

COMBINING TUBERCULOSIS AND LEPROSY SERVICES IN ONE PROGRAMME

Considerations on a marriage of convenience

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ABSTRACT

Reasons are provided for considering combining the services for leprosy and tuberculosis in one programme. Advantages and disadvantages of the combination are reviewed for leprosy and for tuberculosis separately. The place of a partly integrated special programme in general services with a primary health care concept is indicated and the potentially important role of the community health agent briefly described.

TUBERCULOSIS AND LEPROSY HAVE MUCH IN COMMON

Both are chronic communicable diseases caused by a mycobacterium. Many people may get infected but few develop the diseases. Those few people, in endemic countries seldom 1 more than 20 per 10,000 population per year (fortunately the incidence is often much less than that), need to be diagnosed and/or classified by means of a microscopic examination. There is a remarkable similarity in the laboratory work for the two diseases: sputum smears for TB and skin smears for leprosy are made, stained and microscopically examined in almost identical ways.

Thereafter these patients complete a fairly long course of specific chemotherapy. The major part, if not all, of the chemotherapy course is to be taken ambulatorily, at a place nearest to or convenient for the patient. Similar problems may arise from the stigma attached to the diseases. Also the difficulty to attain prolonged patient compliance of drug intake is very similar for the two diseases. The characteristics of these diseases and the kind of health service needed for diagnosis and treatment, make it very convenient to have some aspects of the services combined.+

EFFICIENCY. QUALITY AND INTEGRATION

If health centres and dispensaries participate in the diagnosis and/or the treatment of the two categories of patients, it is first of all a matter of efficiency to have the various activities coordinated and supervised by the same person. Cost of transport and time expenses for supervision are so important that combining the supervisory work for the two diseases appears to be a must.

Also it would be efficient to have one or two persons of the general laboratory staff specially trained and made responsible for the laboratory work. The same person(s) will, however, also participate in other jobs in the laboratory.

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These considerations lead to the aspect of quality. The convenient and operationally efficient combination can also allow for some more specialization of the personnel dealing with the matter, some more training, and for some more specialized technical supervision. Thus the services may reach a higher level of quality in diagnosis, chemotherapy, treatment of complications and hopefully also attain a better understanding of patients' problems. How does this wish or need for

specialization relate to the general trend towards better integration and towards a comprehensive primary health care system? Presently integration is the key-word. Specialization is not fashionable at all in PHC. At least not at the peripheral level.

This is a delicate issue. Each specialist may easily claim that a particular disease or activity in the health services deserves special attention and call for special organization. For leprosy and

tuberculosis it is first of all necessary that the routine treatment becomes part and parcel of all general services. Let the work be integrated. But let it indeed become a "parcel", an activity that is somehow visible and put together (on a special day, in a register, on a special card etc.), so that it can be guided, supported and supervised by special staff. Some special support is necessary for ensuring the quality and continuity. It is for this partial integration and partial specialization that the two diseases should be operationally combined in one programme. If the diseases would each have to be taken care of separately, it would be much more difficult to withstand the waves of the often propagated full integration, which would wash away that small amount of specialized attention each of the diseases needs.

In a provocative manner, the advice would be to get the tuberculosis and leprosy activities combined in one programme, in order to protect the services for these patients against the risk of getting lost or disintegrated in a too enthusiastic, total integration.

While probably much more could be said on the interesting theme of the balance between integration and specialization, I believe it to be more opportune for the situation Ethiopia to take up a discussion of pros and cons of the combination of leprosy and TB activities in one programme.

The following remarks on possible advantages of combined services are based on observations and experiences in other African countries, mainly Tanzania and Kenya. They are presented here as probably valid for Ethiopia also.

ADVANTAGES AND DISADVANTAGES OF COMBINED SERVICES

Specific advantages for leprosy

Achieving better coverage: Leprosy is not evenly spread in the country and amongst the population. In areas where the incidence of leprosy is very low, e.g. less than 1 per 10,000, it is likely that nobody in the general health services knows enough about leprosy and its management. Most probably the area has some more TB. This is enough to justify having some representation of the combined programme the two diseases, running within the general services. The odd leprosy patient living in such an area then still stands a reasonable chance to be diagnosed and treated properly. Health personnel of the general peripheral services will know the person who supervises and supports the TB activities in the services and they may then, because of the combined programme, just have heard and seen enough of that other component of that programme, leprosy, to think at times of the diagnosis and to know where to refer somebody who may have leprosy.

Acceptance of leprosy patients in facilities of general services: Despite some fear also for tuberculosis, TB patients are usually accepted in general out-patient departments and -though often in a special ward -they are usually admitted to general hospitals. These entries are often much more difficult for leprosy patients. In a combined programme it may be easier to arrange that leprosy patients get the same rights and possibilities for treatment and admission.

Out of isolations Leprosy workers who, in some countries and situations have been a special category of personnel with very little working relationship with others, may thus be helped out of their isolation. **Better Chemotherapy regimens:** Leprosy doctors can learn from TB doctors. For tuberculosis various chemotherapy regimens have been evaluated very systematically in controlled clinical trials. In the TB control programmes due attention has been given to the development of drug resistance. Principles were laid down on the systematic prevention of drug resistance. TB had multiple drug treatment (MDT) applied some thirty years earlier than in leprosy.

TB doctors have for long recognized the need for standardization of treatment regimens. They have also known for long the necessity of the supervised intake of certain medicines. These principles and practices which were learnt and developed in the TB services can more quickly and easily become known and utilized in leprosy work in combined programmes.

Duration of treatment and acceptance of relapses: For a long time, the practice in leprosy programmes has been an almost endless continuation of the specific anti-leprotic treatment even after many years of complete inactivity of the disease. One of the reasons for that long prolongation of chemotherapy was (and to a great extent it still is) the fear for relapses. Relapse of the disease after a patient had been declared cured and chemotherapy stopped was and is still perceived as a very serious treatment failure.

In the treatment of tuberculosis, the concept of a standardized relatively short duration of treatment is well known and established. Also the occurrence of some relapses after the treatment course has been completed and the chemotherapy has been stopped, is usually accepted as unavoidable.

It is yet to be learned by leprosy doctors from their colleagues working in TB, that the duration of particular treatment regimen is to be chosen in such a way that an acceptable balance is struck between the risk of overtreating many patients on the one hand and the risk of getting an unacceptably high incidence of relapse, on the other hand. (It should be admitted here that many leprosy doctors feel quite uneasy about this matter because the new MDT regimens have been recommended for routine use before the expected risk of relapse has been assessed in clinical trials),

More insight in epidemiology: On tuberculosis there is much more knowledge of the epidemiology of the infection in the population and its relation to the incidence of actual disease. Also much more is known of the development and spread of resistant mycobacteria. Closer cooperation between medical workers dealing with leprosy and tuberculosis in operational service situations will stimulate and facilitate research to discover the possibly analogous epidemiological relations for leprosy.

The latter three possible advantages seem to be mainly matters of scientific research and of policy decisions based on the results of research. The relevance of practical cooperation in health service programmes is that research activities and policy decisions should receive continuous nutrition, stimulation and guidance from what is needed and what is feasible in the services.

The influence on resources may also be important. Funds and human inputs for leprosy research are for a large part coming from, and directed by, the same resources which also sponsor the leprosy treatment programmes.

It is also because of this aspect that I consider practical cooperation of leprosy and tuberculosis services as potentially beneficial for the direction and development of research and praxis regarding chemotherapy regimes, the occurrence of relapse and regarding the epidemiology of leprosy.

Possible advantages for tuberculosis

Coverage: Usually the leprosy services have got some kind of network of clinics or treatment points, at existing health service facilities, but very often also at several places not (yet) covered by the general health services. Such a situation exists; e.g. in several states in the north of Nigeria and also in several provinces of Ethiopia. The existing leprosy services have such a good geographical coverage that TB services would greatly benefit if these were linked up with the leprosy work.

Auxiliary personnel: Leprosy services often have involved more nurses, health assistants, medical assistants and home visitors or other workers who have means to contact many patients and participate in their treatment.

Motivation: Some of these auxiliaries and paramedicals are remarkably well motivated for the work and have a very good understanding with the patients. Seldom does one discover previous leprosy patients amongst those most valuable workers.

When these three resources -more possibilities of involving auxiliary personnel, rarely very well motivated and reaching the people in the periphery -which are already in use for leprosy work, can be utilized also for the case finding and treatment of tuberculosis, this may amount to considerable advantages for the tuberculosis control work.

Better recording: It can be said, with some justified pride, that many leprosy programmes have relatively good registration and recording systems. The treatment register book in which the recording of drug collections is done for all patients belonging to the clinic, in dated columns per week or per months, is an excellent instrument for a day-to-day overview of case holding. This simple but very practical aspect is something that the TB-services can learn from the leprosy people.

Sources of finance: In a few combined programmes, work on tuberculosis clearly benefits from voluntary external resources coming in for leprosy work, e.g. microscopes, transport facilities, or funds for running expenses of supervisory activities.

International coordination of foreign assistance: The organizations supporting leprosy work have formed an International Federation of Anti-Leprosy Organizations, called ILEP .

ILEP has a fairly unique system of coordinating financial support to leprosy control work. The organizations aim at optimal utilization of available resources. The Federation collects information on programmes and service data and offers guidance for the evaluation of, existing activities. Some elements of this world-wide coordination system might also be worthwhile for the tuberculosis work.

Possible disadvantages for leprosy

Is TB work more attractive? For personnel dealing with both diseases, the treatment of tuberculosis may be more convincingly successful than that of leprosy. In TB one may clearly save a life in a matter of weeks. In leprosy the damages remaining or even still occurring during or after chemotherapy can be very discouraging.

Neglect of disability prevention? In TB control, the emphasis is put almost entirely on the anti-bacterial aspect of the treatment and that is all that is needed. It is also needed in leprosy. The stimulation of a sound and straightforward anti-bacterial attitude towards leprosy has been listed already as an advantage brought in from the TB side. Here, however, also a warning should be sounded: the emphasis on anti-bacterial therapy should not distract the attention from the prevention of disability.

A Leprosy programme that successfully kills the mycobacteria but leaves patients behind with nerve damage, deformity and disability without optimal efforts to prevent or repair these damages is a failing programme.

Stigma: Occasionally, in situations where a leprosy service is grafted on to a strong, well-established TB-service, it might happen that leprosy patients are not properly accepted by the health services personnel, although this then would be against the official declared policy.

Possible disadvantages for tuberculosis

Stigma: Association with the often heavier stigma of leprosy may cause difficulties for TB-patients, and perhaps occasionally for some health personnel.

Relative neglect of TB: When TB activities are to be grafted on to an established leprosy service, there is a risk that personnel, used to leprosy problems for such a long time, may continue to give more and better attention to leprosy patients and thus neglect TB patients. Keep TB patients too long on chemotherapy: Again, in those situations where the leprosy service is established and perhaps rather old-fashioned, the personnel may be inclined to treat TB patients longer than required.

After having thus listed several potential advantages and possible disadvantages for each of the two parties, it may now be easier to formulate some requirements for a successful combination of the services for the two diseases.

REQUIREMENTS FOR A COMBINED PROGRAMME OF LEPROSY AND TUBERCULOSIS CONTROL

Commitment

It is very essential that the policy makers and the senior professionals concerned with the two diseases (in the Ministry of Health, and specialists in the main referral hospitals) have considered the possible advantages and disadvantages and are convinced that the advantages will outweigh the disadvantages.

These authorities then have to make this opinion known and formulate officially and very clearly their commitment to the combined programme.

Balance of expertise, power and resources: From the lists of possible disadvantages, it should be clear that some sort of balance, between the two diseases should be carefully observed.

It is necessary to maintain a balance of expertise: At all three levels in the programme, at central, regional and at district level there must always be ensured a reasonable balance of expertise regarding the two diseases whether that responsibility of dealing with the coordination and supervision of the programme rests with one person or more.

The balance of administrative power is important: It is safest if the overall head of the programme is really equally committed to each of the two aspects of the programme. This then requires that this person should more or less be equally knowledgeable and experienced regarding the two diseases.

Resources made available for the fight against the two diseases should also be reasonably balanced: If the leprosy branch is to be provided with drugs much more regularly or with drugs of better quality than the TB part of the programme, this would lead soon to all sorts of difficulties.

This need for balance also applies to resources like training and consultancies: These inputs should stimulate and improve both parts of the programme more or less equally.

Agreement on procedures

It is important that leprosy specialists and TB-specialists should be in full agreement on the main procedures regarding diagnosis, treatment regimens and treatment duration for each of the two diseases.

These main procedures must be laid down in official written instructions, preferably brought together in a booklet. Such a manual should also contain instructions on all recording and reporting procedures.

Similarity of procedures

It would be helpful to do the recording and reporting on the two diseases as much as possible in similar ways. Some necessary differences must be accepted, but in many aspects the registration and reporting systems can be designed very similarly. This will make instruction much easier and will facilitate the smooth running of the work.

Gradual build-up

The development of a combined programme is not just a matter of a decision in one or two committee meetings resulting in a circular letter sent out from the ministry of health. The agreement on the principles of the programme, the shaping of its structure and the formulation of its many procedures are all to be built up gradually in a process which involves several professionals and paramedical workers. The workshop method may be appropriate for this process.

When after various workshops the programme has been sufficiently shaped to be implemented, it should first be tried out in a pilot project. After some necessary adjustments the pilot area will become a demonstration and training ground for the new programme.

PRIMARY HEALTH CARE (PHC)

What is the relationship between this plea for a combined TB/Leprosy Programme and the main theme of primary health care? If PHC is more or less synonymous with basic health services, then all that has been proposed is really for the combined services to be part and parcel of PHC. The programme may administratively be fully integrated in the basic health services. The only condition is that in its technical aspects it would be coordinated and supervised by some specialized medical and paramedical staff. Where the PHC movement results in the availability of non formal community health workers at village level, it is desirable that the great potential of these additional health agents is fully utilized.

Such grass-root level workers as described in Dr. Ross' report on a primary health care 11 project in J amkhed in India, would in my opinion, not need much theoretical knowledge on leprosy or TB. A community health agent (CHA) would need to learn about the disease(s) only after a patient has been identified in the community. Then he/she is confronted with a problem and needs advice and practical instruction.

Here again it would be beneficial if the instructions and advices would come from the same source: the one combined programme. (It should however be clear that staff other than the specialized staff of the TB/Leprosy Programme would have to serve as teachers and supervisors of the (CHAs.)

WHAT CAN THE CHA DO?

Treatment

Usually the treatment should not be given by the CHA, but he/she can give a tremendous contribution by encouraging the patient to keep coming for monthly drug collection and to continue the daily intake of tablets at home.

Prevention of disability

Leprosy patients can be helped and advised in the day-to-day protection of hands, feet and eyes, A minor wound can be kept clean and rested. In case of a more serious complication, the patient can be advised and encouraged to go to a health centre or hospital in time.

Information. health education

Giving simple general information on the two diseases and on the services that are available is another important part of the CHA's contribution.

Case detection

Finally it is possible that a CHA could, once in a while, contribute to case detection.

When the CHA has been involved in the guidance of a leprosy or TB patient he/she may have come to know some early signs of the diseases.

When such early signs or symptoms are noticed in somebody else, that person would be advised to visit the health centre or health post. Early detection and treatment may then prevent a lot of suffering and may also reduce the further spread of the disease in the community.

In these four modest ways the Community Health Agents may render a tremendous contribution in the fight against leprosy and tuberculosis.

In terms of primary health care the two chronic communicable diseases constitute only a minor part of its complex and wide field of interest and concern.

It is my opinion that it is in the interest of a sound development of the primary health care concept, if some well-organized special structures are made available to help the basic health services. One such special structure which should be very relevant for the primary health care in Ethiopia is a combined tuberculosis and leprosy programme.