

Providing comprehensive leprosy care – The Indian approach



India is one of the few remaining countries with high numbers of new leprosy cases, accounting for nearly 60 percent of all new cases registered worldwide. Disabilities remain the most important factor for social stigmatization of the disease. By far the best way to prevent these is through early detection of patients and treatment with MDT. However, there remain large numbers of disabled people dating back to the pre-MDT period or due to delays in starting treatment or improper management of leprosy reactions. Depending on the nature of the disability, these can be corrected or cared for and prevented from worsening, but the requirement is substantial, as each disabled person may have more than one deformity and may need multiple services.

Thinking longer term

In 1989, the Novartis Foundation for Sustainable Development set up the Comprehensive Leprosy Care Project (CLCP) in India. Its aim was to provide integrated leprosy care, including improved access to MDT treatment, field-based disability care services, and reconstructive surgery and rehabilitation, where required. In addition, the social and economic (re-)integration of patients into their communities was an important objective. In 1994, this project led to the establishment of a nonprofit organization, the Comprehensive Leprosy Care Project & Medical Aid Association, which in 2005 was renamed the Novartis Comprehensive Leprosy Care Association (NCLCA). It is housed in offices belonging to Novartis India Limited.

Learning and healing

Although most disabilities can be avoided through preventive care or subsequently corrected, all too often there are insufficient resources for this. NCLCA started collecting data and information on leprosy patients, compiling experience and developing

pioneering techniques, products, and procedures for the integrated treatment of leprosy patients for little cost. These include simple care procedures that can be provided through the existing network of general health workers at village level. Innovatively, NCLCA has placed increasing emphasis on training personnel in the field – often in disability care camps – as a natural way of increasing outreach while at the same time providing hands-on experience and on-the-job training for health practitioners. For example, in 2006 about 150 participants, including 20 surgeons, were trained at the camps and at a reconstructive surgery workshop held at the Plastic Surgery Department of the Sir J. J. Group of Hospitals.



For patients with irreversible deformities, reconstructive surgery is often the only realistic option. The reconstructive surgery camp and workshop approach has proved beneficial to both patients and surgeons undergoing training. It enables large numbers of patients to receive operations, while offering excellent training opportunities for health care personnel. For example, health workers learn about the criteria for selection or referral for surgery, and physiotherapists learn about pre- and post-operative exercises, plaster casts, and splint applications. The program has proved to be such a success that it was dubbed the “Gujarat Model” by the Government of India, and other states were asked to use it as the basis for improving patients’ access to surgery.

Among the broad range of activities undertaken by NCLCA, all are conceived as part of a wider, more comprehensive approach to leprosy treatment and rehabilitation.

These include:

- Offering health education to patients with insensitive limbs to prevent injury, burns, wounds, and ulcers
- Teaching patients important physiotherapy exercises for each deformity to prevent its worsening and consequent secondary disabilities
- Providing physical aids like prefabricated hand and foot splints that not only help correct the disability but can also be used as an adjunct to pre-and post-operative regimens
- Providing made-to-measure Modulan® gripaids to enable people with advanced, inoperable hand deformities to carry out daily tasks without assistance; prefabricated grip-aids that fit all disabled hands and can be fitted to multiple articles such as a tooth-brush or comb are also being deployed
- Enabling patients to heal foot wounds and ulcers with a specially designed self-care kit
- Providing special footwear made with micro-cellular rubber in attractive designs to eliminate the stigma of wearing single design footwear, which can easily identify the user as being affected by leprosy
- Providing reconstructive surgery for functional improvement, which also leads to increased social acceptance of patients due to the correction of visible disabilities
- Providing economic rehabilitation through provision of equipment and articles for income generation, thereby enhancing self-esteem and social well-being

Over the years, NCLCA has developed a systematic approach to disability care. The starting point is the collection of standardized information on the overall disabled patient load in the area and careful analysis of information in order to set priorities, plan interventions, train staff, and provide the necessary materials and services. The patient data and photographic documentation allow close monitoring of individual patients’ progress as well as clearer project oversight and management. Once disability care services have been provided to most patients in an

area and integrated into the local health service, the NCLCA turns its attention to another region. The disability care component was extended from a small area to four low-endemic districts and finally five high-endemic districts in a phased manner in Gujarat and also to a rural area district in Maharashtra, in collaboration with the state government. In this way, more than 18,000 patients have benefited from these services, and many of the innovative modalities have been adopted by the government and nongovernmental organizations (NGOs) working in the field of leprosy as an integral part of disability care services. As a result of its success with leprosy patients, NCLCA now also provides integrated care to non-leprosy cases.



Providing comprehensive care

NCLCA began its operations in the state of Gujarat, later extending its services to Goa, Maharashtra, and, by collaboration with NGOs, to the rest of India. NCLCA has also supported other NGOs like the missionary sisters of Canossa Convent, who care for leprosy-disabled patients in their clinic; the Missionaries of Charity (Mother Teresa), who offer treatment to patients through their 18 leprosy centers; and Ramakrishna Mission in Chennai. It has also held camps for plastic surgical correction of non-leprosy deformities, with an overwhelmingly positive response.

Education and empowerment

Lack of sensation in the hands is common in leprosy sufferers. Patients must be educated on how to cope with this residual disability in order to avoid burns or other limb injuries and the development of ulcers. The injuries that do occur must be properly treated. NCLCA not only provides for the training of health care staff, it has also developed an empowerment approach for patients, using leaflets, instructions, and practical demonstrations through camps. Teaching simple exercises to keep the joints mobile and providing prefabricated splints and other materials is done at the time of counseling.

The NCLCA self-care empowerment camps teach patients the hows and whys of self-care. The Association has developed a special self-care kit, containing sterile gauze pieces, scissors, sticking plaster, foot scraper, bandages, antiseptic cream, and a moisturizing cream. These are produced locally by the Anti-Leprosy Campaign, making it easier for replacements to be supplied so that patients can continue to take care of their feet. Follow-up clinics held after two months have indicated good compliance with the self-care instructions: nearly 40 percent of cases had healed thanks to use of the kit, while the rest showed dramatic improvement. Once patients and their families are convinced that self-care is effective, it becomes second nature. The self-care kit now forms part of the Prevention of Disability guidelines issued by the Government of India. Other organizations, too, have adopted its principles and are making their own kits with similar materials.

Income generation

As a natural follow-up to its disability care work, NCLCA has also provided eligible patients with tools and equipment, together with vocational training, to help them to earn an income. Priority is given to those who have had reconstructive surgery and those most in need. The most common articles provided include hand carts, sewing machines, carpentry and masonry kits, agricultural tools, and vehicle repair tools. This holistic approach has had encouraging results, for as well as

assisting in their rehabilitation, disabled leprosy patients have been able to pursue occupations that not only earn them an income, but change their standing in the community. It has proved to be a low-cost, high-gain sustainable development scheme. Since 2003, the services have been extended to include other groups of disabled people.

Exporting the expertise

India's comprehensive leprosy care model has also been adopted in Sri Lanka. Hundreds of patients were examined and advised by visiting NFSD consultants. Reconstructive surgery was initiated a few years ago and is gradually being extended to district level through the training of interested orthopedic and general surgeons. On-the-job training of physiotherapists, clinical case studies with dermatologists, group therapy for empowerment, and discussions during consultants' visits have all facilitated bringing leprosy disability care into the mainstream.

Similarly, NFSD has also helped other countries like Mexico and Tanzania to understand the importance of caring for the leprosy-disabled with simple, cost-effective strategies like those employed by NCLCA. The experience so far indicates that, with commitment and innovative thinking, leprosy disability services can be brought effectively into mainstream health care to the benefit of all.

Impact of the comprehensive care program

In India, NCLCA has been able to pioneer a system of prevention, correction, care, and rehabilitation based on simple modalities, which can be mastered by general health care staff. Since its inception, NCLCA has believed in integrating disability care into mainstream health services. The adoption of its modalities by other agencies and their incorporation into medical and health services has been an undisputed success. At Borsad Taluka, NCLCA's first project area, leprosy elimination has been achieved. And in Goa, where the organization was active from 1993 to 2000, the leprosy prevalence rate has come down, paving the way for eventual elimination. By supporting early

new-case detection, improving access to MDT, and training health and medical staff in reaction management, NCLCA has contributed significantly to the prevention of disabilities.

Training surgeons in reconstructive surgery, conducting camps and workshops, devising simple techniques, and transferring technology have all served to bring treatment closer to the leprosy-disabled and accelerated their integration into general health care services. This has benefited thousands of people who otherwise would have developed inoperable deformities with consequent handicaps.

Finally, the focus on income generation and moral support for economic rehabilitation has transformed the lives of many of the poorest of the poor affected by leprosy, and their resulting ability to earn and support themselves has brought about better social acceptance and integration. In recognition of its efforts, the Novartis Comprehensive Leprosy Care Association was awarded the prestigious Golden Peacock Award for Innovative Products/Services by the Institute of Directors, India.

To ensure that the benefits of the NCLCA model are spread, the scope of the program has been extended. Brochures will be updated and reprinted and continued efforts will be invested in rolling out the comprehensive care programs, reconstructive surgery workshops, rehabilitation, and economic regeneration activities. A particular focus will be examination of the child case load, with a view to identifying high-risk cases and promoting early intervention to avoid development of deformities. NCLCA's work is far from over, but its efforts have ensured that – thanks to comprehensive care – leprosy in India is no longer a life sentence.

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