

Report of the Panel on Educational and Social Aspects

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IMPORTANCE OF EDUCATIONAL AND SOCIAL ASPECTS

Conditions governing leprosy are so varied, sometimes even in one country or one region, that there can be no one formula for dealing with the problems raised by the disease. Our approach to the various methods prevalent in different regions of the world has to be tolerant and understanding.

In the past the absence of proved remedies and lack of methods of prevention of deformity cast a gloom over the whole subject of leprosy which was illumined only by charitable missionary endeavour. Leprosy suffered from professional isolation and the leprosy patients from social isolation. With the effectiveness of modern treatment the medical and public health aspects of the leprosy problem naturally assumed a priority.

The education and social aspects of leprosy, however, are so closely related to the medical and preventive aspects that it will be a grave mistake to underestimate them. It is essential that they should form an integral part of the leprosy campaign and adequate budgetary provision for these activities should be made in leprosy control campaigns. Else, the very success of our treatment and control programmes may be retarded.

THE NEED TO IMPROVE STANDARDS OF LIVING

Though there appears to be no clear relation between leprosy prevalence and state of nutrition, climate, social customs, etc., the important contributing factor appears to be the low economic status and the level of hygiene as reflected particularly in overcrowded and insanitary housing. It becomes important therefore that while we should do everything in our power to diagnose cases early and bring them under treatment, we should also side by side endeavour to improve the standard of living of the endemic regions, and especially to improve the housing and to inculcate the hygienic habits amongst the general public, the patients and their contacts.

PREJUDICE AND IGNORANCE SHOULD BE COMBATED ACTIVELY

While prejudices against leprosy and discrimination against leprosy patients seem to have declined in some measure, especially in areas where planned leprosy control activities have been in progress over a

length of time, the deep-rooted prejudice against leprosy are very slow to die. These prejudices, besides causing mental pain to the patient, hinder his early and willing resort to treatment. This is so especially in the more sophisticated levels of society. On the other hand there is also the fact that in many of the areas where leprosy is more prevalent, one meets with a total indifference to the presence of leprosy in the community. Such indifference is equally harmful to successful leprosy control measures. Our educational objective should therefore be to evoke in the public at large, the patients and their families, a reasoned attitude towards leprosy which neither exaggerates the dangers of leprosy nor minimises it.

EDUCATION SHOULD COVER MANY ASPECTS AND MANY GROUPS

Education with regard to leprosy has to cover many aspects and has to be directed towards many sections and groups of the public including the patient and his family. First and foremost, the medical student should receive adequate teaching in leprosy. Hospitals attached to medical colleges and schools should promote active interest in leprosy and a reasoned attitude towards it amongst medical students by making leprosy treatment an integral part of the work of the hospital. Health officials should also be reorientated in the modern concepts of leprosy so that they bring in its handling an outlook similar to that upon other communicable diseases. Since the leaders of the society have largely to influence the action of Government and the community in matters relating to social affairs, it becomes necessary to inform them of the modern approach to leprosy and get their influential support for forward policies with regard to leprosy. Frequently, the educated are as ignorant as the uneducated with regard to leprosy. In fact their prejudices may be more deep-rooted and act as a hindrance to intelligent measures of leprosy control. Persistent attempts should therefore be made to educate the educated and to win the co-operation of leaders of society at all levels and also of the administrators. Such an attempt is most essential especially in highly endemic regions where special efforts to control and eradicate leprosy are needed.

IMPORTANCE OF EDUCATING TEACHERS, SOCIAL WORKERS, ETC.

Teachers should be enlightened about the facts of leprosy and how they can help by disseminating information amongst their pupils, their parents and the general public. All social workers should be given an orientation in the modern approach to leprosy with particular reference to the social problems arising in leprosy. Curricula for schools and colleges of social work should include instruction in leprosy. Leprosy workers should constantly be seeking opportunities to make contacts with the general run of social workers and also to address groups of them. For, some of the social problems created by the indigence of the leprosy patients can be solved only when the social workers come to regard leprosy without fear and with understanding and are prepared to bring those disabled by leprosy or rendered destitute by it and the uninfected children of leprosy

patients within the scope of the general welfare services for the handicapped, the children, etc.

EDUCATION OF THE GENERAL PUBLIC

With regard to the general public, our approach has to be one of providing the right type of information and education and the correct attitude to leprosy rather than one of publicity. Every medium of education should be employed. Newspapers can be very helpful. But due care has to be taken to see that they refrain from sensational presentation of news relating to leprosy. Else newspaper publicity may be a hindrance rather than a help. Persistent attempts should be made to approach the press and to get them to view leprosy in the right perspective, as a preventable and curable disease. It should be impressed upon them that news, stories and pictures regarding leprosy that appear in the press should dwell on the more hopeful aspects which have emerged in recent days and that in whatever they say they should not add to the prevailing ignorance and misunderstanding of the disease. We should also urge that magazines, novels, movies, etc., should refrain from exploiting the theme of leprosy by undue dramatisation and sensational presentation. They should constantly be urged to avoid the use of the word 'leper' which carries an ancient stigma with it and to refer to those who suffer from leprosy as leprosy patients.

Providing information on leprosy to the public at large is a task that has to be approached with caution. Theoretical and speculative information, no matter how thrilling to the research worker, should be withheld from the public. For, newspapers are apt to give undue prominence to these items and the public who are already full of doubts and fears regarding leprosy are apt to get more confused in their approach to leprosy and more confirmed in their old time notions. Although there is still much to be known about leprosy, this limitation should not prevent our working out a realistic leprosy education programme. The educational programmes must take into account the 'knowns' and 'unknowns' and present these to the public in a way that is understandable and reasonable. They should aim at promoting a leprosy control policy which will be based on what is known, what can be deduced and what can be carried out humanely.

EDUCATION OF THE PATIENT AND HIS FAMILY

The education of the patient and his family is very important. Our aim should be to get them to view leprosy without fear, but with the respect due to it, as a communicable disease from which their families and the community at large have to be protected. The patient must be encouraged to take a hopeful attitude to his condition, to persist in his treatment, to co-operate in preventive measures and to learn to look after himself in such a way that he can avoid and overcome deformity. The family should also be instructed in such a way that they will help in keeping the morale of the patient, give him the necessary sympathy and at the same time take preventive precautions to control the spread of infection.

PROTECTION OF CHILDREN

In many endemic countries, infection occurs more commonly in childhood and it becomes necessary to pay special attention to the protection of children. Often, children constantly exposed to infection need special attention. Insistence on regular treatment by the patient and the observance of prophylactic measures within the household is the most practical means to protection. Uninfected children who find themselves cut off from parents or relatives who are in hospital or whose parents or relations are unable to care for them satisfactorily should be admitted to general child care institutions. But arrangements should be made to get them periodically examined. This should be done without any publicity that may mark them from other children. Perhaps the best procedure would be to arrange their examination for leprosy as part of the medical check-up of school children. In the case of infected children except where their condition warrants otherwise, the school authorities should be made to co-operate in letting them take treatment in an out-patient and attending school. These children may need special help for their education where their parents or relatives are too poor to pay for it. Under some circumstances, preventoria or healthy children's homes may have to be run. But with the education of social service organisations and social workers in the correct approach to leprosy, it should be possible to arrange for the care and education of these children in general child care institutions. As far as possible, the family unit should be maintained and attempts should be made for the protection and care of the children in family surroundings.

NO NEED FOR SPECIAL LEGISLATION ON LEPROSY

In the light of modern knowledge, there is really no need for any special legislation on leprosy, and any legal measures dealing with leprosy should form part of general public health regulations. Wherever there is legislation on leprosy which is not in conformity with the modern approach to the disease, Governments should be urged to revise such legislations suitably. It is recommended that where Governments still enforce a policy of compulsory segregation, this should be totally abandoned.

SOCIAL AND ECONOMIC ASSISTANCE TO PATIENTS – ITS IMPORTANCE

Due attention should be paid to the social and economic difficulties of the patients and their families and attempts should be made to relieve them. The methods to be adopted for such relief will depend on the particular circumstances of a country or a region. In countries where public assistance of various types are available to the unemployed, the sick, the disabled, the destitute, etc., the leprosy patient and his family should be eligible for such assistance. Though in countries with a low economic standard priority has to be given to treatment and control measures, the social and economic difficulties of the patient should not be ignored. They have to be attended to, if only because assistance to patients to relieve their difficulties will win their co-operation in treatment and control measures. In these countries the problem of the disabled and the destitute patient

is a serious one. Governments should encourage the care of these patients by voluntary institutions by making suitable grants to them and also promote their care through social welfare departments.

RECOMMENDATIONS

(1) In view of the urgency and importance of combating the ignorance and prejudice that exists amongst the members of the public, an active programme to educate all sections of the public should be promoted. Popular ignorance is a great hindrance to leprosy control campaigns, and therefore health education through every available media should form an integral part of leprosy control campaigns. Moreover the goal of integration of leprosy services with public health services will be achieved only when there is an enlightened and active participation of the community in leprosy control programmes. It is therefore recommended that adequate budgetary provision for health education be made in leprosy control programmes.

(2) Health education should cover all sections of the community, and it is most important that school teachers, social workers, and community leaders should receive orientation in the modern approach to leprosy so that they spread knowledge in their respective spheres and promote right action with regard to the control of leprosy and the problems of the leprosy patient.

(3) It is of the utmost importance that medical undergraduates should receive adequate teaching in leprosy so that the general medical practitioner is able and willing to take an active part in leprosy control programmes which should become more and more integrated with public health services. It is recommended that instruction on leprosy be linked with instruction on Dermatology, Neurology, public health handling of communicable diseases, etc., so that the age-old professional isolation of leprosy may be broken and leprosy may be regarded as one disease among many, entitled to the interest of all doctors and capable of being of deep interest to them.

Refresher post-graduate courses should be frequently arranged for the medical profession.

(4) The social and economic difficulties of leprosy patients should be relieved in ways appropriate to each region so that the patients, feeling happier, are better able to co-operate with treatment and control measures. Moreover, it is important to remember that the needs of the 'individual' should not be forgotten in our concentration on the 'mass' of the problem for purposes of planning.

(5) Special attention is needed to the children constantly exposed to infection by leprosy patients. Uninfected children cut off from parents or relatives unable to care for them satisfactorily, should normally be admitted to child care institutions. In some areas, however, prevention or healthy childrens' homes may still have to be run.

(6) Considering that lack of personnel of various types hinders greatly the advance of leprosy control programmes, it is important that governments and all those interested in promoting leprosy control should finance and

encourage training programmes, preferably in medical institutions and medical research centres or in association with them. In areas where such institutions do not exist a well-staffed and well-equipped leprosy centre or institution should be recognised as a training centre, these training centres being adequately supported by Governments.

(7) The Congress invites increasing and a more active and enlightened interest in the problems of leprosy on the part of newspapers, the radio, the cinema, and other media of communication. We would emphasise that, in doing so, they should adhere to concepts of leprosy consistent with present scientific knowledge of leprosy and refrain from an undue sensational approach to the disease based on mediaeval notions, and also from undue dramatisation of situations and episodes in stories with a leprosy background lest they should, by doing so, increase the existing misunderstanding concerning leprosy.

(8) We endorse the Report of the Panel on Physical Medicine, Rehabilitation, Surgery and Vocational Training, in so far as it relates to educational and social aspects. In doing so we would stress the importance of social and psychological rehabilitation of the patient, as well as that of physical rehabilitation and vocational training. For the ultimate goal of rehabilitation is not only economic self-sufficiency but social and moral welfare leading to the wider opportunities and responsibilities of normal life.