COMMITTEE 6: WORKSHOP ON HUMAN ASPECTS IN THE TREATMENT OF LEPROSY PATIENTS

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INTRODUCTION

Mass treatment and case finding in any endemic area tends to have the effect of dehumanizing the individual patient. Therefore, each member of the team, medical, paramedical and social, while bringing to bear on the patient his own particular expertise, must constantly remind himself of the patient's total needs — physical, emotional and social, and treat him as a fellow human being. The effective moments for the application of the human elements to the treatment of leprosy patients are during the first contacts of the team with the patient.

GENERAL CONSIDERATIONS

The extent of the trauma inflicted on the patient by the diagnosis of leprosy is very important. The word "leprosy" is to be used with caution, since it tends to have a socio-historical, in addition to a medical connotation.

The stigma attached to leprosy can only be overcome by a continuous program of health education at all levels and for all target audiences. The shock of the first diagnosis should be communicated to the patient with kindness. The patient often may not believe it until the deformities appear. This lack of acceptance of the diagnosis is a significant factor, along with socio-economic considerations, in chronic absenteeism from treatment by the patient.

CASE FINDING AND CASE HOLDING

Finding patients in the community and holding their confidence during treatment is a continuing concern. The whole team must be imbued with an attitude of sympathy for the patient. His privacy must be respected and his identity preserved. The method of door to door delivery of medication, and unscheduled follow-up visits to ensure that the patient is taking his tablets has proved useful.

There are many factors which render regular clinic attendance difficult for the patient, and the health education team should take account of these problems in their presentation. The continuing health education of the patient, his family and society should be accepted as requiring the highest priority.

Well qualified social workers with carefully defined job descriptions must be engaged. They should ensure that the other members of the team are trained, not merely in the detection of early lesions and medical aspects, but in psychology, technics of communication and counseling.

CENTERS FOR PATIENT CARE

The old pattern of institutional care has largely given place to field clinics. Institutions, however, still remain a necessity. The nature of the institution is important, and the difference in the psychological impact on patients in a leprosarium and a hospital is considerable.

Emphasis must be given to the need for understanding the patient's emotional reactions, and in the hospital set-up, the staff must take time to care for these too. It is important to establish an interdisciplinary team participation in planning the treatment of the patient.

Hospitalization should be short-term and interrupted. Each admission should be for a specific and documented objective, such as the healing of an ulcer, operation of a hand, treatment of neuritis, etc., the patient being discharged after this target is achieved, to be readmitted later for another reason if necessary. Patients should be taught self-care of their hands and feet at home.

REHABILITATION AND REINTEGRATION

In relation to this subject, health education was again the line strongly advocated by all the participants. The need was stressed to implement the Havana Congress' (1948) decision to educate all levels: the medical profession, politicians and the state administration, schools and society at large, of which of course the patient is also a member. The central place of domiciliary rehabilitation has to be emphasized and the team approach is required to keep the patient in his home environment.

The beggar presents a real problem of socio-economic failure in developing countries. Rehabilitation of these patients is difficult but not impossible. However, efforts and resources should also be used to prevent patients from descending to this level.

Rehabilitation and reintegration of the patient in society, especially if he has deformities, can only be achieved by sustained efforts on the part of the patient, the medical, paramedical and social team, and society as a whole. It is necessary to discover and harness the patient's abilities and not be distracted by his disabilities.

Rehabilitation should be planned after careful consideration as to whether further displacement is essential or not. All measures taken for persons disabled because of leprosy should be in the context of resolutions already adopted by ECOSOC, WHO, and ILO ([1-3]). Care must be taken not to make leprosy a qualification for special privileges.

It has also been proved that it is less expensive to provide appropriate rehabilitation services than to provide the necessary care for an individual who, without rehabilitation, depends on public help.

BASIC PRINCIPLES FOR THE HUMANE TREATMENT OF LEPROSY PATIENTS

a. Health education, both general and specific, must be the basis of all rehabilitation.

b. A natural and empathetic approach to the patient is required to reduce psychic trauma and loss of identity to the minimum.

c. Hospitalization should be for short periods, each with definite objectives. Long-term treatment should be interrupted by periods at home from time to time, to avoid long separations from the family.

d. Much time should be spent by the team in instructing the patient in the care of his hands and feet and the prevention of injuries.

e. The approach to rehabilitation should not be confined to one channel, such as sheltered industry or domiciliary employment, but all efforts should be made to find out the type of rehabilitation most suited to the country, the environment, the patient's aptitude, skills and social status, and the available funds for capital costs per work place.

RECOMMENDATIONS

To encourage further investigation and to carry out the above basic principles, it is particularly necessary:

a. To organize a research center and/or referral library, to collect a bibliography of all publications on social aspects of leprosy patient care, and to make these available to those interested.

b. To inform on a continuing basis and with discernment, every section of the population, especially in areas and countries where leprosy is endemic, utilizing mass media about the leprosy problem and its social aspects where possible in the context of general health education, in order to facilitate the acceptance of leprosy patients.

c. To produce articles, TV and radio features, as well as booklets in different languages on the human aspects of leprosy. Wherever false concepts are being propagated in the mass media, the concerned organizations must contact the authors, request the withdrawal of any misleading ideas and offer in their place the accepted facts of the disease. If necessary a public protest may be made utilizing the same media.

d. To organize in endemic areas and countries regular courses in schools, universities, medical schools, etc., not only on the medical aspects of the disease, but also on its historical, social and economic aspects, pointing out the necessity for humane treatment of the patients.

e. To train in social aspects (by courses, conferences, seminars, etc.) the personnel engaged in case finding and working in health centers, hospitals or other services, and to engage qualified social workers especially for important projects.

f. To bring to the notice of everybody concerned (especially social, medical, commercial and pharmaceutical agencies) these important aspects of leprosy programs; in particular, to encourage investment in research and development, and lower prices of antileprosy drugs.

g. To awake the conscience of governments to provide all facilities for the production of antileprosy drugs and equipment, and where necessary, to waive customs duties and other formalities connected with the import of these drugs and equipment.

h. To draw the attention of intergovernmental organizations such as UNO, WHO and ILO, international non-governmental organizations such as ILA and ILEP, as well as governments and private organizations, to the need for a concern for the social and human aspects in the treatment of leprosy patients, as outlined in this report, taking into consideration recommendations and guidelines already adopted. To achieve these objectives, it is essential that all these agencies act together in close cooperation.

REFERENCES

1. Recommendation No. 99 of the International Labor Organization concerning vocational rehabilitation of the disabled (1955).
2. Resolution A29.68. Disability prevention and rehabilitation, World Health Organization (1976).
3. Resolution 1921 (LVIII). Prevention of disability and rehabilitation of disabled persons, United Nations Economic and Social Council (1975).