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SPECIAL REPORT

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Disease and disease control

Workshop 1–defining disease and antibacterial therapy

DEFINING DISEASE

The WHO definition for a case of leprosy is:

A person having one or more of the following features and who has yet to complete a full course of treatment:

- Hypopigmented or reddish skin lesion(s) with definite loss of sensation
- Involvement of peripheral nerves, as demonstrated by definite thickening with loss of sensation
- Skin smear positive for leprosy.

This definition is meant for public health purposes with respect to the required duration of treatment. However, a person affected by leprosy has several other medical needs consequent to *Mycobacterium leprae* infection. It was pointed out that a complete definition of leprosy would require inclusion of its bacterial, physical, disabling, interpersonal, social and cultural manifestations as well as its impact on women in many societies. Furthermore, cure involves more than the killing of bacteria and the disappearance of outward signs of active disease. The Group discussed these requirements extensively. Because creating such an all-inclusive definition would be difficult, a majority of the Group felt that the basic definition given by the WHO Expert Group is acceptable for operational purposes but is only a starting point for defining the needs of patients beyond the point of bacterial cure. Thus the Group strongly recommended that the programme (either a vertical programme or general health services) retain a registry of persons affected by leprosy since it will need to provide care to the patients, particularly with reference to reactions, neuritis, sensory impairment, iritis etc. and their consequences continuing or arising after treatment. Only in this way will the patient be reasonably assured of access to the necessary care in many programmes which are changing rapidly as prevalence decreases.

After completion of multi-drug therapy, it is expected that programmes will be capable of providing all the services required by leprosy patients to both treat and prevent further complications in addition to continuing to manage the public health component. Thus health services will have the primary responsibility, both to control transmission and to meet their social responsibility to provide medical relief and rehabilitation for the persons affected by leprosy.

ANTIBACTERIAL THERAPY

Antibacterial therapy was considered with respect to duration, safety, efficacy, acceptability, simplicity and cost. All six elements are felt to be important but efficacy was considered as the key factor. The Group further felt that if all other conditions were similar, shorter regimens are preferred. It was also agreed that even beyond the year 2000, MDT should be made available in blister packs and cost factors should not limit the provision of good quality medicines.

It was agreed that if newer regimens become available with more or less equal efficacy but with a similar duration of therapy, there might be little advantage to changing from presently available and recommended WHO MDT.

It was stressed that results of clinical trials should be reported giving information on efficacy and issues related to side effects, reactions and neuritis. Efficacy decisions should be based on clinical and bacteriological improvement and more importantly taking into account relapses. When deciding on implementation of such newer regimens all the above elements should be considered. Furthermore, as regimens become shorter, the likelihood that complications of the disease will more frequently occur post-treatment may increase and if clofazamine is excluded from such regimens the frequency of ENL may rise. Planning for implementation of such regimens should also take these factors into consideration. The cost of such regimens must of course also be considered as well as operational factors.

Workshop 2–early case detection workshop

The members of the workshop discussed the issues related with detection, especially the role of active and passive case-finding and the need to make sure that all cases that are detected are able to complete treatment. The various reasons for wanting to detect cases early (to reduce transmission, to prevent disabilities and to monitor the effectiveness of the programme) was discussed and the members agreed that for operational and practical purposes the focus of this workshop will be on the role of early detection to prevention of disabilities. As such, the *definition* of early detection was defined as ‘detecting a case of leprosy before disability sets in the hands, feet, eyes and face’. This means zero disability at the time of detection (based on WHO disability grading) without considering the time lag before diagnosis.

It was agreed that the present tests available for the diagnosis of a case of leprosy were not reliable and practicable for use in the field. There was also no practical and reliable way to measure the time lag between the onset of disease and diagnosis, except for asking the patient, which most of the participants felt was a subjective measure. The implications of single lesion and indeterminate leprosy in early case detection were discussed. The group discussed low sensitivity and specificity of the diagnosis of single lesion and indeterminate cases (considering that most of the programmes are classifying cases only as PB and MB cases). The possibility of some single lesion cases remaining undiagnosed for several years and the self-healing nature of these types was also highlighted for consideration. By definition, these will be included as early cases because they will not be having disabilities at the time of detection, but will not be used for monitoring purposes.

For *monitoring* early case detection, the group agreed to use the current WHO grading scale for disabilities and recommends to use the proportion of grade zero disabilities among new cases.

With regard to improving early case detection, the group felt that the following measures should be carried out as part of the routine activities in leprosy control programmes.

- To increase awareness about the disease at peripheral levels. This includes preparing different messages for different target groups taking into account rural urban differences, literacy rates and health seeking behaviour. The need to identify the most appropriate people to promote community awareness (apart from the health worker) was considered to be important.
- To integrate leprosy services into the primary health care system so that patients are treated nearer to their homes.
- To make diagnostic and treatment facilities attractive and easily accessible, and to provide good quality care to the patient including POD services.
- The group felt that active case-finding should not be stressed because of the costs, and most of the patients detected through such means are unlikely to accept the diagnosis.

- The group also felt that because of the social problems involved with active surveillance of contacts (need to identify index case), it should not be emphasized for early detection. Educating the patients to bring household contacts in a passive way should be encouraged.

With regard to sustaining early case detection under low endemic situations, the group felt that early case detection should be a goal regardless of the level of endemicity. The following measures were felt to be important in maintaining early detection under low endemic situation.

- Under low endemic situations the early case detection should be aimed to benefit the patient and not aimed at benefiting the community by cutting disease transmission.
- Maintaining public awareness about the disease will be crucial under such circumstances.
- Integration and strengthening the integration process will be the key measure to sustain early detection.
- Training of general health workers for early diagnosis will be important and referral facilities should be made available at a suitable level to ensure that necessary expertise exists to deal with certain diagnostic problems which the general health services may not be able to tackle.
- Leprosy should also be included in the management of common skin diseases at the peripheral levels for which collaboration with the dermatological services is needed, i.e. training.

Workshop 3–organization of leprosy services under low endemic conditions

WHAT IS MEANT BY LOW ENDEMIC CONDITIONS?

We looked at three possible indicators of low endemicity, namely: case detection rate, registered prevalence and prevalence of disability. The workshop felt that case detection rate (CDR) would be the most appropriate measure to use, as that indicates the actual number of patients requiring services and it also drives the other two indicators. A CDR equivalent to a registered prevalence of 1 in 10,000 is about 5 per 100,000, so we took a low endemic situation to be one with fewer than five new cases detected per 100,000 population per year. It was noted that the geographical distribution is such that many countries will have areas of very low endemicity and other areas with more patients (e.g. China, where the overall CDR is very low, but most leprosy occurs in three provinces).

The prevalence of disability may be the significant statistic in describing the leprosy workload in any area: the residue of disability is the major problem for the next millenium.

CASE DETECTION

Even in rich, low-endemic countries, leprosy patients often remain undiagnosed for a long time (4–6 years); it seems likely that as endemicity decreases, the average delay in diagnosis will increase. In richer countries, leprosy patients are referred to dermatologists. For poorer countries with a low endemicity, there will be a need to dismantle the vertical leprosy programmes and change to a policy of suspicion at the peripheral level and referral to a specialized level for diagnosis and management of complications. The private and traditional sectors must also be involved in referring suspects.

TREATMENT

Accessibility is the main issue, with many patients living a long way from leprosy expertise. The provision of MDT could be linked to other programmes such as TB. Peripheral clinics could hold blister-packs for leprosy, according to the numbers treated in the previous year. For very distant patients, treatment can be given for 3–6 months at a time.

MANAGEMENT OF REACTIONS

Reactions are possible at any time in the 5 years or so after diagnosis. After discussion, it was felt that in low endemic situations in poor countries, it would not be possible to provide expertise in nerve function assessment at the peripheral level. As most patients would not be able to go regularly to the referral centre, there must be a much improved methodology for educating patients to recognize symptoms of reactions and neuritis and voluntarily report for appropriate treatment. Such a system could involve former leprosy patients. The same person who is trained to diagnose leprosy should be trained to manage reactions and neuritis, and prescribe steroids.

PREVENTION AND MANAGEMENT OF DISABILITIES

The example of self-care groups in Ethiopia was mentioned, with the leprosy patients' associations potentially playing an important role in helping so support those groups and assist in the provision of rehabilitation services (both physical, social and economic). Stigma was discussed, with the feeling that it may perhaps increase in some situations as the endemicity decreases.

In addition to patients' associations, other organizations (e.g. NGOs, government welfare departments, etc.) should be involved in providing basic services such as protective footwear.

COSTS

While there may be many cost savings in an integrated setting, some additional costs must be considered, especially those affecting patients, such as the costs involved in more visits to a referral centre, which may be some way away. Payment for items such as footwear is also likely to be required.

While savings may be made, it is likely that the quality of the case management of individual patients will decrease in this situation.

URBAN AND RURAL AREAS

While leprosy patients will face different problems in these different settings, it was felt that most are not specific to leprosy; leprosy patients will be similar to other patients in this respect and they will be helped by strengthening the basic health services and the referral system already in place.

MONITORING

The major problem in monitoring is usually that too much information is collected. In this situation, it was felt that a minimum of information should be routinely reported and any further information requirements would be met by appropriate surveys. The minimum data required are: the number of new cases, the number completing treatment and the number of new cases with grade 2 impairment.

TRAINING REQUIREMENTS

Training is required at the peripheral level for suspicion and referral. This has been developed in the field of dermatology, especially in Tanzania. The idea is that the peripheral worker would be trained to identify and treat up to five or six locally important skin conditions; other skin problems would be referred. This worker would not be taught anything specifically about leprosy, except to be able to give out MDT to known leprosy patients.

At the diagnostic level (often at district level), a health worker (nurse, medical assistant or doctor) would be trained to diagnose leprosy and manage the common complications, including reactions and neuritis. This person would also be trained to handle other health problems (either general, or perhaps another related field, such as dermatology or TB). In Tanzania, these staff are trained for 2 years in dermatology, STDs and leprosy, as well as programme management. In some other countries in Africa, district TB/leprosy officers are trained for just 4–6 weeks. Each country would have to determine who, where and for how long such staff would be trained.

Tertiary referral should be possible in every country, where all disabled people (including leprosy patients) can receive appropriate treatment.

Workshop 4–prevention of disability

PLACE OF PREVENTION OF IMPAIRMENT AND DISABILITY (POID) IN LEPROSY CONTROL

Prevention of impairment and disability is integral to leprosy. From the perspective of the patient, impairments and disabilities constitute the essence of the disease. Thus POID should be integral to any leprosy control programme, be it vertical, integrated or otherwise organized. It is understood that early detection and the provision of MDT are the primary means of POID. Yet nerve impairment and resulting disability remain a vital issue in many cases, and need to be addressed at every level. This means that POID activities should be defined, implemented, and recorded effectively. Evaluation should occur using appropriate parameters, adequate teaching material provided, and sufficient resources supplied.

CONCEPTUAL FRAMEWORK AND COMMON LANGUAGE

A comprehensive concept of POID needs to be developed involving all areas of leprosy control, including early detection, provision of MDT, nerve assessments, prevention of nerve function impairment, reconstructive surgery, rehabilitation, and the socio-economic situation of the patient. It is recommended that a common language is adhered to, based on the new ICIDH-2 (WHO International Classification of Impairment Disability and Handicap).

POID AT THE START OF, AND DURING CHEMOTHERAPY

Nerve function assessments should be performed and recorded adequately. It is acknowledged that the technical level of assessment may vary per region or country. The aim is to prevent (further) deterioration of nerve function. Motivation and personal attention by health care staff is essential. A mechanical test is of limited value if it is not followed by appropriate action. Impairment grading should be done before starting, and after completing chemotherapy. Reporting formats should ask for this information to be recorded. Field control cards in particular should be appropriate to POID.

Recent nerve function impairment and reactions should be treated with corticosteroids whenever possible. If the structure of a programme permits, and quality conditions are met, the provision of corticosteroids can be given at field level. Otherwise a referral system needs to be in place.

Health education, training of medical staff at all levels, and provision of sufficient resources are essential for the success of POID.

Referral options for specialist POID care are imperative to make an integrated leprosy control system work.

POID AFTER CHEMOTHERAPY

In addition to comments made above, the following points were made:

Patients need to receive adequate health education so that they are empowered to understand when and where to request care if complications due to leprosy arise after they are released from treatment with chemotherapy.

For high risk patients (e.g. those with initial highbacterial load), it is recommended to organize adequate follow-up after completing chemotherapy in order to recognize and treat nerve function impairment and leprosy reactions in time.

MANAGEMENT OF PEOPLE WITH ESTABLISHED NERVE FUNCTION IMPAIRMENT AND/OR DISABILITY

People with lasting complications due to leprosy in the form of eye problems, ulcers, muscle paralysis, etc. should receive continued care. This is preferably provided at community level (community based rehabilitation), but referral for specialist care should also be available.

ALLIANCES AND PARTNERSHIPS

It is preferable that people with secondary complications due to leprosy are treated in general medical facilities whenever possible. Eye problems, for instance, can usually be dealt with adequately in general eye units or services.

Reverse integration is also possible, where leprosy treatment centres provide specialist care for non-leprosy patients. Examples of this principle are ulcer care for diabetic patients, and hand therapy for trauma victims.

Education about leprosy and leprosy complications should filter into general medical services at all levels in order to facilitate integration and partnerships.

Summary

Four workshops were conducted during the congress under the disease and disease control theme. The workshops were on the issues of defining disease and antibacterial therapy, early case detection, sustaining leprosy control in low endemic situations, and the prevention of disability. These workshops spanned the spectrum of disease and its consequences through from early detection, the definition of disease to the prevention of disability. All of these topics being important contemporary issues challenging leprosy control programmes world wide. Despite the broad spectrum of the topics it was interesting to see that a number of important themes emerged which were common to all topics. It is possible to identify five major themes arising from the output of the workshops which are now described below.

Each of the workshops adopted broad and comprehensive approaches to their topic. In the past, there has been narrowness in defining disease in terms of the need for chemotherapy. The approach taken in the workshop now is for a much more comprehensive approach looking at all the consequences of the disease process rather than the requirement for antibacterial chemotherapy. Similarly broad approaches were taken to low endemic situations, considering comprehensive approaches which are inclusive rather than exclusive. Disability prevention also continues this same theme of comprehensive approaches based on multidisciplinary involvement in prevention of the consequences of the disease process.

The second major theme to be identified in the output of the workshops was the importance of relevance to patients and people affected by leprosy. It is no longer adequate to view programmes in terms of their acceptance to those running the programmes. Control programmes must be acceptable to the people they are designed to benefit. This even impacts on definitions of disease in terms of what matters to patients rather than only restricting this to disease pathology. Similarly, approaches to disability prevention are not merely about measurement of impairments due to nerve function deficit but rather consider the abilities and functions which are most important to the individuals affected.

The third theme which spans all of the workshops is the need to develop partnerships with others in addressing the challenges of leprosy today. Each workshop identified important groups with which partnerships need to be developed included local patient groups, voluntary associations and primary health care services. All of these have a role to play, from early case detection right through to the prevention of disability and the sustaining of control under low endemic situations.

The fourth important theme is sustainability of programmes which need to be developed for the long term benefit of those affected by disease rather than short term goals. Again, this impacts an area such as case detection methods which need to be sustained in the long term. Approaches such as intensive case detection through mass survey are not sustainable given changes to the patterns of disease, whereas involvement of communities and community participation in the process of early case detection is a much more sustainable approach. This is important, as programmes attain low endemic status and is also important in preventing disabilities where the progressive nature of secondary impairments following primary impairments may be lifelong.

The final theme is that of the importance of training, as each area is recommending new approaches to be taken and for new people to be involved in leprosy programmes. The implications are that those to be involved need to be trained and that the training requirements will be different from those of the last ten years. Training programmes will need to adapt to a wider range of individuals and groups being involved in programmes and to much more comprehensive approaches. These implications for training are profound and training centres and training programmes rapidly need to adapt to this changing situation.

These key themes emerging across the four workshops on disease and disease control are significant. They have major implications for leprosy control programmes over the next 10 years.

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