2. The model *promotes understanding and better analysis of patients' problems, and it encourages a more systematic analysis of rehabilitation interventions*. For example when there is loss of sensation in the sole of the foot, the loss of sensation and absence of feedback from the sole is the *cause*, the *problem* is the plantar ulceration caused by ignored injuries. The result is *reduced activity* and because of that *reduced participation by the person in his social activities*. The problem is over if the person does not get ulcers, even though the objective sensory tests do not show much sensory recovery. A partial recovery of sensation enough to allow the person to recognize the walking surfaces may not be recognizable by the usual sensory tests but by a texture recognition test and by the person's ability to recognize uneven walking surfaces while walking and avoid injuries. Thus the emphasis changes to the patient oriented, the function oriented from the medical orientation that is often unrelated to function. Another example is provided by some of the affected persons, under the care of one of the authors, who have some recovery of sensation in the median nerve either after medical or surgical intervention. Objectively there is hardly any recovery of temperature recognition. But the affected person is now free of thermal injuries and can discern warmth or cold when grasping (with the whole hand) a metal container containing cold or warm water. The function has improved, though not necessarily the medical objective assessment of sensory function. Again the analysis of problem and intervention is made here with a change of orientation from purely medical to the patient oriented, to the functional aspect.
3. It also brings structure and order to research. It is now accepted, particularly by the rehabilitation community that the field is as amenable to scientific researches as any other branch of medicine. In leprosy such research needs to be done urgently. Research focused on activity limitation (disability) requires special measurement tools and these have to be developed by operational research.
4. Finally, it has helped to define rehabilitation in terms of Structure, Process and Outcome. It also helps us to better argue the case for a modern rehabilitation system to be introduced in Leprosy

Let us now consider rehabilitation in the terms mentioned in the paragraph above.

The Structure: A rehabilitation service comprises a multidisciplinary team of people who work together towards common goals for each patient; involve and educate the patient

and family and supporters and have relevant knowledge and skills to resolve most of the common problems faced by their patients.

The Process: Rehabilitation is a reiterative, proactive, educational, participatory, problem-solving process focused on all aspects of disability, with the following components:

The assessment and identification of the nature and extent of the patient's problems and the factors relevant to their resolution.

Goal setting Interventions, which may include either or both of (a) treatments, which affect the process of change; and (b) support, which maintains the patient's quality of life and safety

Evaluation to check on the effects of any interventions.

The Outcome: The rehabilitation process aims to: maximise the participation of the patient in his or her social setting; minimise the pain and distress experienced by the patient and; minimise the distress of and stress on the patient's family and those who care.

Rehabilitation, however, is a complex process. It is difficult to define the specific nature of interventions and to isolate their effects from other influences. When outcome is measured at the participation (handicap) level, influences such as employment status, social relationships, and housing need consideration. As mentioned above, the required measurement tools have to be developed by operational research.

Surgery

Surgery is aimed at optimum correction of deformity and disability and consists of:

- *Reconstructive Surgery* to correct the deformity and restore function in a paralysed hand, foot, or the eyelid.
- *Cosmetic Surgery* to correct ugliness, e.g. that caused by loss of eyebrows, deformed nose and ears.
- *Ulcer Surgery*: is aimed at conversion of a complicated to a simple ulcer by eradicating deep-seated infective focus, and then providing skin cover by grafts or flaps.
- *Salvage Surgery*, to stabilize and/ or salvage whatever function one can.

Reconstructive Surgery is mainly by tendon transfers and requires for its success:

A suitable patient, a deformity that is mobile and not fixed, and the availability of an excellent experienced Surgical team.

The Surgical team consists of a well-trained surgeon, physical therapist and a rehabilitation expert together with an excellent infrastructure. Good selection at every level is essential.

The suitable patient is one who is:

- Well motivated, and below 40 years of age,
- Likely to take good care of his hand or foot with sensory loss,
- Has time — about 3 months off from work and
- Ready to go to the special referral center
- Restriction of activity and life-long care of the parts with sensory loss is mandatory to retain the benefits of surgery.

Cosmetic Surgery can be done by any plastic surgeon.

Support by a leprologist is essential.

Ulcer surgery has got to be preceded and followed by instructions on how to prevent recurrence and the provision of appropriate podiatric devices and footwear.

This surgery can be done anywhere, requires minimal training and consists mainly of removal of a septic focus and providing good skin cover.

Salvage Surgery is mainly orthopedic surgery to stabilize joints of a badly deformed foot or a hand and consists of different kinds of joint surgeries and remodeling.

Establishment and continuation of referral centers for the above activities is absolutely essential and is the responsibility of both, the national health authorities and voluntary organizations. Surgery will remain an action with requirements that strict public health concepts cannot guarantee (VIRMOND, 2002). Specialized centers are a must. Surgeons can be visiting but not the centers.

In this regard, we can mention the Brazilian approach, by the Instituto Lauro de Souza Lima, in Bauru, of facilitating the establishment of 20 independent centers of surgical excellence functioning in institutions ranging from huge Universities to district hospitals in Brazil, a wonderful achievement is one solution (DUERKSEN et al., 1999)

The impact of surgery

Very little evidence-based information is available on the impact of surgery in the rehabilitation of leprosy affected persons. LEPRO had sponsored one study on impact of surgery in Sonepur district of Orissa by National Institute of Social Sciences in 1998 wherein 140 individuals who had 226 operations between 1994 and 1997 were studied. Some of the important findings are:

- Surgery was subjectively considered successful in 132 out of 140 persons.

- Economic condition before disease showed that out of 140, 9 were unemployed. - In 90 cases the person's income was used for the whole family while 41 persons used the income only for themselves.

- There was some economic loss due to hospitalization in

all cases, significant in 95 cases, i.e. in 68%. It was well compensated by other family members in 25, while it was substantial in 70 cases. This is an important finding explaining why many cases refuse surgery (Table 1).

Table 1 shows also that in the majority of persons the income before disease, which was very much reduced during

Table 1 - Income Profile (in Indian Rupee Currency) after surgery as compared to that before disease.

Income level	Before disease	After surgery
Not earning	9	9
< 100/month	29	30
101- 1000	84	89
1001 - >5000	18	12

the disease and hospitalization, was regained after surgery In others it was in the process of being regained.

The acceptance by the community also increased after surgery Before the disease non-acceptance by the family was

more than by the community. A recent study, in Lepira India direct projects in 2001, shows even better acceptance by the community and family because of good programs of deformity correction and rehabilitation (Tables 2 and 3).

Table 2 - Acceptance by the community

Level of acceptance	Before disease		After surgery	
	Nº	%	Nº	%
Accepted	95	67,9	116	82,9
Not accepted	45	32,1	24	17,1
Total	140	100	140	100

Table 3 - Acceptance by the family.

Level of acceptance	Before disease		After surgery	
	Nº	%	Nº	%
Accepted	52	37,3	115	82,1
Not accepted	88	62,7	25	17,9
Total	140	100	140	100

What is needed today is a participatory approach by all of us, from that of a giver to that of a helper. Better-planned and funded socioeconomic rehabilitation programs have to be established by voluntary organizations and the community. More operational research is required in various aspects of deformity correction and rehabilitation and this would facilitate better planning and funding.

We also need to give higher priority to well planned

information collection, evaluation, and Participatory Action Research.

The work being done, by different agencies like ILEP and Institutes such as at Bauru in Brazil, in these fields of deformity correction and rehabilitation must be continued and increased and not reduced.

At this point in time it would be appropriate to quote the fears, I hope that it is not a forecast, expressed by Dr. Brand a few years ago (VIRMOND, 1998): "The *greatest danger now is that we, who previously did nothing because we thought nothing*

could be done, will now do nothing because the little we can do seems so small compared with the size of the problem."

We are optimistic and we hope that those who matter will see Light and act, soon.

REFERENCES

- 1 DUERKSEN,E; OPROMOLLA,D.VA; VIRMOND,M.; GARBINO,J.; Teaching and training for surgical rehabilitation in hanseniasis; result of 20 years of activities of the Instituto Lauro de Souza Lima in South America. *Hansen.Int.* v.24, n.1, p.55-60, 1999.
- 2 CORAL, PK. Methods to identify the leprosy patients needing rehabilitation. Paper presented at GOI — WHO Workshop on identifying and assessing the magnitude of the problem of Leprosy patients requiring rehabilitation." At Tirupathy, India 3-5 March 1997. *Índia J.Leprosy*, v.69 n.4, p.438-43, 1997.
- 3 COPAL. PK "Training and placement of leprosy cured persons through rehabilitation." *Dimensions of Leprosy eradication.* Published by Regional Secretariat for India G.L.R.A. AND L.R.VV. Emmaus-Switzerland, pp77-85, 1991.
- 4 KOPPARTY, S.N.M.; KURUP AM.; SIVARAM, M.A Problems and coping strategies of families having patients with and without deformity *Indian J.Leprosy*, v.67, n.2, p.133-152, 1995.
- 5 SANJEEVA, S.; SHARMA, S.K.; SHARMA,; VD. Efficacious efforts for prevention of disability in leprosy in Raipur (K) Block in Reva District. *Indian J.Leprosy*, v. 74, 82, 2002.
- 6 SRINIVASAN, H. Disability and rehabilitation in leprosy: issues and allenges. *Indian J.Leprosy*, v.72, n.3, p.317-337, 2000.
- 7 SRIVASTAVA, AP; MISHRA,A.; SINGHAL, S.; Disability prevention process in Urban Gwalior. *Indian J.Leprosy*, v.74, p.78, 2002.
- 8 VIRMOND, M. Prevention and management of Disability Workshop reports and summaries. *Leprosy Congress, Beijing Annals of the .XVth.* p:31-35, 1998.
- 9 VIRMOND, M; PEREIRA, H. da R. Surgical correction of deformities and disabilities in leprosy patients. *Indian J.Leprosy*, v.72, n.3, p. 401-412, 2000.
- 10 WADE, D.T.; de JONG, D.A. Recent advances in rehabilitation. *British Medical Journal* , v.320, n.7246, p.1385-1388, 2000.