COMMUNITY BASED AND INTEGRATED REHABILITATION OF LEPROSY PATIENTS

GANAPATI R.*, ATUL SHAH**, NEELA SHAH***, KINGSLEY S.**** AND MITTAL B.N.*****

Currently the term "Community Based Rehabilitation" (CBR) of the handicapped persons is used more frequently. If the WHO definition is interpreted properly, it will be clear that the terminology implies that any attempt at rehabilitation should indeed be a community based one, and the patient needing any form of support should not be placed in an "artificial" situation exclusively meant for any particular disease or disability receiving help by way of charity. Moreover, treatment of physical disability is a definite prerequisite.

The phenomenon over the years has created a situation in which it has become very difficult to think of "integrated rehabilitation", which even in the case of the handicapped, as practised in general is not truly integrated. "Community based and integrated rehabilitation", therefore, when applied to the field of leprosy seems indeed a distant dream. However, it must be stated that some noteworthy attempts in this direction are now being made particularly in the Indian context.

The authors present one such attempt which stems out of the assumptions which we have made as a result of our observations over the years.

ASSUMPTIONS :

1. 'Stigma' peculiar to leprosy militates against true rehabilitation concept and arises because of deep rooted belief that the disease causes the deformities. The need for leprosy rehabilitation to a large extent therefore arises as a result of neglected care of disabilities at various stages for which an effective technology is not yet available.
2. Care of the disabled leprosy patients especially in rural areas is virtually non-existent as a field based programme because whatever technology available is institution or hospital based.
3. If at all any care is available to a few patients at the community, it reaches them only in a patchy manner, through some voluntary organizations and not by the government sector which dominates about 80% of the National Leprosy Eradication Programme (NLEP).
4. Attempts at integration are not made particularly by voluntary organizations in offering rehabilitation services even in areas where there is a scope for such integrated services.

STUDIES BASED ON ASSUMPTIONS :

Keeping in view the above assumptions, we studied the problem of rehabilitation mainly with reference to hand disabilities in leprosy. This is because, as compared to lower limb deformities, hand disabilities form a major handicap and seriously affect the patient's performance in domestic and occupational situations. The following is an account of how the above assumptions were studied under field conditions.

ASSUMPTION NO. 1 :

Care of the hands and protection from injuries resulting from the sensory changes is relatively easy to communicate to the patient and manage. However, motor disabilities which lead to visible damage are more difficult to manage. The technology which we evolved, after years of

* Director, Bombay Leprosy Project, 11, V.N. Purav Marg, Sion-Chunabhatti, Bombay-22.
** Director, Comprehensive Leprosy Care Project, Ciba Compound, Diana Cinema Lane, Tardeo, Bombay-34.
*** Research Assistant, Department of Plastic Surgery, J.J. Hospital, Byculla, Bombay.
**** Physiotherapy Technician, Bombay Leprosy Project.
***** Dy. Director General of Health Services (leprosy), Ministry of Health, Govt. of India, New Delhi.

Table 1 : Physical Aids in relation to hand disability.

	Disability		Technology
1.	Inability to adduct little finger.	:	Adductor Band*
2.	Mobile claw hand	:	Finger loop Splint*/Gutter splint*
3.	Claw hand with contractures but no bony block.	:	Gutter Splint*
4.	Adduction deformity of the thumb ('Ape' thumb deformity)	:	Opponenns Splint*
5.	Operable hand deformity	:	Camp-Surgery**
6.	Inoperable fixed contractures of fingers & mutilated hand.	:	Grip Aid +

*Atul Shah et al (1988), Atul Shah (1991, 1992), **Atul Shah (1983), + Ganapati et al (1983), + Yawalkar et al (1992).
The above adaptations were extensively field tested in urban slums before extension to rural situations. (Ganapati and Kingsley, 1991).

experimentation in relation to each type of motor disability is shown in table No. 1.

ASSUMPTION NO. 2 :

As the services should necessarily be field-based, operational research was undertaken in a Taluka in Gujarat consisting of about 785 leprosy patients with 408 deformed patients (Atul Shah & Ganapati, 1992) and extended to two districts in Andhra Pradesh where deformed population alone was to the tune of over 3000. The field programme is also now implemented in the whole of Goa state.

The following shows the magnitude of the problem of leprosy handicap in some of the areas where disability care services are offered through projects operating under the advice of the authors.

Till May 1993, (1) 908 articles used for the activities of daily living such as spoon, tumbler, mug, tooth brush, razor, comb and walking stick, (2) 89 handles of tools and instruments like sickle, hammer, planer, scissors, knife, painting brush, pick axe, pocker, screw driver, spanner, 'Ambar' charka, tri-cycle, patter, farsan and soldering iron used for various occupations, and (3) 15 utensils

Table No. 2 : Magnitude of disability problem.

Sr. No.	Area	Population	No. of regd lep. cases	No. of def. lep. cases	% among pop.	% among lep. pts.
1.	Borsad (Gujarat)	3,71,170	932	408	0.50	21.1
2.	Prakasam (AP)	23,29,571	18,789	702	0.07	9.0
3.	Kurrnool (AP)	29,73,709	28,484	1,496	0.05	5.2
4.	Goa	11,68,622	5,246	185	0.01	3.5

ASSUMPTION NO. 3 :

It was essential to operate the programme at the community level through the vast government staff comprising of para medical auxiliaries, supervisors, physiotherapy technicians, medical officers and District Leprosy Officers. An intensive training based on the above novel technology to all categories of staff was undertaken through field visits and demonstrations.

Table 3 : Training of Personnel.

Sr. No.	Area	Designation	No. of trainees
1.	Bombay City	—Medical Officer	7
		—Non Medical Supervisor	8
		—Para Medical Worker	36
		—Physiotherapy Technician.	10
2.	Borsad Taluka, Gujarat	—Leprosy Supervisor	2
		—Leprosy Assistant.	7
3.	Prakasam District Andhra Pradesh	—Medical Officer	5
		—Non Medical Supervisor	24
		—Non Medical Assistant	111
		—Physiotherapy Technician	5
		—Health Educator.	2
4.	Kurnool District Andhra Pradesh	—Medical Officer	7
		—Non Medical Supervisor	23
		—Para Medical Worker	118
		—Physiotherapy Technician	4
		—Health Educator.	2
5.	Goa State	—Non Medical Supervisor	4
		—Paramedical Worker.	25

The resultant gain in knowledge led them to take keen interest in disability care, thereby change the overall pattern of leprosy care from mere drug delivery to one of disability care delivery along with drugs, thereby increasing the scope of community based rehabilitation.

The following tables show the result of usage of the above adaptations as administered essentially by the government employees.

Table No. 4 : Centres selected for prefabricated standardised splints.

Sr. No.	Centres		No. of Patients
1.	Bombay City & Suburban Slums	:	948
2.	Borsad Taluka, Gujarat	:	99
3.	Baroda District, Gujarat	:	16
4.	Raipur District, Madhya Pradesh	:	140
5.	Prakasam District, Andhra Pradesh	:	698
6.	Kurnool District, Andhra Pradesh	:	954
7.	Goa State	:	20
Total No. of patients provided splints		:	2875

Table No. 5 : Follow-up and results.

No. of patients provided splints	:			2875	
No. of patients followed up	:			2016 (70%)	
No. of patients reporting improvement	:			1175 (88%)	
Usage	No. of patients	%	Improvement	No. of patients	%
Regular	945	47	Marked	420	21
Irregular	705	35	Moderate	585	29
Not using	190	9	Minimum	648	32
Lost	176	9	Nil	363	18

Table No. 6 : Grip aids* provided to leprosy patients :

Sr. No.	Centres		No. of Patients	No. of Grip-aids
1.	Bombay city & Suburban slums	:	84	180
2.	Borsad Taluka, Gujarat	:	49	83
3.	Prakasam District, Andhra Pradesh	:	248	377
4.	Kurnool District, Andhra Pradesh	:	198	250
5.	Goa State	:	11	27
6.	Leprosy Hospitals & organized colonies	:	64	95
	TOTAL	:	654	1012

(* Grip aids made from Modulan (R) epoxyresin-Ciba-Geigy).

used for cooking purposes out of which 7 utensils heat insulated were made as grip aids.

Assessment showed that 407 (75%) patients found grip-aids useful in their day to day activities.

CAMP SURGERY was undertaken wherever possible. This technique, which is again not in vouge in general consists of a reconstructive surgery team operating in a district at Taluk level hospital, with the aim of increasing the coverage of surgical operations.

Approximately 100 operations have been performed at various hospitals. The transfer of this technology is the slowest as its application is multifactorial. The greatest advantage was to make the service organisations like Lions, Rotary etc. to get interested in the care of leprosy afflicted and in many instances camps were supported by them.

It must be stressed that splintage at the earlier stages had obviated the need for reconstructive surgery in many cases.

CONCLUSION :

The authors firmly believe that as far as leprosy is concerned community based disability care is the first step to community based rehabilitation. If the community is to accept leprosy patients without reservations and help rehabilitation of leprosy patients within itself, the

ASSUMTPTION NO. 4

Rehabilitation of leprosy patients is still practised by voluntary organizations functioning in an institutional setup. Some of these are supported by international agencies which have still not adopted an integrated approach to training and rehabilitation. The establishment of Leprosy Rehabilitation Promotion Units of the Government of India is also institution based, and community based rehabilitation, especially in the field of leprosy is interpreted by individual organisations in their own way and may not be necessarily community based.

Attempts at integrated rehabilitation confined to Bombay, (see map) an urban or super urban situation have led to the development of a model which is ready for adoption to any comparable situations. Non-leprosy institutions (Table No. 7) offering general rehabilitation services to handicapped patients living in slums have now included leprosy rehabilitation as part of their service programme. In an urban areas, these virtually are places where patients from slums make first contact for care of deformities and rehabilitation

Table No. 7

Sr. No.	Institution	Govt./NGO	Services offered	No. of beneficiaries
1.	Vocational Rehab. Centre	Govt.	– Vocational training in electronics, typewriting, fitter and motor mechanic	6
			– Job placement following vocational training.	107
2.	Naseoh India	NGO	– Vocational training in carpentry and cycle repairing.	9
			– MCR foot wear	45
3.	3 R society	NGO	– Employment in sheltered workshop	2
4.	Fellowship of physically handicapped	NGO	– Economic assistance & telephone booth	3
5.	Adams Wylie Memorial Hosp. (Indian Red Cross Society)	NGO	– Vocational traianing in Soap making	33
6.	Shramik Vidyapeeth	Govt.	– Vocational training in tailoring & screen printing	97
7.	All India Institute of Physical Medicine & Rehabilitation	Govt.	– Aids, appliances, prosthesis, moulded footwear and disability certificate	72
8.	J.J. Hospital	Govt.	– MCR footwear	6715
			– Reconstructive Surgery	306

various components of the community, consisting of the leprosy patient, his own fellow patients, his family, and the neighbours will first have to be convinced that disability care is indeed practised by the health programme at the door step of patient, just as drugs are distributed at their doorstep. Splintage and grip aids could be dispensed at the door- step by any leprosy worker. We have dovetailed the disability care into the ongoing MDT programme and found that community acceptance of comprehensive leprosy care is quite high in rural areas (Independent

Evaluation Team NLEP 1991).

The above unprecedented experiment in diability care which is community based and operated through the existing government workers who are already offering treatment to leprosy patients at the field level has demonstrated its usefulness and with little more effort even the community may learn to take care of disability by itself.

The present experiment is carried out through leprosy workers of NLEP. If such community based effort has to be integrated with general health care services, the multi purpose worker (MPW) has to dispense these aids. Since the technology is quite simple we visualize that MPWs can perform this task and that training can be imparted to any MPW, provided the large army of MPWs can be made available for systematic training.

ACKNOWLEDGEMENT :

The authros thank Ciba Geigy Leprosy Fund, Hindustan Ciba-Geigy, NORAD, German Leprosy Releif Association and LEPRA for the financial assistance provided for various facets of research. The Govt. officials of Gujarat, A.P. as well as staff extended wholehearted cooperation in this research to whom we are thankful.

Secretarial assistance provided by Mr. K. Sreedharan, Mr. P. Radhakrishnan and Ms. S. Sujana is gratefully acknowledged.

REFERENCES :

1. Atul Shah, Physiotherapy & Surgery, Ch. 21 & 22, Leprosy a Concise text by Dr. K.K. Koticha, Published by D.K. Koticha, Bombay, 1991.
2. Atul Shah, Review of Reconstructive Surgery Camp in Leprosy. Kusht Vinashak, 1992.
3. Atul Shah, "Prevention and Correction of Claw Hand by splintage – A new approach to Deformity Care", Training & Education Series No. 1, Comprehensive Leprosy Care Project, Ciba- Geigy, Bombay, 1992.
4. Atul Shah and Ganapati R. "Comprehensive Leprosy Care Project – A New Approach"; paper presented at XVII Biennial Conference of Indian Association of Leprologists, Durg Bhilai., 1992.
5. Atul Shah, N. Bhagat, R. Ganapati. "A study on the use of Standardised prefabricated splints for prevention & correction of hand deformities in leprosy", XIIIth International Leprosy Congress, The Hague, Netherlands, 1988.
6. Fourth Independent Evaluation Report – NLEP (1991) : P. 38, 1988.
7. Ganapati R., Don Caston, Rego D.J., Bodkhe L.D. and Kulkarni D.R. "Epoxy Resin Mouldings as Aids for Leprosy patients with Deformities"; Journal of Rehabilitation in Asia; 19-25, 1983.
8. Ganapati R., Kingsley S.; "Simple Field Technique for Care of Hands on Leprosy"; paper presented at the Annual Conference of Indian Association of Physical Medicine and Rehabilitation, New Delhi, 1991.
9. World Health Organisation. Technical Report Series No. 221, 1960.
10. Yamalkar S.J., Atul Shah, Ganapati R., Bin Y.L., Guo-Chen Z., Hong C., Kennet W., and Werner O.,; "Modulan Grip-aids for Leprosy patients"; Int. J. Lepr, 60, 2; p 250-254, 1992.