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SYMPOSIA
Operational Issues of Leprosy Case Finding and Treatment

Introduction. Dr. J. P. Bréchet and Dr. Alexandre Tiendrebeogo

The elimination strategy is based on 2 key elements: Early diagnosis of leprosy and effective Treatment with a standard M.D.T. treatment.

However the implementation of these key elements is fraught with many difficulties such as:

- Problems in training and communication due in part to the low level of skills at the periphery where health centers constitute the front line in contact with the population, and also where exists low awareness of leprosy about symptoms, access to treatment and gratuity of M.D.T.
- Problems of Organizing activities at the Health Unit level where detection and treatment are often part of a vertical program, and where treatment is either prolonged or cases recycled due to deformity or reaction.
- Problems of Access to detection and treatment centers due to low geographical coverage, financial constraints (transport cost and loss of salary while going to Health center)and social stigma.

This symposium looks at operational aspects of detection and treatment through the shared experience of different approaches in Africa, which is the continent with the greatest number of countries having a high prevalence of leprosy.

Detection of Leprosy.

a) Active and passive detection by Dr. Alexandre Tiendrebeogo Passive detection is examination of suspected cases presenting themselves spontaneously, it needs to be supported by health education campaigns and availability of free M.D.T. The advantage is that it facilitates integration of leprosy into general health services, is cheap and is appropriate in areas with good health coverage.

In Active detection, suspected cases are gathered in a village and examined during a visit in the village, it needs to be accompanied by flexible distribution of M.D.T. and a repeated visit after 2-3 months. The advantage is that hidden cases are more easily found and community participation helps to reduce stigma of leprosy in isolated areas or those with poor health coverage.

Treatment likewise can be adapted to monthly supervised M.D.T. distribution, flexible M.D.T. distribution for 2 to 3 months and Accompanied M.D.T. distribution of the whole course of treatment.

A good combination of all these strategies will ensure a high success rate of detection and treatment adapted to the prevalence, health coverage and context of leprosy in the area.

b) Active and passive detection in Mali by Dr. Samba O. Sow

Comparing 2 strategies of leprosy cases finding it was found that active case finding is more efficient but expensive, allows early detection, treatment and prevention of disabilities, should be repeated for 2 to 3 years in remote areas according to the prevalence, while Passive case finding should be accompanied by education sessions in order to be more efficient.

The 2 strategies need to be combined in most endemic countries for leprosy elimination

c) Urban leprosy and detection in Madagascar by Dr. Claude Rattrimoarivony

The case of Antananarivo, capital of

Madagascar with a rapidly growing population coming from the rural areas. Although the Prevalence rate is low (0,14 /10 000) the number of new cases detected is constant and is mainly constituted by MB cases (94%) . Reaction appear in 20% of cases. This may be due to having only one Dermatology reference center for Confirmation of Diagnosis. To improve detection staff need to be trained in active case finding and follow-up in the suburbs as well as to raise awareness of the indifferent population. The case for social assistance in the urban context is made so as to look for defaulters and improve the cure rate.

Quality of Diagnosis.

a) Results of ULR in Cameroon – Dr. Charles Nsom Mba

Updating of Leprosy Registers was performed in 10 Provinces over 2 years and resulted in a marked reduction of the Rate of Prevalence from 0.82 to 0.46 per 10 000. The main lessons learned were that detection depended on the information about leprosy and level of awareness of the community. The health workers required updating about leprosy and improvement in M.D.T. coverage in order to achieve the reduction in Prevalence. Hence the recommendation to pursue this activity as a routine supervision activity.

b) Validation of diagnosis in Angola – Dr. J. P. Brechet

With an increase in case detection and Prevalence, justification to validate the diagnosis of leprosy became obvious. First high endemic Provinces were visited, registers updated, patients examined and staff assessed in their skill to diagnose Leprosy. The impact of previous training was poor and a new strategy of in service training during supervision visits was introduced. The validation included 3 elements: Patient examination, validation of information support (charts and Register) and validation of statistical reports.

Thus the main elements to confirm diagnosis include: patient examination by 2 trained technicians, systematic review of nerve assessment (sensitivity, muscle strength testing, deformity grade) and clinical diagnosis In Angola only 60 % of cases were confirmed, 6% were wrong diagnosis and 34 % were non leprosy cases disappeared due to migration of population and poor follow-up. It is recommended to expand the confirmation of diagnosis by involving dermatologists and medical doctors as well as to strengthen formative supervision visits.

Strategy in Leprosy Treatment.

a) Accompanied M.D.T. in Madagascar. Assessment by Dr. A. Tiendrebeogo

Due to a low cure rate (55%) in Madagascar and in an effort to improve the treatment completion rate, accompanied M.D.T. was introduced in 2000. Over a 3 year period up to 21,000 new cases of leprosy were treated. An assessment of this strategy was performed by taking a sample of 962 cases treated in 2001 in 32 districts and examining them in 2003, after completing treatment. The results showed a high cure rate (98%) against a lower cure rate for supervised M.D.T. distribution (86%). Patients living more than 10 km from the health Center showed lower cure rate with supervised M.D.T. It is therefore recommended to pursue Accompanied M.D.T. distribution for people living more than 10 km from the Health centers and to continue supervised M.D.T. distribution to those living near the Health Unit.

b) Comments about Leprosy Treatment by Dr. V. Pannikar

The current M.D.T. blister packs is still the main form of treatment and W.H.O. will continue to provide free M.D.T. to all countries treating leprosy patients up to the year 2010. Other treatment schedules are being studied and the results will not be published until 2010.(ROM and Uniform M.D.T., 5 year prospective study to assess relapse rate)

The key points are Flexibility in M.D.T. distribution (how and when to adapt distribution to where patients are living), elaborating joint guidelines for finding defaulters, developing tools to diagnose relapse and to be aware of the risk of Rifampycine drug resistance.

c) Strategy for Leprosy Control in a low endemic country –case of Sudan by Dr. E. Tanyons

In Sudan Master clinics were developed in each Province according to population density and accessibility. These clinics confirm diagnosis of suspected cases and start M.D.T. treatment. This is a method to facilitating supervision and makes good use of scarce medicines and Human resources. The Seminars for increasing awareness of leprosy are undertaken for health staff and community leaders. The expected result is reliable and valid reports.

These topics raised some very practical issues such as active versus passive detection, financial aspects involved in these strategies, despite the fact that pockets of leprosy exist and require to be detected, in any case and by any means available.

Diagnosis of leprosy can be improved by careful examination and confirming the diagnosis by 2 examiners, including where possible dermatologists and performing formative supervision visits of Health workers.

Treatment schedules need to be flexible and adapted to the patients taking into account distance, follow-up and community participation, so as to minimize defaulters and obtain a high cure rate.

Dr. J. P. Bréchet
Dr. A. Tienderébéogo

Symposium on REACHING THE UNREACHED

Preamble. As an introduction to the symposium, the moderator made the following remarks:

- The current strategy for Leprosy Elimination centres on early detection and prompt treatment with M.D.T.
- For many years it was recognized that in some countries and regions, there were pockets of patients that could not be easily accessed through the conventional leprosy elimination programs.
- This situation continued to persist in spite of claims of high geographical coverage and the integration of leprosy services into the Primary Health care package.
- Innovative approaches spearheaded by W.H.O. namely Special Action Projects for Elimination of Leprosy (SAPEL) and Leprosy Elimination Campaigns (LEC) were implemented by several countries leading to significant successes in reaching underserved and detecting and treating hitherto hidden leprosy cases.
- In spite of the efforts, new leprosy cases continue to be detected in numbers and with established deformities. This suggests that leprosy cases continue to occur in the community but are not detected in time.
- The possible explanations include factors that prevent the cases from accessing the health services, e.g. long distances, cost and stigma.
- Some patients with suspect symptoms do present to health facilities but are not detected due to the lack of relevant knowledge and skills among the health workers.
- This symposium was meant to review the achievements made through the previous innovative approaches, to decide if some aspects are still relevant. Country presentations, especially from high prevalence countries, would highlight the problem of unreached patients and the measures taken to reach them. The overall output would be a collection of recommendations and possible approaches to reaching the unreached.

Presenters. The symposium was moderated by Dr. H. Joseph Kawuma (Uganda), and the country presentations chaired by Dr. J. Chwuku (Nigeria).

There were brief presentations by: Dr. L. Bide (W.H.O./AFRO); Dr. B. Njako (Tanzania); Mr. Mitiku Ensermu (Ethiopia); Dr. J. Mputu (DRC); Dr. Samuel Hermas (Madagascar); Dr. Ndeve A. (Mozambique).

Synopsis of presentations. The World Health Organization (W.H.O.) Medical Officer reiterated the contribution of Africa to the global leprosy burden referring back to his key note address on Leprosy Elimination in African Region of W.H.O.

Describing the successes achieved with

LEC and SAPEL projects in the past, he indicated how these were no longer appropriate in the form used then but that innovative approaches could still be used to address the yet unreached patients.

The presentation from Tanzania described factors behind the uneven distribution of leprosy cases in the country. While some areas were simply high prevalence pockets, the distribution was also influenced by: geographical coverage by the National Elimination Programme due to, among others, bad terrain and lack of training of health workers. Dr. Njako listed the measures taken to overcome some of the problems with particular emphasis on the gains made through increasing the skills of health workers in over 80% of health units and promoting functional integration.

A presentation from Ethiopia described the current leprosy elimination status. There are no apparent high endemic pockets or hard to reach areas. This leads to the optimism that, if the present strategy is sustained, the leprosy burden will continue to show a downward trend. The current PHC strategy in the country is focusing on improving health in the home or household. The challenge to the NLEP is to ensure that aspects relevant to early detection and treatment of leprosy will be integrated in this strategy.

The Leprosy Programme Manager of DRC justified the thinking that there are still many unreached cases. There is an increasing number of newly detected cases in spite of poor geographical coverage as result of war and a poor road communication network. Attempts to use community volunteers especially in the underserved areas were frustrated by unforeseen demands for remuneration (for would be volunteers). The strategy will continue to be pursued but engaging volunteers identified by the community.

Madagascar has, perhaps, the most severe leprosy burden in the region. The country presentation reported that the strategy to reach yet unreached cases was based on intensified community mobilization and education.

Mozambique's health services in general were affected by the protracted war. The brief country presentation described a gradual improvement of the elimination programme between 1994 and 2003. Prevalence rate at the end of 2003 was 2.2 per 10,000. To reach unreached cases, they invested mostly in training of staff in government and private health services, social mobilization and health education. Coupled with a systematic updating of registers, they are optimistic that the leprosy burden will continue to go down.

Comments, conclusions and recommendations. The contents, recommendations and discussion points arising from the various presentations can be summarized as follows:

(i) Deliberate efforts should be made by National Programmes and their partners to continue the search for underserved areas and populations in order to reach the yet unreached leprosy cases and to provide them with M.D.T. services.

(ii) "Reaching the unreached" is a Primary Health Care strategy aimed at ensuring equity in health care. Leprosy control strategies should aim at improving access of underserved populations to general health services including M.D.T. services and should target equal not greater access.

(iii) Particular attention should be paid to strategies to increase access of women to health services, and ensure coverage of urban and peri-urban areas including slums in view of increasing urbanization in the different countries.

(iv) Efforts to Increase geographical coverage should be sustained. This could be by using volunteers in areas in which basic health infrastructure does not exist. Experience shows that it is essential that the volunteers are identified by the communities served and that, as a pre requisite, adequate training is carried out, logistics ensured and a referral system put in place.

(v) Existing organized groups should be used for sensitization and mobilization. Examples: School Children to identify suspects and direct them to volunteers; Religious Groups that are active in the hard to reach areas for communication, advocacy and social mobilization; and Ex-Patients for mobilization.

(vi) The following general measures may be taken to ensure that leprosy related priorities remain in the correct places.

- To ensure that leprosy continues to be

given deserving emphasis in country health strategies e.g. the focus on families and households in Ethiopia.
- Services for diagnosis and treatment , training and re-training of existing staff must be sustained.
- Intensify use of dermatological services as an entry point to identify leprosy suspects.
- Ensuring inclusion of leprosy in the curricula of medical schools and other health training institutions.
- Organizing operational research in the suspect pockets.
- While LECs and SAPELs are no longer appropriate in their original design, it is possible to apply selected, sustainable elements of LECs in the known pocket areas.
- Community Rehabilitation and Social Economic Rehabilitation Programmes should be maintained on the agenda for their primary purposes but also because they present good opportunities for community mobilization.
- It is important for leprosy related bilateral and multi-lateral agencies (referring to the particular case of W.H.O. and the ILEP Organizations) to improve their internal coordination in order to avoid sending conflicting messages to countries.

H. Joseph Kawuma
GLRA
P.O. Box 3017 Kampala, Uganda
Kawuma@infocom.co.ug

Symposium on
COMMUNITY-BASED REHABILITATION (CBR) FOR PEOPLE AFFECTED BY LEPROSY

Introduction. Many people affected by leprosy live with the long-term physical and psychosocial consequences of the disease. In 1998, the number of people living with leprosy-related visible impairments was estimated to be 2 million. Social problems resulting from stigma are often not restricted to the person who has had leprosy him or herself, but affect whole families. Therefore the number of people indirectly affected by leprosy will be much larger than this. The physical impairments may lead to continued risk of further disability and to limitations in activities of daily living. Visible impairments (deformities), activity limitations and/or stigma may lead restrictions in social participation, such as problems in family relations, marriage, education or employment. A substantial proportion of people who suffer such adverse circumstances will learn to cope and overcome their disadvantages. Yet others may require assistance to restore or optimize their functioning and social integration. Services offering a wide variety of rehabilitation interventions to meet such needs have traditionally been offered in and through institutions. Elsewhere, specialized socio-economic rehabilitation outreach programmes have attempted to improve the social participation of people affected by leprosy. However, the coverage of both institutes and outreach programmes is small compared to the global need for such services.

The same is true for people with other disability. An estimated 600 million people worldwide live with one or more disabilities. Only a fraction of these have access to rehabilitation services. The reasons include poor geographical coverage of existing services and the high cost involved in specialised, particularly institution-based services. Community-based rehabilitation (CBR) has been devised as a strategy to make basic rehabilitation services widely available to all people with disability. CBR is defined as “A strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services." (UN, W.H.O., and ILO. Joint position paper, 1994)

It is important to realize that CBR and institution-based rehabilitation are complementary. For many people, CBR services may be sufficient to meet their needs. However, an estimated one third of people with disability will require specialist services (e.g. reconstructive surgery) at one point or other during their rehabilitation. Another important point to realise is that there is no one "method of doing CBR." Essential characteristics of CBR are that programs or services are participatory, involving the client and his or her family as key stakeholders, and that the services empower the people concerned to take control of their own lives and optimize their abilities. Often, CBR programs are multi-disciplinary and multi-sectoral, including staff, services and/or skills from medical, paramedical, social, educational and vocational disciplines. Since CBR is a community-based service, often people with many types of disability are included. However, traditionally, this has not included people affected by leprosy, either because separate rehabilitation services catered for their needs or because stigma against leprosy was and is still present within CBR programs also.

Because the needs of people affected by leprosy are very varied, ranging from physical prevention of disability activities to education and vocational training, these can be addressed well within the context of a general CBR program. Leprosy programs should therefore aim at integration of the rehabilitation needs of people affected by leprosy into general CBR programmes. This is also called "mainstreaming" of leprosy rehabilitation.

Stigma and discrimination by Dr. Wim van Brakel. A major factor leading to social exclusion of people affected by leprosy is the stigma against leprosy found in most societies around the world. Stigma has major impact on psychosocial life of individuals, families and communities, it leads to violation of human rights, has strong negative consequences for public health programmes. Currently, there is no widely accepted intervention model or even a standard definition of stigma and a comprehensive, strategic approach to interventions is missing. In principle, many of the negative consequences of stigma can be addressed through CBR. There is also an indication that the empowerment that results from client-participation in CBR activities reduces stigma. However, the impact of such activities is often not measured and, as a consequence, the effectiveness of CBR in reducing stigma is not known.

Stigma measurement is usually fragmented and often condition-specific, e.g., only community attitudes to leprosy are assessed. This is partly because there is no generic set of instruments available for a comprehensive assessment of stigma.

In November 2004, the Royal Tropical Institute Leprosy Unit in the Netherlands organised an international research workshop on health-related stigma. Seventy researchers, experts and people affected by stigmatized conditions discussed their concepts, findings and experiences regarding stigma related to leprosy, HIV/AIDS, tuberculosis, Buruli Ulcer, mental illness, epilepsy and physical disability. A striking finding was that, despite marked differences in determinants of stigma, the experiences and consequences of stigma appeared very similar across different health conditions and cultures. Because of this, common conceptual frameworks, strategies for stigma reduction and stigma measurement tools appear feasible. A new consortium, the International Consortium for Research and Action Against health-related Stigma (ICRAAS), was launched to reduce health-related stigma and its harmful consequences, including discrimination and social exclusion.

The role of self help groups in community-based rehabilitation of people affected by leprosy by Ms. Jannine Ebenso.

In Nigeria, the planning cycle is used in the management of CBR programs.

Planning. Needs analysis. SHG can help them to analyse their own problems and brainstorm strategies. SHG can have an important role in identifying the real needs in a community. In Nigeria, we have been involved with groups in various communities. We have seen the value of sharing the local knowledge and personal experience of groups of people with disabilities (not all as a result of leprosy) in the planning process of our projects.

Implementation. Groups can decide the duration, standard, quality, and quantity etc of all aspects of the CBR project. Group members should be the prime movers, not outside "experts."

Monitoring progress. Are we on track? Will we achieve this year's objectives? Any minor amendments needed? Are resources sufficient / allocated wisely? Need re-allocating?

Evaluating impact. Have the aims and objectives been achieved?

The Gwada Community Development Association in Nigeria has built itself up over the last 3 years. Meeting monthly, the groups discuss and plan for their development. Even though most are affected by leprosy, there are also interested members of the community in the group. To date the group have planned prevention of disability activities including a successful eye care screening programs in an onchocerciasis endemic area by the eye team attached to the leprosy program and distribution of protective footwear to people with plantar anaesthesia. They also organized socio-economic rehabilitation activities like micro-credit schemes, where the members are responsible for setting up criteria and limits, deciding on the beneficiaries, monitoring repayments, tracing defaulters and setting interest rates.

Self-help groups can be review using the criteria presented by Cornielje, *et al*. (2000), which were developed for the evaluation of CBR projects.

(i) *Restoration of quality of life*. Self-care groups (SCG) in Ethiopia have seen benefits of their activities in terms of reduction of ulcers and improvement in the skin care of the hands and feet. Group members mentioned feelings of "belonging to a group," improved self-respect and dignity and confidence to participate socially. In Nigeria, SCGs are just coming up, but the initial feedback is very encouraging, with neighbours and friends assisting one another in finding solutions to the problem of recurrent ulcers. Small cooperatives have developed that are concentrating on improving the socio-economic status of the group members. IDEA Nigeria was launched in December 2003. A National Committee has been formed and each state is being encouraged to form their own branches and committees. Already letters of introduction have gone to the Federal Government of Nigeria informing them about the needs of people affected by leprosy.

(ii) *Locus of power*. Effective empowerment requires that clients participate in all aspects of the process so that ownership is achieved and benefits are sustainable. Equality of access to local resources and services is a common objective. In many instances empowerment is realized through (in-)formal education, (vocational) training and paid employment, but it may equally take place through participation in self-help groups, community-based organizations and through processes of active participation in the development of co-operatives. A successful example of empowerment is the community development group in Kuta Village, Niger State, Nigeria. After they had voiced their needs and started to get organized, they managed to meet several of the main needs by themselves.

(iii) *Involvement of others*. Integrating previously stigmatized or excluded individuals in the community demands a level of community involvement, though this may vary from acknowledgement or mere tolerance through to active encouragement, participation and ownership. Community participation is seen as indispensable to empowerment since only through such participation social, economic and political changes will take place. These changes are imperative in the process of enabling people with disabilities to become integrated into mainstream society. CBR may be defined as a system that uses existing resources of manpower and material within the community to promote integration of disabled people in all spheres of life.

(iv) *Range of activities*. Often, the focus of rehabilitation is only on specific disabling conditions that require (specific forms of) rehabilitation, e.g. the improvement of locomotion through physical therapy, or the prevention of disabilities by making appropriate footwear available. In Nigeria, the Joint National Association of Disabled People (JNADP) is a self-help group for people with all manners of disability from many different of causes. People affected by leprosy are represented on the National Committee. At the JNADP annual meeting in May 2004, representatives of the Federal Government of Nigeria were present. A national policy on rehabilitation of the disabled is being put in place. As people affected by leprosy were in attendance, their needs will also be taken into account. In Kebbi State, the people affected by leprosy have joined this group and have brought about an increase in the number of services offered by the rehabilitation services. Partnerships have been developed between government, NGOs and community associations as well as the group members and there is good collaboration and information and resource sharing in the three groups that are members so far.

(v) *Benefits of small groups in CBR.* They provide an opportunity to share experiences, develop new attitudes and acquire new life skills.They create a public voice for the rehabilitation process and encourage participation.They develop confidence as individuals "go public" about the impact of leprosy. They provide a powerful voice when confronting officialdom.

The Ethiopian National Association of Ex-Leprosy Patients (ENAELP) by Ms. Birke Nigatu.

The ENAELP is an association legally established by leprosy-affected persons to advocate their rights and create awareness in the society about leprosy, which is badly misunderstood and unnecessarily feared. In addition, the ENAELP is committed to socio-economic rehabilitation of its members to enable them to regain dignity and self-esteem. Currently, the association has 20,000 members in 54 local associations in the seven regions of Ethiopia. To achieve its objective, the ENAELP has been implementing awareness, advocacy and socioeconomic rehabilitation projects, in partnership with national and international agencies.

The awareness and advocacy work of ENAELP ranges from publishing a bilingual annual magazine called the "Truth" to printing of posters, brochures and caps and radio broadcasting using the government media. Commemoration of World Leprosy Day, which was started by ENAELP in 2000, has been also an important event to advocate the rights of persons affected by leprosy. ENAELP also lobbies the government and all others concerned for equal participation and equal opportunities of persons affected by leprosy. So far the association has protected and averted the displacement of members from their settlements and it is doing its level best in advocating the availability of quality treatment and POD for affected persons. ENAELP is the founder and an active member of the Ethiopian Federation of Persons with Disabilities. ENAELP has a good relationship with the Ministries of Labour, Social Affairs and Health, who assist the association through a steering committee established together with the ENAELP.

Parallel to the awareness and advocacy work, ENAELP carries out socio-economic rehabilitation activities for its members. They belong to the most disadvantaged groups because of stigma and poverty. To speed up integration, it is essential to empower persons affected by leprosy socially and economically. This will demonstrate that they have the potential and the skill to be productive like any other citizen. To this end, ENAELP works with revolving fund schemes for members to enable them to engage in dignified income generating activities. The association also provides primary and higher education opportunities for children of members, empowering families to break the cycle of stigma and accompanied poverty. With the same aim, ENAELP organises self-help groups for women affected by leprosy, providing training in handcraft production. So far, these strategies have proved very successful.

A Key to success in CBR: Designing an appropriate program using a participatory approach by Dr. Denis Byomungu.

There are many who are in need of rehabilitation. There are many patterns of CBR conducted in Africa. There is an urgent need to evaluate CBR programs in order to identify the most effective CBR approach. This paper reports lessons learnt by The Leprosy Mission in the DR Congo in designing a CBR program using a participatory approach.

The following questions were asked:

(i) What is the community? People affected by leprosy vs. all community: in DRC rural areas: community in a defined area and in urban areas: members of self help group.

(ii) How does the community participate? All the community, through representatives or beneficiaries: Rural areas: through rehabilitation committee members and in urban: through members of self-help group.

(iii) Expected level of participation: full community-led vs. provision of services within the community: The programs in DRC was community-led with some guidance.

(iv) Beneficiaries: People physically disabled by leprosy vs. community affected by leprosy, other disabled in or excluded. In DRC, people with leprosy-related disability and their household and people with other disability were considered (up to 15% of the budget).

(v) Depth of outreach: how to deal with the poorest (destitute). ignore there special needs vs. welfare: Targeting the helper (usually family member), breaking the cycle of poverty through scholarship combined with income generating activities , assisting the community to care for their poor through communal projects and using services from other organizations caring for the poor.

(vii) Meaning of rehabilitation: welfare vs. development: micro-credit schemes, community awareness and advocacy work.

(viii) Program against stigma: community awareness and advocacy.

(ix) End point of rehabilitation: approximately 3 years or 3 loan cycles.

(x) Long term goals: *Client*: Re-insertion, respected role, self-esteem, earning and supporting the family, personal learning and development. *Community*: CBR and Community Development and *Project*: Sustainability through Revolving Loan.

Conclusion. For sustainable transformation to happen, we need to see in our projects the principles described in an old Chinese poem on community development: "Not a showcase, but a pattern; Not odds and ends but a system and Not relief but release." This starts by designing an appropriate CBR program with full participation of all stakeholders, including beneficiaries and communities where they live.

Issues related to integration of rehabilitation activities related to leprosy in CBR programs by Sunil Deepak, Jayanth Kumar, and M.V. Jose

The progressive integration of vertical leprosy control programs into primary health care services, has been accompanied with calls for integration of rehabilitation activities related to leprosy affected persons in community-based rehabilitation (CBR) programmes. Keeping this in mind, during the last twelve years, AIFO/Italy through its partner organization AIFO/India has organized a series of workshops and training courses in India to promote the conversion of vertical leprosy control programs in CBR programmes and integration of persons with leprosy-related disabilities in these CBR programmes. At the same time, CBR projects targeting all people with disability, including persons with leprosy-related disabilities, were initiated.

Recently a participatory evaluation exercise was carried out in three AIFO-supported CBR projects in Karnataka state of India: SRMAB project in four sub-districts of Mandya district; MOB project in three sub-districts of Mandya district; and AMSK project in Bhalki sub-district of Bidar district. This evaluation, carried out through focus group discussions, looked at two specific aspects.

Integration of persons with leprosy-related disabilities in CBR activities. CBR projects have many components including medical, educational, social, etc. Integration of leprosy-affected persons in CBR was evaluated mainly by looking at their participation in heterogeneous self-help groups (SHG). Implications for change in role from vertical leprosy workers to CBR workers: the feelings of ex-leprosy workers, who were now working as CBR workers, need to be carefully considered.

- Regarding inclusion of leprosy affected persons in SHGs, the discussions brought up the following issues:

(i) CBR workers, people with disability and leprosy-affected persons all agree that integration of persons with leprosy disabilities in SHGs is problematic and requires proper planning and follow-up.

(ii) Persons with more visible deformities face more problems.

(iii) Self-stigma or perceived stigma among leprosy-affected persons, their fear that they will not be accepted, is a big obstacle.

(iv) Other disabled persons may express negative feelings about integration of leprosy-affected persons, but usually this obstacle can be overcome through awareness and discussions.

(v) The integration was gradual over a period of many years – examples of leprosy-affected persons active in a SHG stimulate more persons to join.

- Regarding the feelings of ex-leprosy workers, the discussions showed that the change of role from leprosy worker to CBR worker is perceived as a big problem, especially by persons with long-standing experience as leprosy workers. Some of the issues that came out included:

(i) Higher workload: "before we just distributed drugs and explained a few things, now the work is never over…"

(ii) Loss of expertise: "before we had clear cut competence, now we have to facilitate but problems are more difficult to solve…"

(iii) Closer contact with persons and their families by home visits: "earlier, people had to come to the ambulance, now we have to go to homes…"

For these reasons, for contemplating any change in (vertical) leprosy programs to start CBR activities, the ex-leprosy workers made the following recommendations:

- The role-change of the health workers from prescriber to facilitator is a key issue and needs to be tackled by sufficient planning and discussions.
- Workers need support in the transition period through training, dialogue, sharing of experiences and opportunities to talk about problems.
- Change must be planned and gradual.

In conclusion, integration of leprosy-related rehabilitation services and CBR is feasible and it improves the sustainability of the project activities. The CBR approach has a great deal to offer for integration and rehabilitation of leprosy-affected persons. However, both these aspects require careful planning, preparation, support and training and a gradual implementation process.

Dr. Wim van Brakel
Ms. Jannine Ebenso
Ms. Birke Nigatu
Dr. Denis Byamungu
Dr. Sunil Deepak

Symposium on
PREVENTION OF BLINDNESS IN LEPROSY IN AFRICA

The problem of eye involvement as a cause of disability in leprosy is well recognized. ([3]) Often, however, the focus is on the unique pathology, rather than the significant impact on the stigma associated with leprosy and on the quality of life of people affected by leprosy. Lagophthalmos, besides being a condition that is potentially blinding, is also disfiguring and disabling, perpetuating the stigma associated with leprosy. Vision loss, whether due to cataract or corneal disease secondary to lagophthalmos, significantly decreases quality of life. As life expectancy is increasing worldwide, the prevalence of visual impairment and blindness, associated with aging, is also increasing. For these reasons we must continue to address the problem of eye disease in leprosy in Africa.

Recently, the primary shift in the discussion of ocular leprosy has been from the clinical conditions found in patients affected by leprosy to a discussion of the best approaches to integrating eye care and leprosy control activities to increase awareness, access to, and acceptance of eye care services by people with leprosy. In Africa it is recognized that there are deficits in the number of eye care professionals; in some countries there are fewer than one ophthalmologist per one million population. Consequently, it should be recognized that access to and the quality of service delivery received by leprosy patients will only be as good as that which is available to the general population. Nevertheless, with the recent launch of the VISION 2020 Initiative (9) to achieve elimination of avoidable blindness by the year 2020 there have been significant improvements in planning for eye care delivery in Africa. Clearly, blindness cannot be eliminated; the initiative focuses on those causes of blindness that either can be prevented (e.g., trachoma, onchocerciasis) or cured (e.g., cataract). By putting systems into place in Africa it is hoped that utilisation of services such as cataract surgery can be high enough in a defined population that no one becomes blind due to cataract. It is critical that leprosy patients be integrated into these national and district VISION 2020 programmes to ensure that avoidable blindness is eliminated in leprosy patients at the same level as in the general population.

Burden of potentially blinding eye disease in leprosy patients in Africa. Findings from the Longitudinal Study of Ocular Leprosy (LOSOL) has indicated that approximately 11% of newly diagnosed MB patients will have potentially blinding ocular pathology at the time of their disease diagnosis. (2) Findings suggest that there is little difference in the prevalence of ocular pathology between different countries, once age and other demographic factors are controlled for in the analysis. Older patients have a considerably higher risk of having eye disease, probably due to a wide-range of reasons, than younger patients at the time of their disease diagnosis.

Work carried out among Tanzanian patients currently on M.D.T. (n = 371), sampled from regions listed as endemic, suggest that 13.5% have some form of leprosy related ocular disease and that 9.4% have potentially blinding pathology. Blindness (<6/60 in the better eye) was recognized in 6% of the study population. Similar to the LOSOL study, old age was associated with potentially blinding pathology, as was the duration between recognition of clinical signs (by the patient) and enrollment in M.D.T. Cataract was the leading cause of vision loss and few of the patients had sought eye care services. Separately, a study carried out in Nigerian leprosy villages (8) demonstrated a three-fold higher prevalence of potentially blinding pathology and a three-fold higher prevalence of blindness (17.9%). In both settings it was noted that these patients were not part of any routine, integrated eye care service.

Guidelines for the management of eye disease in leprosy and for integrating leprosy patients into general eye care services. In 2001 ILEP sponsored a workshop of leprosy control program managers, ophthalmologists, epidemiologists, and others to develop guidelines for the management of eye disease in leprosy and on integration of leprosy patients into general eye care services (5). Key components of these guidelines include:

(i) Creating a strong collaborative relationship between the national leprosy control program and the national prevention of blindness committee.

(ii) Establishment of 4 key signs to be detected at the time of leprosy diagnosis to guide eye care management and disability prevention. At the time of leprosy diagnosis all patients should be examined for lagophthalmos (any gap in mild closure), visual acuity, the red eye, and presence of a facial patch. All people with lagophthalmos, decreased vision (<6/18), persistent red eye (2+ weeks in duration), and/or a facial patch in reaction should be referred by the basic health worker to a higher level for clinical evaluation, or as per guidelines in the national leprosy control and prevention of blindness programs. It is estimated that approximately 20% of newly diagnosed leprosy patients will require referral to a supervisor or an eye care professional.

(iii) Steps to be taken at the time of discharge from anti-leprosy treatment At the end of anti-leprosy treatment all patients must be educated regarding the risk of eye disease and informed that they should return for examination if they develop lagophthalmos, diminished vision, a red eye, or a facial patch in reaction. Explicit instructions regarding referral must be given to each discharged patient. All patients with lagophthalmos should receive continued periodic follow-up.

(iv) Suggested revisions to the current W.H.O. disability grading system for eye disabilities (see below).

(v) Strong encouragement to provide cataract surgery with implantation of an intraocular lens, when feasible.

(vi) Adoption of different procedures,

other than simple tarsorrhaphy, for the correction of lagophthalmos.

These guidelines serve as a basis for the integration of leprosy patients into the general eye care infrastructure in leprosy endemic countries. Nevertheless, it is recognized that a failure to operationalize the guidelines will lead to the continued poor access to eye care services and continued stigma, poor quality of life, and blindness in leprosy.

Disability grading of the eye in leprosy. Recent research carried out in Tanzania showed significant discordance in the grading of eye disability when done by an eye care professional compared to an integrated health worker (IHW). IHWs recognized 3 people with grade 2 disability while the eye care professional recognized 13 people; similarly the IHW recognized 8 people with grade 1 disability while the eye care professional recognized 60. Improved training could assist with assessment of lagophthalmos and testing of vision, however, without significant efforts and training and provision of instruments, IHW are not going to be able to assess iridocyclitis and corneal opacities. The current disability grading system for the eyes is impractical for most programmes. Accordingly, it is recommended that visual acuity (either visual impairment [visual acuity <6/18] or blindness [visual acuity <6/60], depending upon the setting) and lagophthalmos should become the primary indicators for monitoring disability (grade 2) and that corneal hypoesthesia, corneal opacities, and uveitis should be removed from the leprosy disability-grading scheme.

Lagophthalmos surgery. Lagophthalmos surgery should be provided to patients who need it. Evaluation of the need for lagophthalmos surgery should be based on one or more of the following conditions: size of lid gap, corneal exposure, corneal hypoaesthesia, visual acuity, and/or cosmetic difficulties. Research in Egypt (over 300 surgeries) has shown that the modified lateral tarsal strip procedure ([1, 6]) had excellent success; over 80% showed a reduction of lid gap of more than 3 millimeters and complete lid closure was achieved in 50% of eyes. Lid closure was associated with during of lagophthalmos; the longer the duration the less degree of closure. Less closure was also found in patients with severe lagophthalmos and of an older age. The advantages of the modified lateral tarsal strip procedure were that it was simple, could be carried out in one stage (yet, repeated later, if necessary), it does not require long term follow up or physiotherapy, corrects ectropion and entropion, is cost-effective, and has a cosmetically appealing result. The "Prevention of Blindness" manual ([4]) will have a section on this procedure. Simple tarsorrhaphy should be discontinued, expect in emergency cases. There are many barriers that prevent patients from accepting lagophthalmos surgery, one of which is the poor cosmetic result of tarsorrhaphy. With the adoption of better surgical techniques, programmes need to be developed to increase the uptake of lagophthalmos surgery.

Cataract and cataract surgery. Cataract related vision loss is higher in leprosy patients than in the general (age-matched) population. Cataract is the leading cause of blindness in leprosy affected persons and many do not have access to general eye care services. Experience in Nigeria has shown that the cataract surgical coverage (% of people receiving surgery among those who need surgery) is generally quite low in leprosy patients. ([7]) Many patients had opted to have couching performed by itinerant traditional healers; outcomes of this procedure (using a thorn to puncture the cornea and dislodge the lens to the back of the eye) are very poor. The barriers to use of service noted in Nigeria, a similar throughout Africa fall under the headings of awareness (of the service, of where to go, of the expected outcome) , access (high cost of surgery, inadequate transportation network), and acceptance (fear of poor outcome, fear of discrimination by hospital staff, and social support in the family). Improving uptake of surgery requires that surgical management should be carried out in base hospitals rather than as an outreach activity in order to assure high quality of surgery and to manage any surgical complications. This will also, with time, reduce the stigmatization of leprosy. Similar to the general population, in which "bridging strategies" are successful in increasing access to surgical services leprosy patients need to be brought to the base hospital for surgery. Clear policies regarding subsidies for surgery need to be developed and implemented.

Surgical experience from both Asia and Africa has shown that leprosy patients, even with complicated cataract, can generally benefit from implantation of an intraocular lens. There is no evidence to suggest that post-operative inflammation is more common in patients with a history of chronic uveitis. Not implanting an intraocular lens will, in most cases, result in a patient that is still blind.

Integration of leprosy patients into VISION 2020 at the national and district level in Africa. Integration of leprosy patients into general eye care services can best be accomplished through the development and implementation of national and district VISION 2020 plans. There are a number of steps recommended to achieve integration.

(i) *Assessment of needs and capacities*. Evidence in Africa would suggest that approximately 10% of newly diagnosed leprosy patients and three times this number of leprosy settlement patients have potentially blinding pathology. These figures can be used to calculate the needs in most African settings. Assessment of capacity for eye care should include listing of ophthalmologists and cataract surgeons by region and compilation of information on routinely used referral practices, in particular the use of "bridging strategies" to identify and get patients to hospital. Skills of integrated health workers in the 4 key signs of ocular leprosy and the skills of eye care providers in lateral tarsal strip procedure for lagophthalmos and implantation of IOL for cataract surgery should also be determined.

(ii) *Establishing a national strategy and national policies*. Most every African country has a national prevention of blindness committee (NPBC), comprising the Ministry of Health, NGOs, service groups, and others. The Leprosy Control programme and the NPBC should meet and review the needs assessment and capacities in the country. Together the two should develop strategies for integrating leprosy patients into general eye care services in the country. Policy decisions regarding such issues as the cost of cataract surgery for leprosy patients and the potential for subsidy and waivers should be determined.

(iii) *Clearly defining the training needs required for integrated health workers, supervisory personnel, and the referral eye care providers*. It is anticipated that integrated health workers will need to upgrade training. Also, supervisory personnel, and eye care workers (ophthalmic clinical officers, cataract surgeons, and ophthalmologists) will likely require some upgrade training regarding lagophthalmos surgery. Training should also cover procedures for monitoring uptake of eye care services (primarily cataract and lagophthalmos services), and the outcome of services received.

(iv) *Implementing integration at the VISION 2020 planning level*. VISION 2020 implementation planning occurs at the district level; a district being defined as having a catchment population of between 1 and 2 million people. At this level there is expected to be at least one ophthalmologist or cataract surgeon and a team supporting these individuals. Each district should have a VISION 2020 Task Force. The district leprosy control officer should meet with the Task Force to plan out and implement the integration strategy. The aim is to integrate leprosy patients into the routine system for service delivery, eliminating the need for special structures and personnel for leprosy patients.

(v) *Program monitoring*. Monitoring should be built into the district VISION 2020 plan whereby the district leprosy control officer can verify eye care coverage and outcome of services.

Strategic planning and implementation are critical tools for leprosy control and prevention of blindness to ensure that persons affected by leprosy are fully integrated into general eye care services in Africa. By doing so it is possible to eliminate avoidable blindness by the year 2020.

Prepared by: Paul Courtright (1), Swapan Samanta (2), Essam el Toukhy (3), Hemed Kilima (4), Caleb Mpyet (5), and Muthiah Arokia Rajan (6)

1. Kilimanjaro Centre for Community Ophthalmology, Tumaini University, Moshi, Tanzania (pcourtright@kcco.net)

2. Gouripore State Leprosy Hospital, Bankura, West Bengal, India (swapan_samanta1@rediffmail.com)

3. Cairo University, Cairo, Egypt (eeltoukhy@yahoo.com)
4. Department of Ophthalmology, KCMC/Tumaini University, Moshi, Tanzania (drkilima@yahoo.com)
5. Department of Ophthalmology, Jos University Teaching Hospital, Jos, Nigeria (mpyetc@yahoo.com)
6. Sacred Heart Leprosy Centre, Kumbakonam, Tamil Nadu, India (pratheepa_rajan@hotmail.com)

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NEWS and NOTES

Damien-Dutton Award

The 2004 Damien-Dutton Award was presented to Dr. Michael F. R. Waters, OBE, FRC P, by Trevor Durston of the Leprosy Mission International of London and Dr. Wayne Myers of the American Leprosy Mission, at a ceremony held in London, England on Tuesday, November 30, 2004. Dr. Waters has a wide knowledge and experience on leprosy and is well known for his demonstrations and lectures. He served from 1959 to 1976 as the Director of Leprosy Research in Malaysia. He has published numerous papers on leprosy and its treatment. His ability to communicate with enthusiasm and lucidity to non-medical workers has earned him the praise of many throughout the world. He received numerous honors throughout his lifetime.

Dr. Waters wrote, "I am both very honored and humbled by the kindness of the Damien-Dutton Society on being named as the recipient of the Damien-Dutton Award for 2004. Although the leprosy world has changed drastically since I first started my work in 1959, we all continue to pray that the love and compassion of Christ may continue to be shown to all of those suffering from leprosy just as it was shown so remarkably by Father Damien."

Photo: Dr. Waters (right) and Dr. Meyers