Plenary / Split Plenary Sessions

S-1 : Achievement in Leprosy Elimination and Future Leprosy Work - Global & National Perspectives (Symposium)

L-16
Achievement in Leprosy Elimination and Future Leprosy Programme – India’s Perspective
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The National Leprosy Eradication Programme has seen many achievements during the last decade which saw the programme reached elimination of leprosy as a Public Health Problem at the national level. This achievement was possible due to proper planning and hard work by all involved in the programme with strong political commitments, infrastructural facilities and availability of adequate resources. The national programme received valuable support while working together with the partners like WHO, ILEP, Nippon Foundation, Novartis, National NGOs and others. During this period the leprosy services were integrated with the General Health Care system. NLEP is still a centrally sponsored program and is a component of public health services under the over all umbrella coverage of National Rural Health Mission. During the 11th Five year plan period referral services are being strengthened by involving PMR departments of medical colleges. Opportunities of village health & sanitation committee and Rogi Kalyan Samiti, under NRHM are being utilized. Quality of services has been given higher emphasis under the new paradigms and monitoring & supervision has been streamlined. New case detection rate and the Treatment Completion Rates are the main epidemiological indicators. Inter & intra departmental coordination and inter – ministerial links and periodic review meetings with state program officers helped in solving many problems. Decentralized district plans, flexi funds and logical approach will further help in steering the program in right direction.

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L-18
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L-19
Achievements of Leprosy Elimination and Future Leprosy Work : Global and National Perspectives
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The introduction of MDT in 1982 followed by the progressive implementation of short, fixed duration chemotherapy gradually reduced the numbers of leprosy patients registered for treatment. The World Health Assembly Resolution of 1991 accelerated this decline through an intensified elimination strategy. Important components of this strategy were simplified diagnosis and classification, and improved delivery and access to a high quality drug supply free at the point of delivery. However many components of this intensified strategy while successfully attaining the 2000 elimination target were unsustainable. The ‘final push’ strategy continued the momentum in a number of countries but a new, sustainable strategy was needed to maintain the elimination achievements, sustain access to quality leprosy services, and further reduce the burden of leprosy. We are now in a new era, more than 7 years on from elimination. The successes of elimination are in danger of leading to complacency and the evidence at various levels indicates we are failing to deliver sustained, accessible and quality services for leprosy patients. While we can celebrate the achievements of the last century, we need to wake up to the realities of the 21st Century otherwise we are in danger of witnessing the reversal of everything that has been achieved. The WHO strategy 2006 – 2010 sets out a new strategy fit for purpose – a strategy that emphasises quality and accessible services at a local and a referral level, human rights and participation by those affected and their communities, and tackles both the physical and the social consequences of disease. Quality leprosy services are defined as those accessible to all who need them with high coverage and no geographical,
economic or gender barriers. Quality services need to be patient-centred and observe patients’ rights, including rights to timely and appropriate treatment, and to privacy and confidentiality. The services need to be evidence based and include each aspect of case management – diagnosis, treatment, management of reactions, prevention of disability, referral for complications and rehabilitation as well as skill transfer for self-care. The challenge is now the implementation of that strategy – operational guidelines have now been produced and a training programme for national programme managers is now being rolled out so that programme managers, WHO, JLEP and those affected by leprosy, can work together to further reduce the leprosy burden at local, national and global levels.

Achievements of Leprosy Elimination and Future Leprosy Work: Global and National Perspectives: Presentation by Nippon Foundation

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The Nippon Foundation (TNF) previously known as JSIF started its involvement in global leprosy programme in 1974, because of its founder and the first President, Mr. Ryozo Sasakawa, had a deep concern over the welfare of leprosy patients because of his own personal experience as a child. On his 75th birthday, he decided to make contributions to the leprosy problems, more systematic by utilizing his personal as well as JSIF’s huge fund through two channels, one through the Leprosy Unit of WHO HQ in Geneva, and the other through newly established Sasakawa Memorial Health Foundation (SMHF) in Tokyo and these contributions by TNF which amounted to more than US$300 million over the past 32 years, is likely to continue further, under the current President, Mr. Yohei Sasakawa, who is the WHO’s Goodwill Ambassador for Leprosy Elimination, as well as Japanese Government’s Goodwill Ambassador for the Human Rights of Leprosy Affected People. This arrangement of utilizing two channels prove to be an excellent set up. WHO has ready and direct contacts with the health authorities of leprosy endemic countries in the world. WHO could advice on or even direct national leprosy control of these countries. However by being a huge international bureaucracy, WHO is bound by many official protocols, past precedents, and its action could be slow and non flexible. SMHF on the other hands, being a newly created small NGO, did not have ready access to the health authorities of a country. But its actions could be both quick and flexible, so that it could meet the existing needs of drugs, equipments, training material and others much more readily country by country. Thus using these two channels TNF’s fund has been utilized quite effectively, significantly influencing the global leprosy scene toward the “Leprosy Elimination, as a Public Health Problem”. WHO’s original goal set by the 44th WHA in 1991 is almost achieved now. Original Contribution to WHO for leprosy was US$ 1 million a year, however once WHO’s recommendation for MDT was published in April 1982, there arose a necessity for fund to purchase drugs as well as to train field workers, so the TNF’s contribution to WHO was increased to US$ 4 million annually and that level was maintained until recently. Another important contribution was US$ 50 million over the 5 year period to WHO Drug Fund, so that every leprosy patients could get MDT free of charge from 1995–1999. With expansion of MDT rather slowly in ‘80s but much more rapidly to cover all existing leprosy cases once 44th WHA Resolutions were put into effect throughout the world, global leprosy scene changed dramatically as we can see now, which could not have been even imagined in ‘80s when MDT started. SMHF as a NGO has quite a unique policy among leprosy NGOs, to give its support primarily to the national leprosy programme of the central government, and not to have its own programme, and this made SMHF acceptable to leprosy endemic countries as well as to WHO. SMHF from its beginning in 1974, had a strong interest in the Chemotherapy of Leprosy. More specifically on how to stop the dapsone resistance spreading rapidly and globally in the ‘70’s. Our workshop held in Manila in January ’77 with many global experts, probably the only one before WHO meeting of 1981, came to the conclusion that dapsone monotherapy should end, and either rifampicin or clofazimine should be given simultaneously with dapsone at least for MB cases. SMHF has been providing large amount of dapsone to various countries since 1975, but once WHO’s MDT was announced, SMHF started supplying MDT to about 10 countries in early ’80 and it expanded to nearly 30 countries by late ’80. It also assisted training of field workers on MDT, by financing training sessions of national governments, supplying training materials including the Atlas of Leprosy, providing transport facilities etc. SMHF also financially supported many research activities both in Japan and out. SMHF collaborated with WHO in organizing many international meetings on various subjects, such as epidemiology, immunology etc, and more on global leprosy elimination programs, such meetings in Hanoi, Delhi, Abidjan, Brasilia, Yangon and published some of its transcriptions on JLEP or Leprosy Review. Now with Mr. Yohei Sasakawa, TNF as well as SMHF’s concern is gradually shifting to the “Social Aspects” as we endeavor toward a “World without Leprosy”. Here, Human Rights of leprosy affected person is the basic issue, a difficult problem, because it is not a technical issue solved by experts but involves change of basic attitude of life of all the people in the world.
Achievements of Leprosy Elimination and Future Leprosy Work: Global and National Perspectives: Presentation by Novartis Foundation

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First of all, I wish to thank Dr. Klaus Leisinger and Ms. Vera haag Arbenz for giving me this opportunity to present Novartis views on achievements and future of leprosy work. I would like to trace back to history of MDT development and its effect on leprosy elimination followed by foundation's involvement in care of leprosy affected persons. To trace the history, Novartis research laboratory developed clofazimine in 1962 for other diseases but found it effective in leprosy. Geigy introduced clofazimine under the trade name Lamprone in 1968. Ciba and Lepetit in Milan developed rifampicin in 1968 under trade name Rimactane by Ciba for the treatment of various bacterial infections. The first result of treatment of leprosy patients with rifampicin were published in 1970. The results of Languillon's trial of once monthly rifampicin were presented by Yawalkar at the international Leprosy Congress in 1978. WHO recommended MDT regimens, published in 1982, were the first to include once monthly supervised administration of 600mg rifampicin. MDT has been the most effective, economical and worldwide accepted therapy for the cure and control of leprosy since 1982. The involvement of the Novartis foundation in leprosy field programs was a natural extension of Novartis tradition in leprosy drug development. Since 1986 foundation supports field programs, in order to understand and overcome the obstacles to improving the access to MDT treatment for leprosy control. Novartis has committed itself to: Provide sufficient quantities of high quality MDT including buffer stocks, to treat and cure all the leprosy patients in the world and provide WHO with the necessary funds for the shipment of MDT and independent quality control. In 1987 Novartis introduced the first MDT blister pack, containing a month's treatment with each day's treatment clearly marked. New packaging was introduced in 2002 brightly colored patient's packs with information in four languages and serve to reinforce patient's confidence in the treatment. Novartis and Novartis foundation joined Global Alliance for Elimination of Leprosy at its creation in November 1999 in the final push to eliminate leprosy. Novartis contribution to GAEL is the MDT donation and country level support. The country level support at Sierra Leone, Indonesia and Democratic Republic of Congo concentrated on fulfilling the prerequisites for the successful introduction of MDT. Later, in 1988, Novartis Foundation developed a social marketing approach for leprosy elimination at Sri Lanka. This involved in large scale advertising campaigns to create the awareness of leprosy and dispel the fear surrounding the disease. This initiative, helped find hidden cases and as a result, leprosy was eliminated at the national level within eight years, by 1996. A scaled down version of the campaign was later adopted by the Mexican authorities. After leprosy was eliminated at a national level, efforts focused on the remaining states. At the global level, the Novartis Foundation collaborates with WHO in the production of information and communication material. At the country level it has supported Brazilian efforts to project a “positive” image for leprosy and a decentralized leprosy services. The foundation has also encouraged patients to come forward for treatment by a special campaign developed in partnership with WHO for Madagascar. At Nepal, the Novartis Foundation supported mobile clinics and subsequently helped to establish the Butwal referral clinics which addressed a pressing need, especially for disability care. From 1990-1996 in Turkey, mobile teams traveled by air and road to bring MDT treatment closer to patients reaching almost 94% of all registered cases in the country. In 2000 the Novartis Foundation helped the Sri-Lankan Ministry of Health develop the blueprint for integration and supported its implementation for five years. Leprosy is now part of the job description of every medical officer in the country and is treated within the general health services. From the very fact that even before the “elimination” (1991) became a buzzword in leprosy field, Novartis Foundation is involved in “caring” for leprosy patients. In 1989, the Foundation set up the comprehensive leprosy care program (CLCP) in India. Its aim is to provide comprehensive care to patients i.e. MDT treatment and disability prevention, correction and care services. CLCP improved the access to MDT at Borsad Taluka and introduced MDT Blister packs at Goa. As a result Borsad reached the redefined goal of elimination and at Goa the prevalence was brought down drastically. However, the most important aspect of CLCP was pioneering the care of the leprosy disabled persons. Over the years, CLCP has established the key modalities which include health education, physiotherapy, splints, self-care kit, MCR footwear and grip-aids as part of Disability Prevention services. Medical rehabilitation is provided with reconstructive surgery as Camp and Workshop Approach and complemented with articles for income generation given free. CLCP approach has been hailed as holistic approach. Many of the disability care modalities have been adopted by the government and NGOs at India and abroad. With an estimated cure of more than 11 million cases with MDT (4.5 million through Novartis donation) and reaching thousands of disabled cases for care, Novartis Foundation is firmly committed to achieve a world free of leprosy.
**S-2 : Achievement and Future of Leprosy Work-Technical Perspectives**

**Case Detection**

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There are many things in leprosy not understood, or ill understood. One of them is case detection trend. For several years intensified leprosy control under vertical programme generated a large number of new cases especially in endemic countries like India. While some countries could achieve elimination as a main consequence of new case reduction while under vertical control others did after integration. India which continues to contribute substantially to global new case load has seen a drastic reduction in new cases especially in the last four years which could be due to one or more operational factors. How to overcome the influence of these factors and ensure quality in case detection is the issue that needs to be addressed.

**Treatment Issues**

Laundry Bide

**Integration of Leprosy Care into General Health Services**

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Leprosy control programme was one of the successfully implemented disease control programmes on a global scale. The case load was large at the initial phases. Different strategies were defined at the country level depending on the endemicity and country policy. Many leprosy endemic countries resorted to vertical setup as intensive programme activities were planned. Specialised work force was created to implement the activities. As the endemicity lessen an integrated approach was adopted. Health care personnel were trained to take up the task with assistance from remaining specialised workers from vertical setup. Wrong diagnosis was minimal and treatment delivery was good. Accessibility was one of the major advantages with integrated services. Semi vertical system was adapted in some countries as it was not possible for complete integration. It was also demonstrated that other programmes were integrated with leprosy programme where the personnel had expertise in public health approach. Though there are few difficulties - mostly administrative - it was encouraging to observe that primary health care system did perform well in most of the situations. Characteristics of geographical regions differ and challenges still remain.

**Prevention of Disability : Who is Preventing What ?**

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The most significant factor in the reduction of leprosy related disability is the early detection and treatment of leprosy so that the disease process can be arrested before the onset of peripheral neuropathy. The prognosis for people who will contract leprosy in the future however, is poor, because concomitant with lower detection rates there is almost certain to be an erosion of the clinical expertise required to detect the disease early or to manage nerve function impairment adequately. A salutary conclusion is that people will continue to develop secondary impairments with associated activity limitations and participation restrictions. A stronger focus on interventions to address such issues is, therefore, a pragmatic imperative. The prevention of secondary and tertiary disabilities is now recognized as a significant concern by the WHO which, in ratifying its revised strategy in 2006, brought the issue of disability prevention and management squarely into the domain of leprosy control. Realities of the disability issue in the changing scenario of leprosy services challenged delegates at the Consensus Development Conference (CDC) on the prevention of disability (POD) in 2006. A consensus was reached that the fundamental POD research theme requiring concerted attention was how to achieve a greatly enhanced global coverage of self-care and footwear requirements. However, foundational research on which these interventions should be developed is scarce. The assessment of footwear is problematic due to the diversity of independent variables that affect outcomes. The issue needs to be addressed because with the lack of alternative evidence, specially made footwear for people with insensible feet due to leprosy is still considered by many to be mandatory. Very few have challenged this concept even though it was a development contemporaneous with Dapsone treatment. Self-care is, and will continue to be, the mainstay of POD where prevention of nerve impairment cannot be realized, but the acceptance and sustained adherence to self-care is subject to a very complex array of health expectations and motivational factors. The Innovative Care for Chronic Conditions (ICCC) is introduced. At the core of the model the impact of chronic conditions is determined by affected individuals who are supported by adequately prepared teams of health workers and also by informed and activated communities. Acceptance of the model requires a radical paradigm shift which will challenge the prevailing “Industrial Age” model of health delivery to which most of the developing world still adheres.
Management of Disabilities in the Field

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The Management of Disabilities in Hansen’s disease (HD) is ideally based on the WHO International Classification of Functioning, Disability and Health (WHO, 2001). It is important to routinely measure and monitor body functions and structures, the ability to execute activities and the ability to participate socially within the context of one’s own environment. The prevention and early detection of impairments, limitations in ability to do activities and/or restrictions in social participation, should direct planning and execution of POD/Rehabilitation interventions. Changes in impairments, activity limitations and participation restrictions should be regularly monitored and evaluated to indicate if the results of POD/Rehabilitation interventions (self-care, footwear, surgery, etc) have achieved their objective to prevent and/or minimize disability. Disability management is required during MDT and after MDT. Careful attention needs to be given to those persons at highest risk of developing or furthering disability, which includes persons with nerve function impairments, reactions and/or with a WHO Grade of 1 or 2 at diagnosis or after release from treatment (cure). POD/Rehabilitation coverage, the quality of services and the development of the services are dependent on a well organized plan and clear guidelines. Strategies which integrate activities to prevent and control disability within HD control programs begin in the community with basic health care services and extend to include specialty referral health services. The participation and collaboration of all levels of health provision improves POD/Rehabilitation awareness, access and quality of services. Self-care and self-help groups can be a very effective strategy for managing and sustaining disability prevention. Basic POD knowledge and skills training is essential for front-line health workers, persons affected by HD and their families. Training programs need to plan adequate time and opportunity for health workers (doctors, nurses, therapist, etc) to develop their skills to do POD essentials. This ability gives them the confidence to implement, practice, develop and advocate the activities after training. Systematic in-service training during supervision can be an effective way to develop the capacity of the health team, the patient and the family, to prevent and manage disability. The use of patient records (visual acuity, neurological exam, WHO grade, SALSA and Participation scores, etc), after-care registries and Impairment Summary Forms (ISF) are essential for monitoring and evaluating the success of individual patient and program disability management. The local health team can, and should, learn how to monitor and evaluate its own services. However, the greatest challenge to disability management is that most health services have limited time, limited technical and financial support and/or limited opportunities to learn about how to manage documentation, organize services and implement activities, in an effective and efficient manner. It will require the collaboration and coordination of government and non-governmental projects and programs to work together.

Self - Care Promotion

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Long ago in 1966 Dr. Paul Barnard said there is hope of saving the hand, feet & eyeof the leprosy patient only when it is widely recognised, the whole problem is one of mechanics. As we know leprosy patient needs cure of leprosy,Prevention of disability & Rehabilitation. Prevention of disability our goals & aims are no new disability & no worsening extending disability, For that we haveto practice more Skin care, Nerve care , Joint care , Wound care , & eye care. Routinely patients should follow seven principals Look , Soak , Scrape , Oil massage , Exercise, Dressing & Priteecting. Patients should know the importance of Soaking, Oil massaging & M.C.R. sandel , For all this team work is ideal , Specially the patient is an essential member of the team , We cannot do much unless the patient understands the problem himself.

Current Concepts in Reconstructive Surgery in Leprosy

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It is estimated that of the 500,000 existing disabled cases nearly 100,000 (20 %) are eligible for reconstructive surgery. Some of these cases require more than one surgery. However, considering the paucity of experienced surgeons, it is necessary to adopt a multi-pronged approach. The specialized institutions and super-speciality departments of the medical institutions have provided their services and have been the apex center for training of surgeons, in simple techniques. Another major concept established recently has been the “Camp & Workshop Approach”. Here, a large number of surgeries are carried out, along with practical training being imparted to interested surgeons. However, what needs to be taken into consideration is that this Camp & Workshop Approach is a short term activity. The real integration of reconstructive surgery can only be achieved through the
involvement and support of medical colleges and district institutions. Simple techniques of Reconstructive Surgery need to be adopted by district institutions for medical rehabilitation. Hence, over the years, various techniques and methods for performing reconstructive surgery have been developed. These methods aid any surgeon with basic surgical knowledge to perform reconstructive surgery successfully. Thereby, with due respect to all, I, endeavor to present some of these techniques here. Briefly, one in four lasso (Atul Shah, 1986) for correction of claw hand and TRAC operation for transverse arch correction are simple to perform and teach. Also, in majority of cases, a reasonable result is achieved. In other common deformity of plantar ulcers, it has been realized that it is easier to utilize local fascio-cutaneous transposition flap to provide cover with similar tissues rather than complicated myocutaneous flap. Both yield almost similar results in long term. The only exception to simple technique is the neurovascular island pedicle flap from the great toe, for coverage of ulcer on first metatarsal head which though technically difficult, provides a sensate skin and prevents recurrence in majority of the cases. The self-care teachings with self-care kit for healing plantar ulcers have been described with excellent results. Recently I have been working on reviving the technique of plantar skin graft. This simple procedure can be implemented even at a district hospital. Another important deformity in any leprosy case is lagophthalmos. Timely tarsorraphy or a temporalis sling has been a standard method for its correction. However, few plastic surgeons and some ENT surgeons prefer gold implant, due to the simplicity of the operation. A very small percentage of cases require saddle nose correction and eyebrow grafting. These operations being those requiring cosmetic correction are better left to experienced surgeons. Finally, whether for cosmetic reasons or restoring function, reconstructive surgery helps to remove stigma, elevates self-esteem, and re-integrates a person in society. At Novartis CLC Association, "we not only support reconstructive surgery but also follow-up the patients, through provision of rehabilitation aids." These aids are made available to those patients, who want to revive their lives, following reconstructive surgery. Hence, it may be said that, "every single step taken puts a surgeon in charge of rehabilitating individuals rather than merely correcting deformities."

Leg and Foot Problems in Leprosy Patients

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There are two important problems involving leg and foot of the leprosy patients: leg ulcers and neuropathic leprosy ulcer. Both related to predilection of M. leprae to peripheral nerves1,2, infecting the Schwann cells and consequently initiating a nerve damage in leprosy3. In a sample of 79 leprosy patients, 32% presented cutaneous ulcers and these seemed to be related to disability grade II and to positive bacilli detected by both spectral and operational classifications, and almost 70% of the ulcers were localized in lower extremities, according Guzzo et al4.

Considering the leg ulcers in leprosy patients, there is a problem with wound classification, because they present clinical characteristics as a peripheric skin sclerosis, a bottom covered by granulation tissue, and not painful, being classified wrongly as venous or mixed ulcers. Frade at al (2006) observed that approximately 80% of leprosy patients with leg ulcers presented a normal venous duplex scan exam and their ulcers didn’t present the distal edema and hyperpigmentation resultant of chronic venous insufficiency (CVI) as showed in Figure 1. Although unknown the real etiologic mechanism, these results showed that the leg ulcer not frequently is consequent of CVI in leprosy patients, needing a specific classification and consequently different treatment and guidelines5.

About foot ulcers, related with sensitive and motor neuropathy during the leprosy evolution, there is a consensus that the foot protection is fundamental to prevent ulcers, infections and amputations consequently. The ulcer prophylaxis is possible trough the early neuropathy diagnosis, physiotherapy and appropriated footwear insoles and sandals. During the follow up of leprosy patients their use is difficult and not regular, and it requires exchange every four months. Alterations in foot dynamics due to neuropathy cause frequently abnormal distribution of plantar pressure and results in the formation of the callous and new ulcer, infections and future amputations. To evaluate the modifications of the neuropathy and plantar pressure the dynamic computerized baropodometry offers good results and can help the health professional to implement or modify their cares. The magnetic resonance (MR) is a gold standard to eliminate the risk of osteomyelitis focus. Considering the difficult of use of sandals, the follow up by baropodometry and MR, we present an original pilot case of a leprosy patient with plantar pressure disarrangement treated with nonbiodegradable filling agent (polymethylmetacrylate - PMMA), used commonly to tissue augmentation in HIV patients6,7, applied around the points with high pressure (yellow and red points by baropodometer).

A 53 years-old female white patient, with lepromatous leprosy treated 15 years ago. She presented complete anesthesia plantar bilaterally, superficial callous in distal head of the 1st left metatarsus; paralysis of right posterior tibial nerve with thick callous in distal head of the 1st metatarsus, first toe and between third and fifth right metatarsi, near the surgery scar of fourth metatarsus and toe amputation. By baropodometry there was yellow area in the first right metatarsus and red areas in first left metatarsus and between 3rd and 5th right metatarsi (Fig. 2A). It was applied 1mL of PMMA per point infiltrated by retroinjection through blue
areas around the right pressure points using the three-dimensional baropodometry image, and 1mL applied linearly in lateral plantar surface as scheme (Fig. 3A,B) with tissue augmentation (Fig. 3C). After two months, the patient presented a redistribution of the plantar pressure points in right foot and modified indirectly the pressure in the not infiltrated left foot as showed by baropodometry without yellow and red areas represented (Fig. 2B). Clinically the patient related more equilibrium in the walking and presented decreased of the callous thickness bilaterally. Now, after 8 months of infiltrations, the pressure distribution maintains and no reaction occurred.

Thus, these reports can offer an opportunity to discuss about leprosy leg ulcer classification and to show the results of PMMA as filler to be able to augment tissue, protecting the pressure points and redistributing the plantar pressure, improving the life quality of the patient.

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**Comprehensive Care of Disabled**

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**Introduction:** The success of MDT has seen fewer new cases detected with disabilities. Proper management of reactions further prevents the deformities in the field areas. However, in any given area today among the cured/RFT cases, there exists a mix of disabled cases. It does not matter whether they were treated with monotherapy, monotherapy/MDT or MDT alone. They are the major sufferers. A conservative estimate puts their number at 0.6 million at India. WHO estimates global case load of disabled as between 1 to 2 million. Therefore, management of nearly a million disabled cases is a challenging task. It requires the implementation of disability prevention, correction and care activities with such tools and techniques, which can be handled in the field area with ease. Novartis Foundation, since 1989 supports Comprehensive Leprosy Care Program at India not only for cure of the disease but also for the comprehensive care of those disabled due to leprosy. In recent years, after integration of leprosy the program also provides comprehensive care to non-leprosy disabled. Besides medical rehabilitation, comprehensive care aims to look after them with income generation aids following reconstruction or rehabilitation thus making comprehensive care a holistic approach.

**Key Components of Comprehensive Care of Disabled:**

**Health Counseling:** Identification of high risk cases particularly in children age group and providing for post-cure surveillance for disability prevention is a part of the comprehensive care. Thus, high risk cases with nerve involvement without manifest deformity, those with anesthesia (WHO disability grade 1) and those with visible deformities (WHO grade 2) are offered the health counseling. Since major group of disabled is those who self-neglect, health education pamphlet to prevent secondary deformities was developed. It has been translated in to many languages.

**Physiotherapy** While grade 1 patients can do with health counseling and protective footwear, the grade 2 patients need more disability care services. A simple way is to have two pronged approach. Health workers are trained in teaching “one exercise for each deformity” and at camps NCLCA advocates ‘group therapy’. Thus, one can cater to backlog of the disabled and their interaction becomes like a self-help group.

**Prefabricated Standardized Hand Splints:** Splints not only prevent worsening of hand deformity but also help in correction of deformity to a certain extent. Splints were pioneered for field area application by the CLCP. Its prefabrication is possible even at village level, its application is simple and results demonstrate its effectiveness. Used as an adjunct to reconstruction, it is a tool for care pre-op as well as post-op. Not only leprosy but also in other conditions like injury to nerves and paralysis the same splints are used thereby not differentiating leprosy disabled. **Grip-Aids Kit:** It has been a long time since Modulane® Grip-Aids were developed and advocated by NFSN for leprosy and orthopedic handicaps. NCLCA has continued the search for better alternatives for comprehensive care. It was noted that majority of those in need of grip-aids need it only for help in ADL (activity of daily living). The VR (Velcro–Rubber) Grip-Aid is a prefabricated grip-aid and can be applied in a minute. It facilitates the grip with a crippled hand and enables a patient to eat, drink, comb the hairs or brush the teeth with the “Grip-Aids Kit”. They feel instant improvement in their quality of life.

**Foot Care:** The research and development in
providing care to patients with disabilities of feet in leprosy and similar locomotor disabilities has been one of the highly appreciated programs of the NCLCA field activities. Importance of tackling the dryness of feet cannot be overemphasized. CLCP advocates the self-care with any oil or Vaseline. Foot Drop Splint: There are two types of splints. The dynamic foot drop splint pulls the dropped foot into dorsiflexion at ankle and static splint provide only support to stabilize ankle in neutral position. The former is used while expecting recovery with steroid therapy and as pre or post splint for reconstruction. The latter is preferred as life long support when patient refuses operation. Self-care Kit: A “Self-care Kit” has been designed and distributed to empower the patients in carrying out domiciliary care by them after they have attended the “Self-care Camp”. Excellent results have been obtained by this technique of empowerment and form the guiding principles of participation of people in their own well being. Its acceptance and replication by many has seen its spreading to thousands of cases. Protective / MCR Footwear: While those not using the footwear have to be persuaded to use protective footwear, patients with insensitive feet need MCR footwear to prevent injuries and ulcers. To enhance acceptance of MCR footwear by patients, CLCP advocated its making with different commercial designs and lately commercial production. Its research has helped establish priorities for its distribution in field areas. Reconstructive Surgery: Reconstructive Surgery (RCS) continues to have an important place in medical rehabilitation. Besides the nominated institutions, we advocate it as integrated activity at all medical colleges. Its important role in surgery on nerves whether for biopsy for confirmation of leprosy or for abscess is undeniable. In order to reach the entire backlog of cases in need of reconstructive surgery, NCLCA advocated the “Camp & Workshop Approach”. At Gujarat, it was a major partner and Gujarat example has been hailed as a model. Economic Rehabilitation: This aspect forms an important part of the comprehensive care of disabled. ‘The knife is not enough’ were the words of Sir Henry Kessler, a rehabilitation specialist. Moreover, what good is reconstructive surgery if a patient is not going to use his hands after corrective surgery? Currently, activities for economic rehabilitation are undertaken as either gift in cash or kind, microfinance/loan for occupation or housing and special grants or pensions. NCLCA follows the holistic approach in which patients who are eligible for support benefit by various aids e.g. handcarts, sewing machines, agriculture or carpentry kits etc. The economic rehabilitation program is carried out with participation of local leaders, political personalities and opinion makers to gain wider acceptance of leprosy cases in the society. In conclusion, through Novartis CLC Association, a pragmatic approach has been developed for disability prevention and medical rehabilitation. Simple cost-effective tools have been researched with which it is relatively easy to care for not only leprosy disabled but also those with similar locomotor disability. Thus, combination of scientific and holistic approach as practiced by Novartis Comprehensive Care Program has assured that leprosy is no longer a disease to fear of and has made a qualitative difference in the life of a disabled patient.

S-4 : Epidemiology of Leprosy

M.leprae in Healthy Individuals and Transmission of Leprosy

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Sources of infection, mode of transmission, patterns of exposure and the early pathogenesis of M.leprae infection remain to be elucidated. Our current understanding of transmission is largely based on assumptions and hypotheses rather than on evidence. A series of studies have been conducted notably, in India and Indonesia, using polymerase chain reaction methods to identify the presence of M.leprae in the upper respiratory tract of healthy people living in leprosy endemic areas using nasal swabs. The prevalence of PCR positive individuals in communities varied from 1.6% to 7.8%, while a similar study in a non-endemic community failed to find any positive nasal swabs. Follow-up of the individuals tested showed that the PCR positivity was transient and one study showed a marked seasonal variation with most positive swabs being found in the wet seasons over several years. The findings from these studies in different countries indicate that the presence of M.leprae in the upper respiratory tract as detected by PCR methods is transient but it is not associated disease frequency, contact status or BCG. However mucosal and serological markers of the immune response in the same studies were found to be associated with disease frequency, contact status and BCG. Chronologically exposure would precede development of an immune response, which is influenced by many other factors such as the nature, and frequency of exposure, presence of co-infections and genetic factors in the immune response. Other bacterial infections such as streptococcus and meningococcus also show transient carriage in the upper respiratory tract that does not appear directly related to disease. The very slow rate of multiplication of M.leprae, the long incubation period, the variable host immune response and the very low incidence of disease make it extremely difficult to link exposure to disease. The transient presence of M.leprae in the upper respiratory tract in leprosy endemic communities is hard to interpret but may well have relevance to patterns of exposure and transmission.

[17]
Risk of Infection and Its Relevance to Chemoprophylaxis

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Prevalence of leprosy has decreased dramatically in all endemic countries, mainly due to the generalization of the WHO recommended MDT regimens. In most countries, case detection rates of leprosy are decreasing much more slowly, if at all. One reason might be that many leprosy patients are detected relatively late, and transmission of the infection to the surrounding population has already taken place before the index cases are put on treatment. Consequently, interest has risen again during recent years for additional interventions such as chemoprophylaxis. A number of trials had taken place in the past, based on dapsone or acldapsone. More recently, Rifampicin based trials were conducted. Protective power was generally the order of 40 to 60 %, but it usually waned over time. Another problem is the fact that, as leprosy is a rare disease, the number of people needed to receive prophylaxis in order to prevent one leprosy case is usually unacceptably great, except in carefully selected population groups. Serological test have been developed in order to try and diagnose sub-clinical leprosy infection. Tests based on the PGL-I antigen have shown good sensitivity to detect MB cases. It is however much lower for PB leprosy. Research is still ongoing, aiming at developing new tests with increased sensitivity and specificity, and permitting to identify the people with a very high risk of developing the disease in the subsequent months or years. This could permit to better target people who could really benefit from a chemoprophylactic intervention. Individual and public health benefit for the use of these tests prior to chemoprophylaxis will be discussed.

Leprosy Trends, and Factors Which Influence Them

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*Mycobacterium leprae* and human leprosy probably originated in Africa or Asia thousands of years ago, from where it spread over much of the world. After becoming established on all continents and in most large island populations, the disease is known to have declined to disappearance from several wealthy populations, in particular in northern Europe, starting several hundred years ago. The classic example is Norway, where the well documented decline from 1850 to 1950 suggested correlates (eg increasing age at onset and increasing proportion lepromatous) which might be searched for in other populations. Information on numbers of leprosy patients became widely available during the dapsone monotherapy era (c. 1950 – 1981). Recorded trends over that period are confusing as programmes were extending their coverage and data emphasized registered prevalence (numbers of cases on treatment, which was life-long), though most registers had no means to remove cases who died or moved away. The result was a steady increase in reported prevalence, in most populations. The introduction of short course regimens between 1981 and 1995 had a huge impact, reducing global prevalence figures by more than 80 %. This decline was due largely to cleaning of registers (removal of deceased and left individuals) and shortening of treatment duration (from life-long to 12 – 24 months). It was this dramatic decline – in prevalence, but not incidence - which gave confidence to launch the so-called “elimination” programme in 1991. The past decade has brought further confusion over actual trends, due to the elimination initiative’s emphasis upon a “prevalence” target of 1 per 10,000, and major operational changes which influenced reported case numbers: active case detection surveys (LECs) and special action projects (SAPELS) which increased numbers of “new” cases; changes in registration practices which tended in general to reduce numbers of cases; as well as changes in classification as a consequence of which it is no longer possible to trace proportions of tuberculoid/paucibacillary versus lepromatous/multibacillar over time. It has thus not been possible to use the “Norway paradigms” to interpret trends. Leprosy incidence trends are clearly influenced by socio-economic factors, consistent with the observation that leprosy is associated everywhere with poverty. BCG vaccination must have decreased numbers of new cases worldwide in recent decades, though its precise impact is difficult to measure as vaccination was introduced and expanded alongside other control measures. Case finding and treatment must also have reduced infection risk and hence disease risk to some degree, though the extent of this effect is contentious, and there is little convincing evidence of declines in incidence in recent years. It is unfortunate that the success of the global “elimination” programme in reducing the leprosy case burden worldwide, and providing free treatment to all sufferers of the disease, has been tarnished by its having eliminated our ability to monitor what has actually happened to this disease. This problem has been taken into consideration in the current Global Strategy (for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: 2006 – 2010), which recommends a shift away from prevalence targets to an emphasis upon numbers of new cases. Only by consistent reporting of new case numbers will we be able to monitor the actual trends of leprosy over time.
Epidemiology of Disability

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The WHO often quotes 600 million as an estimate of the prevalence of disability world-wide. However, national statistics on disability vary widely (e.g. Nigeria 0.5%, Norway 33%, 1991), depending on the method used for assessment, the types of disabilities included, the demographic profile of the country, the stigma attached to disability and the disability awareness in a particular population. In many countries, no recent reliable figures are available at all and estimates, if any, are based on small studies done in certain areas. Hardly ever do such estimates include data on activity limitations and participation restrictions, which, according to the International Classification of Functioning, Disabilities and Health, are part of the definition of disability. In a recent major ICF-based random sample survey in Zambia, 11% of nearly 30,000 people surveyed reported disabilities. This figure was just under 5% in a recent survey in South Sulawesi, Indonesia. Information with regard to leprosy is slightly better, in that data on people with visible disabilities have been collected systematically for over two decades. However, these relate only to physical impairments. In addition, no systematic figures are available on the prevalence of disabilities at release from treatment, or, indeed, on the prevalence of leprosy-related disabilities among former patients who are still alive. In 1995, WHO estimated the prevalence of grade 2 impairments to be between 1.4 and 3.4 million. In 2006, the proportion of new cases with grade 2 disability was reported to be 4.7% (or 12,449 out of 265,661 new cases, WHO 2007). The proportion with grade 1 disability is often similar, which would put the total annual incidence in 2006 at ~25,000 (9.4%). This is likely to be an underestimate, even of impairment, since many patients in integrated leprosy programmes do not receive an adequate disability examination. If the impact of stigma, which often causes restrictions in social participation, was taken into account, the disability estimate may be much higher. In a large cohort study in Bangladesh, the incidence rate of new nerve damage was ~1/100 person years at risk (PYAR) among PB and 16/100 PYAR among MB patients in the 5 years following the start of MDT. 93% of episodes occurred during the first two years. However, regional differences in the risk of leprosy reactions and nerve function impairment should be taken into account. This risk appears to be higher in South-East Asia and some African countries (e.g. Ethiopia, PB 11 and MB 25/100 PYAR) than elsewhere. Continued vigilance for the occurrence of reactions and regular nerve function assessment continue to be essential components of quality leprosy control programmes. There is an urgent need for better estimates of the prevalence of disability and for data on actual needs of people with leprosy-related disabilities to inform planning of prevention of disability activities and rehabilitation services. In several countries, data have been or are being collected as part of studies or disability needs surveys. Some recent data obtained in different countries will be presented. Acknowledgement: sponsorship was kindly provided by Netherlands Leprosy Relief

S-5: Reactions & Neuritis

Risk Factors & Clinical Features for Developing Reactions & Neuritis

Peter Nicholls

Mechanisms of Nerve Damage

David Scollard

[ 19 ]
Treatment of Reactions and Neuritis

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Reactions are caused by delayed type hypersensitivity inflammation and this requires treatment with anti-inflammatory agents. Corticosteroids are the first line of treatment. Practical management points include warning the patients who has been started on treatment about reactions and educating health workers to recognise reactions. Nerve function (NF) monitoring with Semmes-Weinstein monofilaments is important to ensure that early and silent nerve loss is picked up quickly. The current WHO Global Strategy document recommends treating type 1 reactions with steroids for 3-6 months. However only 60% patients will have improved nerve function. The evidence base for improvement with steroid treatment is very weak and a recent Cochrane systematic review of Corticosteroids for treating nerve damage in leprosy identified only three randomised controlled trials (RCT) that met the review criteria. Further RCTs are needed to identify the best treatment regimens. Duration may be more important than dose; a randomised controlled study comparing different steroid regimes showed that patients with T1R who received 20 weeks of prednisolone had better outcomes than patients who received only 12 weeks of prednisolone. The TRIPOD 3 showed that treatment of patients with steroids is not beneficial if their NF impairment has been present for longer than six months. It is important to establish the role of second line agents in patients who do not respond to prednisolone or who have contra-indications to taking steroids. Azathioprine in combination with a short course of prednisolone was as effective as a 12-week course of prednisolone in the management of T1Rs in Nepal. Ciclosporin has been used in pilot studies in Nepal, Ethiopia and Brazil with some success. Two RCTs are in progress, one looking at the potential role of Methyl prednisolone in the treatment of T1R and a large RCT using azathioprine in North India. Silent neuropathy is present when there is asymptomatic nerve function impairment. It is therefore only detected if physicians perform a careful examination of the peripheral nervous system. In Nepal 13% of patients developed SN. The majority of SN was present at diagnosis or developed during the first year of MDT. The treatment of SN is the same as for T1R. Better tools are needed for the assessment and monitoring of leprosy reactions in both the clinic and research setting.


Role of Surgery in the Management of Neuritis

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Introduction: We would not be here today, gathered together in a Leprosy Congress, if leprosy would be only a skin disease with a substantial immunological background. Unfortunately, nerve damage is a major component to leprosy and the resulting disabilities and deformities accounts greatly for the burden of leprosy – fear, rejection, stigma, social and emotional burden. In the last 50 year Clinical treatment has achieved remarkable advances. WHO MDT and other special regimens have contributed for a deep change in the scenario of leprosy epidemiology and, ultimately creating a new face for an old disease. However, prevention and treatment of nerve damage is still not adequate and results are poor. Prevention: Prevention of deformities, simple or complex, depends on modification of patient’s behavior and, for any disease, this is a challenging task and it would not be different to leprosy. In this sense, and in a very broad way, it could be said that decrease in deformities rate in the last decades is due to early diagnosis and MDT rather than to actual implementation of prevention actions (Figures 1 and 2). However, techniques for preventing damage due to loss of sensation and muscle palsy are important to prevent worsening of disabilities already present and such techniques have an important role to play in the comprehensive treatment of any case of leprosy. In any case, one should remember that investments should be made in the early detection of cases in order to minimize the need for lengthy, difficult and costly rehabilitative measures. However, if present, these conditions should receive detailed attention from health professionals and in a very multidisciplinary approach. In this sense, nerve surgery has been a controversial item that need further and in deep discussion (RICHARD, 2004).
Nerve surgery: Surgical intervention on nerves in leprosy is not a novelty. Back in the 30's of the 20th Century there are many reports of operation on nerves in countries such as Brazil and India. Later, Paul Brand and A. Carayon (1969) introduce a new and more technical scope on approaching surgical treatment of damaged nerves in leprosy. Interventions for nerve release started to become a common practice in many leprosy programmes and an array of distinct technique were proposed. Among them it is possible to cite release of fibrous tunnels or ligaments, epineurotomy, inter fascicular release, anterior transposition, epicondilactomy and neurolysis with intra neural injection of long standing steroids. After an initial boom, surgeons started to become more cautions on indication neurolysis. Indeed, results have been poor since the beginning – apart from pain, a symptom that consistently disappeared soon after surgery. A brief review of the literature on this issue reveal that the methodology employed was poor to support any valid result. Most of the studies are retrospective, what by itself is not necessarily faulty, and the studied groups were definitely not homogeneous to draw consistent conclusions. Prospective studies on results of neurolysis are scarce (may be not more than 3 so far) and the follow-up is too short for reliable conclusions. Despite of that, it is a common sense among most clinicians and surgeons that the constriction of the inflamed nerve trunks in leprosy is a reality and that surgical release of this anatomical constriction in selected sites is necessary. In fact, regardless of the innovative findings that dystroglycan, a M. leprrae-targeted Schwann cell receptor, and its associated molecules in myelination, demyelination and axonal functions suggests that these molecules may have a role in early nerve degeneration (RAMBUKKANA, 2004), anatomical constriction is a macroscopic event that calls for some major intervention. Therefore, surgery has a role to play in the treatment of leprosy neuritis – what is still to be determined is the extent of this role and the point in time for its effective application. 

Indications for surgery: Before more reliable information is obtained of the results of nerve surgery, a careful indication for nerve intervention in selected cases should be the routine. It is also understood that fine technique, use of magnification and qualified surgeons are unavoidable conditions for ethically acceptable interventions (DUERKSEN, 1997). Nerve abscess: In presence of nerve abscess surgery should be considered, mainly in those cases of a large swelling fluctuating mass around the nerve truck. Careful exposure of the cavity should be made and the caseous material removed without harm to the underlying nerve bundles. Lack of improvement of nerve function with adequate steroids Presently, all cases of frank neuritis should be treated with enough steroids, if within 3 to 4 weeks there is not a clear improvement in nerve function (sensory/motor), a nerve release is indicated. This indication is controversial and only a controlled randomized trial would launch some light on this issue. However, the common sense favors this sort indication. Intermitent neuritis: Another indication is those cases in which the use steroids gives relieve of pain and improvement of nerve function but, as the storied is tapered off, pain recurs and nerve function suddenly worsen. Nerve release seems to give some solution to this sort of intermittent or recurrent neuritis. Surgical technique: It not anymore time to believe that leprosy affected persons accept any quality of medical attention. They should have the best available treatment. This is particularly true for nerve surgery. These operations should be performed by experienced surgeons with sound knowledge of the different techniques. The use of magnification and fine instrumental is mandatory if epineurotomy is indicated. Pre-operative clinical preparation is mandatory and ambulatory procedures should be avoided. The use of specific techniques varies form surgeon to surgeon. However, some points are common to all. Among them, the need for full release of fibrous tunnels, such as the carpal tunnel for median nerve release and the release of acserycerony anatomical structures such as the fibrous margin of the Flexor carpi ulnaris in ulnar nerve release and the fibrous arcade of the Abductor hallucis in the posterior tibial nerve release. In what concern ulnar transposition in the elbow, surgeons now-a-days seems to be more conservative and left it to very clear condition of nerve subluxation. In the same line, epicondilactomy should be avoided due to its invasiveness and secondary complications. It seems that, for the ulnar, the simple release of the ulnar tunnel is enough, besides the advantage to keep its fine and important blood supply. Conclusion: After some heroic phase, nerve surgery in leprosy seems to enter a cautiousness phase- this is quite welcome since it is clear that more studies are needed to arrive to concrete conclusions on the real role of nerve surgery in the management of leprosy neuritis. In this sense, controlled and randomized trials, although difficult to conduct, are the choice. Meanwhile, nerve surgery should still be part of the
armamentarium of management of neuritis. In the sake of security for patients, all the limitation and precautions listed above should be taken into consideration. However, a note of reproach should be launched to groups that are systematically trying to bring discredit to nerve surgery as something false and useless. There are some evidences that, in carefully selected cases, reasonable improvement of pain and nerve function can be obtained by carefully conducted nerve surgery – clinical should not deny to theses cases this concrete possibility.

References:

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**S-6 : Chemotherapy & Drugs Resistance**

An Overview of WHO Regimens for Treatment of Leprosy

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The leprosy elimination programmes all over the world have been based on the application of multi drug treatment (MDT) based on WHO recommended regimens. These regimens are based on three drugs rifampicin, clofazimine and dapsone. While all of these three drugs have continued to be core drugs during the last 25 years, there have been changes in the classification of the cases for treating and appropriate paucibacillary or multibacillary regimens and also in deciding the duration of treatment. The duration of MB regimen has changed from end point of initially bacteriological negativity to two years and ultimately one year which is currently being used all over the world. While this reduction to one year was not initially acceptable to some investigators without proper trials, no increase in relapsed rates has been reported and results have been generally satisfactory. This may be possible due to decrease in their number of bacteriologically positive cases specially more than 3+ Bl or the follow up in the recent years and monitoring might have missed some cases. The WHO regimen of 6 months for PB leprosy has shown good results in most parts of the world and continues to be acceptable. Alternative regimens have been recommended for cases having intolerance to one or other drugs of the current antileprosy regimens. These basically include drugs like minocycline and ofloxacin. As clofazimine reduces the reactions and also activity in both MB and PB leprosy, common regimen like uniform MDT has been proposed and is undergoing clinical trials. While the overall results with WHO regimens have been good and acceptable in terms of low relapsed rates and prevention of emergence of drug resistance, the search for combinations/regimens to reduce the duration of therapy further continues. It would be important to have proper surveillance programmes to monitor these parameters in a meticulous manner so as to undertake improvements wherever necessary.

**L-40**

Newer Drugs and Possible New Generation Multi-Drug Regimens for Leprosy

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1. The needs of new regimens which are more effective and operationally less demanding may be summarized as follows.
   i. Administration of the daily component of current MDT regimen is not supervised, thus the regimen for MB leprosy is not rifampicin (RIF) resistance-proof.
   ii. The duration of treatment for MB leprosy is still too long. Because dapsone (DDS) and clofazimine (CLO) are weak bactericidal against *M. leprae*, it is highly unlikely to further shorten significantly the duration of treatment without dramatically modifying the composition of the current regimen.
   iii. Some patients with RIF-resistant leprosy or even multidrug-resistant leprosy have already been identified, and the World Health Organization is planning to create an international network to map the distribution and to determine the magnitude of RIF-resistant leprosy. As part of the strategy to manage the emergence of RIF-resistant leprosy, naturally, a safe and
effective alternative regimen should be developed for those patients with RIF-resistant leprosy or who cannot tolerate RIF treatment.

In brief, two different new regimens should be developed: one is to simplify the treatment and facilitate the supervision of drug administration, the other is to treat RIF-resistant leprosy or patients who cannot tolerate RIF. Whatever the objective, the major advance is going to be achieved by introducing new antimicrobial agents with very promising bactericidal activity against \textit{M. leprae} into the new regimen.

2. Newer drugs: Since the introduction of the current MDT regimens, as shown in the Table, a number of antimicrobial agents with various degrees of bactericidal activity against \textit{M. leprae} were identified. The unit costs of these newer drugs are, in general, expensive; it would be prohibitively expensive if they are administered on daily basis, but the costs could be manageable if they are administered once monthly.

3. Possible compositions of the new generation MDT regimens for MB leprosy:
   i. For the regimen aiming to simplify the treatment and facilitate supervision of drug administration, the following combination is proposed, and the dosages are for adults:
      \[ \text{RFP 900 mg (or, RIF 600 mg)} - \text{moxifloxacin (MXF) 400 mg} - \text{clarithromycin (CLR) 1000 mg (or, minocycline (MIN) 200 mg)} \]
      once-monthly under supervision. Due to the inclusion of MXF as the second component, the proposed regimen is likely to be more bactericidal than the current MDT regimen from MB leprosy, but the proposed regimen is probably not powerful enough to render its duration of treatment significantly shorter than that of the current MDT regimen for MB leprosy. Therefore, for the time being, the proposed regimen should be administered for 12 months for MB leprosy.
   
   ii. For the regimen targeting patients with RIF-resistant leprosy or who cannot tolerate rifamycin derivatives, the choice of composition is rather limited. Because the regimen always consists of several less effective and ill-tolerated drugs, and will be administered daily during the initial 6-month intensive phase, the treatment is less efficacious, often associated with adverse effects, and rather expensive. The proposed regimen consists of two phases, \textit{i.e.}, an initial 6-month intensive phase, followed by an additional 18-month continuation phase, as the following:
      \begin{itemize}
      \item \textbf{Intensive phase:} MXF 400 mg - CLO 50 mg - CLR 500 mg - MIN 100 mg, daily for 6 months;
      \item \textbf{Continuation phase:} MXF 400 mg - CLR 1000 mg - MIN 200 mg, once monthly for an additional 18 months. Every dose of treatment, either daily or monthly, should be administered under supervision. For patients who had not been treated with longer duration (\textit{i.e.}, more than one year) of DDS monotherapy previously, either CLR or MIN may be replaced by DDS during the initial 6-month intensive phase.
      \end{itemize}

4. Clinical trials: The two proposed new regimens are designed mainly based on the results of mouse experiments or on short-term clinical trials in which the tested compound was often administered as monotherapy. Therefore, it is premature to apply either regimen in the routine programmes until its efficacy and safety are firmly established in carefully conducted clinical trials among patients with MB leprosy. Because the new regimens include some ill-tolerated components, as the first step, the clinical trials should begin with evaluation of the side effects in a small number of human subjects, either healthy volunteers or leprosy patients. If the tested subjects are patients with previously untreated MB leprosy, the preliminary trial may also provide early evidence of effectiveness (\textit{e.g.}, clinical and histopathological improvement, evolution of the bacterial index and viability of \textit{M. leprae}) of the regimens for treatment of MB leprosy. Once the preliminary clinical trials demonstrate that the simplified regimen (\textit{i.e.}, the regimen for patients supposed to be RIF-susceptible MB leprosy and is administered once-monthly for 12 months) is reasonably well tolerated by human subjects and showing early evidence of effectiveness for treating MB leprosy, then should enter the second step of clinical trials, \textit{i.e.}, controlled clinical study. The objectives of the controlled clinical study are to confirm that the new regimen is effective for MB leprosy, and to prove that its sterilizing activity against \textit{M. leprae} is at least as effective as the current MDT regimen for MB leprosy. In the controlled clinical study, multiple regimens, including the current MDT regimen as positive control, are compared. Unlike tuberculosis, there is no surrogate marker of sterilizing activity in leprosy treatment, the gold standard in assessing the sterilizing activity or long-term efficacy of treatment is to determine the relapse rate of MB leprosy after completion of treatment. Because MB relapse rate may be relatively low among patients treated with current MDT regimens (unless among patients with high initial BI, \textit{i.e.}, average BI $e^* 4^+$) and relapse occurs late (in average, at least 5±2 years after completion of treatment), each arm of the trial requires at least several hundreds of MB patients, and will be followed-up at least 7 years after completion of treatment. Consequently, the controlled clinical study is bound to be long-term, has to be conducted simultaneously in multiple centres, and relatively expensive. With respect to the new regimen for patients supposed to be RIF-resistant leprosy, its long-term efficacy is neither feasible nor ethical to be tested in controlled clinical study among patients with previously untreated MB leprosy. Its efficacy should only be evaluated among patients with proven RIF-resistant leprosy.
Table. List of newer drugs with various bactericidal activities against *M. lepra*e

<table>
<thead>
<tr>
<th>Drug</th>
<th>Class</th>
<th>Bactericidal activity in mice*</th>
<th>Bactericidal activity in human*</th>
<th>Unit cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pefloxacin</td>
<td>Fluroquinolone</td>
<td>+</td>
<td>+</td>
<td>Moderate</td>
</tr>
<tr>
<td>Ofloxacin</td>
<td></td>
<td>+</td>
<td>+</td>
<td>Moderate</td>
</tr>
<tr>
<td>Moxifloxacin</td>
<td></td>
<td>+++</td>
<td>++</td>
<td>High</td>
</tr>
<tr>
<td>Clarithromycin</td>
<td>Macrolide</td>
<td>+</td>
<td>+</td>
<td>Moderate</td>
</tr>
<tr>
<td>Minocycline</td>
<td>Tetracycline</td>
<td>+</td>
<td>+</td>
<td>Moderate</td>
</tr>
<tr>
<td>Rifapentine</td>
<td>Rifamycin</td>
<td>+++</td>
<td>Not done</td>
<td>High</td>
</tr>
<tr>
<td>R207910</td>
<td>Diaryquinoline</td>
<td>+++</td>
<td>Not done</td>
<td>Not commercially available</td>
</tr>
<tr>
<td>Linazolid</td>
<td>Oxazolidinone</td>
<td>+</td>
<td>Not done</td>
<td>High</td>
</tr>
</tbody>
</table>

* Based on the activity of (+) for dapsone and (+++) for rifampicin.

Laboratory Aspects of Drug Resistance in Leprosy

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The determination of drug resistance in leprosy has been difficult due to non-cultivability of *Mycobacterium lepra*e in any accepted *in-vitro* medium system. Mouse foot Pad (MFP) the acceptable tool to detect and determine the levels of resistance. The scenario has undergone many changes during the last 25 years. In 1970s and early 1980s, there was increase in drug resistance to sulphones and also some cases were reported to resistant to other drugs. WHO led multi drug campaign all over the world have produced a sea change in the situation. Overall the prevalence of the disease has decreased but qualitatively the proportion of the bacillated cases has also decreased. This leads to a reduction in the utility, usefulness of MFP to detect and monitor drug resistance. Institutes that have proper capability and infrastructure for MFP work have also decreased in number. Considering this situation, one has to debate and decide about the utility of other techniques which could be used to undertake the drug susceptibility test. Over the years, several alternative methods based on phenotypic and genotypic markers have been described for determination of viability and drug susceptibility testing. These include growing *M. lepra*e in macrophages and/or in media system showing limited growth and use various markers like enzymes, ATP, isotope uptakes, change in the receptors etc to detect viable bacilli. All these methods require certain minimum bacillary numbers and again will have a limited usefulness in the current scenario when the proportion of multibacillary cases has become lesser. In the present situation, molecular methods for direct detection of mutations in the genes responsible for resistance like rpoB for rifampicin, folP for dapsone gyrA for quinolones will have a greater scope of application. It is important to debate the current experience of use of various methods for drug susceptibility testing which will be important mostly for surveillance rather than patient care in the near future.

Molecular Biological Techniques for Detecting Drug Resistance

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Implementation of multidrug therapy (MDT) in leprosy control markedly decreased the prevalence of the disease in the world during the last two decades as expected, but isolates with resistance to one or more antibiotics have been detected in some areas. Susceptibility to drugs has been examined by mouse foot pad methods since 1960s, however, molecular biological methods for detecting drug resistance to key drugs, such as dapsone, rifampicin and ofloxacin, have been developed and implemented over last two decades. Dapsone targets dihydropteroate synthase (DHPS) encoded by folP1 and inhibits folic acid biosynthesis by acting as a competitive inhibitor of p-aminobenzoic acid (PABA). The target for rifampicin is the beta-subunit of the RNA polymerase which is encoded by rpoB. Rifampin mediates its effect through inhibition of transcription. Ofloxacin inhibits DNA replication by binding to A-subunits (GyRA) of the DNA gyrase, a type II topoisomerase. The nucleotide sequence mutations conferring resistance are located at specific sites in the respective genes and are primarily point mutations. Resultant
Amino acid substitutions result in resistance by affecting binding sites for these drugs. PCR-direct DNA sequencing has been the most definitive assay for mutation detection because it identifies specific nucleotide changes within a particular drug resistance determining region (DRDR). Samples collected by the slit skin smear or biopsy are applicable for this assay and can be preserved in 70% ethanol at room temperature until template DNA is prepared for analysis. All intermediate- and high-level dapsone-resistant mutants, rifampicin-resistant mutants and ofloxacin-resistant mutants harbor mutations in their respective DRDR. The prevalence of clofazimine resistance in M. leprae is negligible and resistance to minocycline in leprosy has not been reported. Accordingly, mutation detection at the molecular level is feasible for monitoring drug resistance in leprosy and could become practicable for field laboratories with simplification of monitoring tools.

**Chemoprophylaxis in the Prevention of Leprosy**

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In recent years a number of field trials have been carried out to assess the efficacy of rifampicin chemoprophylaxis for the prevention of leprosy in contacts of leprosy patients. Results from these trials are now being analysed and published. A meta-analysis of previous trials with dapsone [1] and the initial results of studies with rifampicin show that there may be a role for chemoprophylaxis in the prevention of leprosy. In a study in Indonesia a double dose of rifampicin showed a protective effect of 75% after nearly three years of follow-up [2]. This effect had waned after 6 years follow-up (Bakker et al., manuscript in preparation). In a large double-blind, placebo-controlled field trial in Bangladesh with a single dose of rifampicin a protective effect of 56% was observed after 2 years (Moet et al., manuscript accepted for publication). Initial results of a double-blind randomized controlled trials in India show that after 4-5 years follow-up chemoprophylaxis with a single dose of rifampicin gave a risk reduction of 74% (Declerq, unpublished results). The main limitation found in the first two studies was that chemoprophylaxis with the regimens used was most effective in the groups living further away from the patients. During an expert workshop that was held in December 2006 the results available to date were discussed. The following conclusions and recommendations were formulated [3]:

1. Contacts should be screened by a health worker for leprosy and TB prior to the provision of chemoprophylaxis.
2. Chemoprophylaxis should be provided under direct observation.
3. A system for recording and reporting of prophylaxis distribution should be in place.
4. Health workers need to be informed of such a policy and those directly involved need to be trained in selection and distribution.
5. People receiving chemoprophylaxis should receive proper information about its effects so as to leave them with realistic expectations.
6. A system for antibiotic resistance monitoring should be in place.
7. There is a need for discussion and approval of any such programme with the TB (and other infectious disease) authorities. Some of these requirements are not normally met in leprosy control programmes. For others, practical solutions need to be found. Therefore, before chemoprophylaxis can be implemented in such programmes, careful operational and/or health systems research should be carried out to determine the programme conditions required, and to develop practical guidelines for a successful implementation of a chemoprophylaxis policy. Finally, a number of critical issues need further investigation. Practical diagnostic tools are necessary to detect sub-clinical leprosy, and prophylactic regimens are needed for the highest risk groups.

**References:**

S-7 : Human Rights
Women’s Issues

Natalie Marcal

The Right to Family

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I was diagnosed as having Hansen’s disease at the age of 14. Following my diagnosis, I was segregated from my family and community and was sent to a sanatorium where it was expected that I would spend the rest of my life. After I was taken to the sanatorium, both my house and school were disinfected. My family went through unbearable and unthinkable suffering. I had to take up a false name when I entered the sanatorium. At that time, sanatoria in Japan were certainly not places for treatment and all the work there was done by the patients. I could not get used to my life without privacy and so missed my home and my family. Marriage between patients was allowed on one condition — the man had to get a vasectomy. If a woman got pregnant, she was forced to have an abortion. I myself got pregnant. A doctor urged me to have an abortion. With no freedom and no money, I had no choice but to follow his advice. The number of unborn babies of people living in Japanese sanatoria exceeds 3,000, and recently some of those fetuses were found, preserved in formalin in the corner of a war-house. The government finally acknowledged its responsibility for what had happened, and buried them in 2006. I left my sanatorium 40 years ago. My life has been very challenging — one problem after another. I worked for a company for 30 years after I left the sanatorium and had to struggle with all sorts of discrimination. However, that 30 years was not a waste. It has given me the strength and confidence to live. I had the opportunity to attend the International Women’s Conference in Seneca Falls, NY in 2002. The IDEA-hosted conference was wonderful. There, I learned that hospital staff and doctors have helped and supported women in other countries so that some work as counsellors and nurses. They have a place in society, and some have children. Many people said they were very happy. The word “happy” echoed in my mind for a very long time. That was when I realised the misery of those of us in Japan. People with family, no matter how poor they are, are very lucky. Those of you who have family need to know that you are very lucky and you should be happy for this. I had six brothers. All of them except one younger brother have now passed away. I saw my younger brother a short while ago. It took me more than 50 years to finally get to see him. Just as if we had opened a time capsule, our childhood memories came rushing back. I have never had the chance to have my own family. This is something that cannot be allowed to happen to anyone again. I am doing all I can so that the same tragedy will never happen to another person. Let us all work together for this.

Addressing Human Rights Violations in Nigeria

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In Nigeria, people affected by leprosy have encountered a lot of stigma and discrimination in the past. We suffered psychological and even physical abuse, to the extent that some of us were killed or burned alive. Those that were lucky to have their lives spared were either forced to be separated from their families and taken to leprosy settlements or taken to an isolated area in the jungle. Among the problems we faced were the following: Nobody wanted to associate with us, sell to us, buy from us, or marry us. Our children were not admitted to public school. We were discriminated against in hospitals and employment. The discrimination even extended to places of worship. This discrimination has resulted in a high level of illiteracy among people affected by leprosy and many have no alternative way of earning a living but through begging. In 2003, we launched IDEA Nigeria and from its inception, we have been able to unite the people under one umbrella in order to face the challenges ahead. We have visited all the States and our fundamental purpose has been to educate our people to understand that we are human beings like every other human being and that our role in society is vital. At the same time, we want to create avenues to promote self-reliance in order to eliminate begging and enable our children to go to school. With the help of IDEA, things in Nigeria have changed considerably and there is a great reduction in stigma and discrimination. However, we still face discrimination, even by the Joint Association of Persons With Disabilities. In 2004, the Federal Government called for a meeting of this Association but excluded people affected by leprosy from the program. However, through our determined effort, we were recognized, admitted to the meeting and I was even elected as the chief Whip of the Joint Association of People With Disabilities. Earlier this year, one chapter of The National Association of the Blind wrote a petition objecting to the inclusion of people affected by leprosy as part of the national body of the Association. We argued against the petition and have kept our position in the Association. In the past, one of our members, Bello Jibril was denied his dream of going on a pilgrimage and IDEA addressed this discrimination. We
have also advocated against people obtaining divorces on the grounds of leprosy. IDEA Nigeria has also asked and succeeded in receiving recognition and assistance from the Government in many ways and many members of IDEA are employed in different government departments. Our children now get admitted into public schools, people accept us amongst them, we attend social gatherings, eat with them, drink with them, etc. These things have become possible because of selfless service rendered by our members day and night till the government listened to us. Through IDEA, we now have one voice that can speak on behalf of others, represent us in government programs and assist our members psychologically and financially.

Ensuring Human Rights Through Legislation

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Hansen’s Disease has a particular stigma and the label of Hansen’s Disease always follows a person even if they are completely cured. People with other diseases can freely return to their homes without any restriction, but often this is not the case for those who have had Hansen’s Disease. I was diagnosed with Hansen’s Disease in 1968 and immediately hospitalized at the National Sorok Island Hospital. After two years I was discharged from the hospital. However, I still cannot overcome the high and thick walls of stigma, even though I was completely cured medically of this disease 40 years ago. The forced segregation law for people affected by Hansen’s Disease was abolished in Korea on February 9, 1961. In reality, there were no hospitals to admit Hansen’s Disease patients any more. That is why they ended forced segregation for people affected by Hansen’s Disease. The Korean Government left them out in the cold to face the cruel social stigma. They could not go back to their home and community as before. They had no opportunity for further education and no adequate jobs were available for them. The only way to survive was wandering and begging for food. The Korean Government’s solution was to forcefully capture the persons affected by Hansen’s Disease who were begging on the streets in the name of a social clean-up program. They were forcibly sent to the hospital again and cured people were locked in a vicious circle. Their human rights were violated as they were imprisoned, abused and sterilized. They had to endure a harsher loneliness and were more bereft of hope than ever before. And, the stigma keeps being passed on to the second and following generations, even if it has nothing to do with them. The successful resettlement village program, developed by the people themselves, is, unfortunately, not a complete answer in terms of achieving human dignity. Most people will pass from this world without ever saying they had Hansen’s Disease. This is a dereliction and omission of our duty. Therefore, we began a strong effort to regain our status as human beings with dignity. As a result, the Korean Government and the Korean National Assembly finally passed a legislative bill for persons affected by Hansen’s Disease on September 20, 2007. The reason for this bill is to apologize for the Korean Government’s systematic wrongdoing in their care of persons affected by Hansen’s Disease and to compensate for the great human losses. The law also examines and explains the truth regarding the violation of human rights and finally looks at how to prevent a repetition of similar incidents in the future. The law was promulgated by President of the Republic of Korea October 17, 2007 and will become operation after October 2008. Those affected by Hansen’s Disease in Korea are buoyant with great expectations that this law will restore respect and recognize our equality as citizens.

Legal Issues and Advocacy

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Introduction of Nepal: Nepal is between two massive country India and China, where 2,50,00,000 people are living. Between two countries its area is 467 Sq. Km. in rectangular shape. In the northern part of Nepal Mount Everest is standing as the rooftopt of the world. Present pictures of leprosy in Nepal: As the National data at the beginning of 2007 from Leprosy Control Division, more than 1,00,000 people are cured of leprosy and national data shows that there are 4,670 cases. In Nepal prevalence rate of leprosy is 1.45 per 10,000 people. Where there are 2.45 percent of total cases have deformity. Situation of leprosy in Nepal: Mainly in remote area of Nepal people who are affected by leprosy are out of care from their family and society. Main serious problem of this area are hidden cases. Because of social stigma and discrimination people who gets leprosy hide their disease. They know that they have to face many difficulties, if society knows that they are affected persons. Here are some difficulties which leprosy affected people have to face in their life, as follows:

1. Affected People are denied to access to temple. 2. Affected people are denied to participate in social and religious functions. 3. People of society separate them; they are not allowed to stay in their community. 4. Affected people find difficulty in possessing in family property. 5. If the affected is female the misery multiplied by many folds. Why leprosy affected people are increasing day by day? Leprosy affected people are increasing day by day because of traditional thinking. In Nepali language leprosy is called “KUSTHA ROGI”. People who are affected by leprosy are called “KUSTHA ROGI”. Not only illiterate people but people who are
well educated they too are suffering from traditional thinking. Even, those dictionary writer defines Leprosy is incurable disease. They define “KUSTHA ROG” as “MAHAROG” which means non-curable disease and their dictionary defines leprosy-affected people as “MAHAROGI” which means people who carry non-curable diseases. Although those well-educated people and dictionary writer know that leprosy is curable but they too wants to be separate from leprosy-affected people. They think that this kind of disease is caused by the curse of God. “...” They know medicine is freely distributed in all health centers and it is freely cured in different hospitals. Besides taking them there, they behave those affected people as second-class level or like as animals. They send them to jungle where they survive their life in cave. In this period they don’t support them but usually they say that “... You MAHAROG! You did many sins in former birth and now you are getting undergone pain in this birth...” They laugh on them and say, “...this is a sweet gift from God... you have to survive on it! Leprosy, Madness, Tuberculosis, Asthma, Diabetes, Stone, Problem in stomach and syphilis (Sexual Transmitted Disease) are mentioned in the Dictionary, Health textbooks, Law books and Scriptures as non-curuable disease, although Leprosy is curable. Not only in Nepal but in India too leprosy is defined as Non-curable disease. People of India and Nepal used to say leprosy is “MAHAROG”. Even, the 2nd edition of medical dictionary, which is published in India, is effortless for the definition of leprosy, that it is curable or non-curuable disease. By this way in this 21st century too national and international dictionary defines leprosy as “MAHAROG.” Is this fare for them? I want to give advice to well educated people from all over the world... please don’t give any synonyms to Leprosy affected people. They too are the human beings. I want to ask you a question what will you want if you are leprosy affected... Legal position for leprosy affected people: From the 11th edition’s book of law of Nepal’s Law code of the land (Muluki Ain) 2058 B.S. describes that if the men or women who are married are affected by leprosy they can be divorced. This is the special gift from the law of Nepal. We all know that if leprosy is not cure in time they will have deformaty case. It means they can loose their any part of their body. And they will be disabling person. In the book of law of Nepal’s disable protestation Act 2051 B.S. do not response any kind of facility to those leprosy-affected people who are disable. The government of Nepal and Nepalese law did this kind of difference. Equality for leprosy affected people as other people: The word ‘equality’ is a noun which bears the meaning, “the state of being equal, esp. in status, right etc.” The meaning of equality is defined in Black’s Law dictionary is “the condition of possessing substantially the same rights, privileges and immunities and being liable to substantially the same duties.” By this definition we can gene knowledge that the whole scenario of this world at present is surrounded by the equality concept, but if we research in the field of leprosy, most of the leprosy-affected people are surviving in the wire of poverty and social heritage. Book of law of Nepal’s Law code of the land (Muluki Ain) 2058 B.S. part poor and poverty describes in act no. 7 & 8 that if some body is affected by leprosy, he or she must be transferred there where Central District officer will refer them. In this situation they will loose their family and all the basic needs. Is this can be majored in equal ratio as other people who are not affected by leprosy? Exploitation of Human rights for Leprosy affected people: When people born in this world they have rights for food, clothes, shelter, education and health. Most of the Leprosy affected peoples are out of their basic human needs like food, clothes and shelter. People from their society don’t let them to stay with them and with their family too. People who are well educated they have only the theoretically knowledge. They don’t show their human feelings in their practical life. Following topics are written in the constitution of Nepal 2063 B.S. as fundamental rights but those rights are only tales for leprosy affected for leprosy affected people.

1. Right to Equality 2. Right to Freedom 3. Press and Population right 4. Right to information 5. Right to property 6. Cultural & Educational Right 7. Right to religion 8. Right to against exploitation 9. Right against exile 10. Right to privacy. 11. Right to Constitutional remedy. Work for leprosy affected people in Nepal: Me and Mr. Shovakhar Kandel, Administrative Officer of the Leprosy Mission Nepal discussed why is Leprosy not eradicate in this 21st century and we found the solution that its main cause is definition of Leprosy in Dictionary. The constitution of Nepal also provides chance to divorce between Husband and Wife if any one is effected by leprosy by them both. It is stated in a part of a law palace of marriage, in a section of law No. 4.5. All religious and ritual say that only the blessing of God can cure Leprosy. By this reason Leprosy affected person are out of care with Medicine and other equipment. Mr. Kandel and I remain unfair and make opponent of Government of Nepal, Prime minister and office of council of minister, ministry of Health, Leprosy eradication council, all Dictionary writer and publisher of Nepal like Nepal Pragyaa Prathisthan, Publisher Chakrapani Chalise Memorial Committee, Ratna Puatak Bhandar etc. and resistered a case in a supreme court from two year ago, saying that the definition of the Leprosy must be change. The definition must be this: Leprosy is a general disease, which can be cured by using medicine. And now here we are attending this case and try to change the definition of Leprosy till now. I promised to Ms. Mary ‘O’ Friel if there is not any technical problem in the judgment of this case, it will be finalized on 18th June 2007. I will surely attend this meeting with a dictionary having changed definition of Leprosy according the order of Supreme Court. I hope we will win the case because we were in the strong side of this case, the definition of the Leprosy will be change according to the order of Supreme Court, dictionary will define it as a general disease, and society will run in the order of law, but due to the technical problem the final judgment of Supreme Court is moved on 5th of March. If we win in this case violation of Law is punishable act, so society cannot discriminate leprosy patient. Therefore, we are being ready and have hope of success. Nepal will be the first country to change the definition of the word Leprosy from dictionary according to the order of count and the whole world must change its definition. The whole world must define leprosy by this way, Leprosy is a general disease and affected persons are not second-class level people of the society. The main functions of the law are to be punishing the people who will discriminate the people affected by Leprosy. I am very much thankful with IDEA Nepal, who is contributing me in every step of this case. In my coordination last year IDEA Nepal conducted one-day legal literacy program in Kathmandu valley with the help
of Lalitpur Bar Association like this way we are planning to have same program in all 75 Districts of Nepal with the help of Nepal Bar Association. However, here is an economical problem to conduct those programs. Social discrimination to Leprosy affected people is a crime and that is punishable act. This is the main agenda to put forward in this meeting. For the complete cure of stigma, Medicine and equipment are not sufficient but change the thinking of people is the most, so human rights of Leprosy affected people will be protect fully and they should not be socially discriminated. Taking this main theme, we all people who are working in this holy job have to as our visions for leprosy affected People. Lastly, IDEA Nepal is getting and will get full support in this case and we hope again IDEA International will support us fully and will collect the moral International support for this case. I hope the whole world will think their duty to change the definition of Leprosy from the dictionary and discriminate law from the world as we are doing in Nepal.

Leprosy and Human Rights: A Global Perspective

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Article 25 of the Universal declaration of Human Rights of 1948 starts by asserting, “Everyone has the right to a standard of living adequate for the health and well being of himself and his family including food, clothing, housing and medical care and necessary social services.” The UN Convention on the Rights of People with Disabilities was adopted in December 2006 and will be an extremely useful tool for people with leprosy-related disabilities. But the human rights that pertain to people affected by leprosy should not be seen as relating only to health or disability. People affected by leprosy have the same human rights as all people. And yet millions of people affected by leprosy, including their families, continue to experience stigma and discrimination. It is perhaps most appropriate therefore, to focus attention on the basic human rights proclaimed in the International Covenant on Economic, Social and Cultural Rights adopted by the UN in 1966. Specific practical strategies are needed to promote the obligations of States to respect, protect, fulfill and promote the rights enshrined in this Covenant and other appropriate conventions. Some of these strategies might usefully include: Better use of the media and language - The media in all its forms is still not used enough to promote and reinforce positive attitudes. Indeed, in many instances it can still be found guilty of perpetuating negative and disempowering attitudes. Vigilance and persistence are required to promote more inclusive terminology and appropriate language. Much has been done already in the case of HIV/AIDS so why not in leprosy? We need to lose the unacceptable and stigmatising labels, Legislative reform - Attitudinal change often comes about only when society has been forced by law to respect certain basic human rights. In the case of leprosy, collation of data on existing legislation, both good and bad, might give a focus for future campaigns for change. In theory, rights and justice are reflected in the way we relate to each other. Human life finds its meaning in relationships. Working Together - Traditionally, those affected by leprosy were isolated, stigmatised and segregated. People who are marginalized, disabled or oppressed, including those affected by leprosy, need to engage more broadly with each other in order to promote the rights of all. Initiatives focusing only on the human rights of those affected by leprosy will risk failure and their advocates will themselves continue to be marginalized and excluded from the development process unless a more inclusive and universal rights-based approach is taken. Such strategies are geared towards making rights-based development more inclusive and require us all to act locally in our own contexts but also globally in the wider context of human rights for all.

Early Human Rights Advocates - The Voices of Humanity

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In 1892, Frans Jacobs, who was isolated on Robben Island in South Africa due to leprosy, wrote to Queen Victoria: “We write to our revered Queen Victoria. . . . oh let us hope that we shall be made free. Let us go to our families. We live as if we were dead on this Island. . . . help us and support us as our Ruler. It is so dark here . . .”. That same year, Kaluaikooalau, a young man in Hawaii who had been diagnosed with leprosy, resisted being sent to the remote Kalaupapa peninsula because his wife was not allowed to accompany him. His wife later recalled his words: “I am denied the helping hand of my wife, and the cord of my love for her is to be cut, and I am commanded to break my sacred promise before God and live alone in a strange land; the power of man has severed the blameless ones whom the power of God has joined as one.” Frans Jacobs and Koolau lived on opposite sides of the world more than 100 years ago and represent two of the earliest human rights advocates in the history of leprosy. There have been many others who stood up against oppression and injustice, often alone. Throughout history, people affected by leprosy have worked to regain their rights and the rights of others. In addition, poetry, books, music, and artwork reveal a legacy of creative expression that represents a form of non-violent resistance to the laws, practices and attitudes that sought to crush identity and the human spirit. As the discussion of leprosy and human rights becomes more widespread throughout the world, it is essential that we remember and acknowledge the early human rights advocates who had leprosy themselves and paved the way for our current efforts. Acknowledging contributions and affording people their rightful place in history is a crucial component of getting rid of the stigma. In addition, the words of those who stood up as powerful voices of humanity, are as relevant today as they were 20, 50, and even 100 years ago.
Drug Supply Logistics and Management

Denis Daumerie

Case Definition and Detection

Kawuma

Campaign Approach to Leprosy Detection

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Introduction: Leprosy is being eliminated as a public health problem at national level throughout the world. Campaign approach was used during two periods: dapsone monotherapy and multiple drug therapy eras. Campaign approach in Dapsone era: From early 1950s to late 1970s, leprosy control was mainly carried out through vertical programmes with specialised health staff running all activities from Central to Peripheral levels. Mass campaigns for case detection and treatment were organised with “mobile teams” comprising medical doctors, paramedical staff and lab technicians. Dapsone era campaigns were highly effective in reducing leprosy burden. Campaign approach in MDT era: Campaign approach for leprosy detection was used during so-called LECs (Leprosy Elimination Campaigns), SAPELS (Special Action Projects for leprosy Elimination), SML (Social Mobilisation campaigns for Leprosy) and Leprosy Days or Health Education Campaigns (HEC). Theses interventions combined IEC, Active case finding and Case management with MDT. They allowed to diagnose and cured millions of cases of leprosy, accelerating the achievement of leprosy elimination as a public health problem. Conclusion: With the support of the WHO and ILEP member NGOs, the remaining 4 endemic countries should achieve leprosy elimination as a public health problem by the end of 2010. Implementation of the strategy for further reducing the burden of leprosy should lead other countries to durably reach a detection rate less than 1 case per 100,000 inhabitants and open the way to eradication of leprosy.

Leprosy Control Strategy for Low Endemic Situations

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During 2006, there were 68 countries reporting less than 100 new cases and 27 countries reported between 100 to 500 new cases. However, globally 95% of the disease burden in terms of annual new case detection is mainly attributed to 16 countries. Strategy proposed for low endemic countries in the WHO’s “Global Strategy for further reducing the disease burden and sustaining leprosy control activities 2006-2010” are: integration of services within the general health care system and strengthening of referral facilities which are integrated to provide specialized care such as diagnosing difficult cases, treating patients with major complications, prevention of disability and rehabilitation.
Information Systems in Leprosy

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The concept of Information Systems includes equally Information and Communication Technology (ICT). For the World Health Organization (WHO), an Information System is a mechanism for the gathering, processing, analysis and transmission of information, in order to plan, organize, operationalize and evaluate health services. Information should be a detection instrument for priorities, leading to the planning and execution of actions which shape and transform reality. In the area of leprosy, information systems are focused on gathering data on morbidity rates for the disease, generating epidemiological or operational information. There has been a significant advance in information about leprosy. Information systems should provide information, aid in analysis and the return of information to its sources. They should also inform about the disease and minimize its spread, contributing to a reversal of the current situation. An information system needs to be developed with analysis of data at the point of origin, with support for planning and initiatives aimed at improvements in care. As such, it must include sentinel systems for avoidable situations, as in advanced multibacillary (MB) and GII cases which require immediate treatment and investigation. It should also be used to alert managers to critical situations, as in cases involving children. Leprosy elimination programs need to take advantage of information and communication technology in order to improve education and dissemination of knowledge about the disease. Maintaining and updating of case records in information systems is a means of evaluating progress in eliminating leprosy. Amongst those information technologies most useful in this area are digital versions of imaging, sound and physiological signals. Computerized mapping systems such as GIS provide an excellent means of analyzing epidemiological data, revealing trends, clustering of cases, dependencies and interrelationships that would otherwise remain hidden in data shown only in a tabular format. GIS can therefore be seen as a valuable management tool in the leprosy elimination program, strengthening national, regional and sub-regional capacities for surveillance and monitoring. Other technologies, such as the World Wide Web and Electronic Patient Record (EPR), favour the quality of care for the leprosy patient, and should be more widely used. The major obstacle is human nature: computerization demands an evolution in the mentality of health professionals towards a uniform language with which to codify medical records. The EPR, the main component of a health information system, offers remote and simultaneous access, speed, trustworthiness, ease of use, security, integration with other systems, support for research and constantly updated data. By means of the Internet, an outline of human/machine interaction – medical cyberspace - is being traced. A “virtual medical community” is possible, as seen in projects like the Hospital Virtual, discussion lists and in the increased use of e-mail and the Web. Using the “Ciberambulatório”, a doctor can fill in a patient’s details and receive a second opinion regarding the diagnosis. The “Tutor Eletrônico” offers educational content about various diseases. Telemedicine related to leprosy promotes medical assistance and education in geographically distant places. Most influential in terms of medical literature is MEDLINE but other sites, such as MedScape, HealthGate and HighWire Press offer medical information. Lists of note are those of the WHO, the French-language Association of Leprologists and Dr. Noto’s List. It should be mentioned that this presentation on information systems in leprosy has followed all the steps in the formulation of an information system: content research on the World Wide Web, data gathering, and dissemination of current and future applications in the treatment of leprosy.

Referral System for Leprosy Patients in the Integrated System of Health Care

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Buoyed by the achievements of WHO propagated MDT - The broad policy recommendations (starting 1998) were to integrate vertical leprosy services within existing general health care delivery system. By March 2004 the strength of the erstwhile leprosy staff were reduced to 25% of the original-to sustain leprosy services in the periphery. The Programme Implementation Plan (PIP) for continuation of NLEP had indicated that under MDT services a suitable referral system is to be developed. Formations of the district nucleus under District leprosy officer was to be the backbone and it was to continue. To further reduce the burden of leprosy and to extend better utility of services after the integration, WHO (2005), ILEP (2005) and IAL (2005) prepared documents and recommended better coordination between government and non-government agencies, local health agencies, dermatologists, other related specialists (in government service and Medical colleges) and private practitioners to aid in the system of correct diagnosis and delivery of MDT. Realising the need to sustain expertise ILEP promised to continue to provide their assistance in capacity building of generalists till they acquired the skills to take care of problems such as reactions, planter ulcers and disability prevention care and medical rehabilitation (DPMR) being part of the referral system. Because of many different ways leprosy patients are managed by different health services in different countries (health services --coverage, quality, training, 

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supervision) same guidelines cannot be applied to every situation being considered for referral. Referral however, would remain an essential component of the integrated health services to provide quality leprosy services to ALL. Integration and referral are supposed to ensure wider equity and accessibility, cost effectiveness and long term sustainability, reduction of stigma and discrimination and AVAILABILITY OF THE EXPERTISE TO ALL. Referral means sending of a difficult or complicated case to a specialist for proper care. There can be different levels of expertise available and so different levels of referral. Peripheral, Intermediate and Specialized care. Peripheral level: care would only involve referring all patients with suspected leprosy. Intermediate level: Confirmation of diagnosis and provision of treatment, slit skin smear, disability testing and grading, physiotherapy, medical, surgical, ophthalmic and dermatological care, treatment of reactions and POD. Specialized care: Same as above- additionally sensation and muscle testing, skin biopsy, reconstructive surgery, community based rehabilitation (CBR). It needs to be emphasized that this division about the availability of the services is not absolute. Health workers may be doing much more at the peripheral level and similar maybe the situation at the intermediate level- providing the best of the services especially in the leprosy endemic areas. Referral is primarily required for: 1. Diagnosis of doubtful cases especially when the cardinal signs are not clearly discernible. 2. Cases with reactions not responding satisfactorily to 4 weeks of steroid treatment. 3. Complications with involvement of the other system(s) including the eye. 4. For reconstructive surgery. 5. Suspected relapse / drug resistance. 6. Counseling, rehabilitation and CBR. 7. Severe infections of hands and feet. 8. Serious adverse drug reactions. All referral cases have to be sent back from where they came for further management to maintain contact with local health workers. It is to be remembered that supervision is essential at all levels of patient care. So recording, reporting and monitoring are essential for the PROGRAMME to know the trends, viz. Proportion of new cases presenting with grade 2 deformities, child cases, sex ratio and ratio of multibacillary cases, new cases correctly diagnosed, defaulters and relapses to: Review, Formulate new strategies and Organize Logistics. Healthier health system and a good referral set up will automatically take care of the human rights and reduce/even eliminate discrimination and stigmatization of the leprosy patients. To sum up, the basic aim of the referral would mean that the shift has to be from numerical to quality (targets to be avoided) in management POD and community based rehabilitation.