

COMMITTEE 7: WORKSHOP ON SOCIAL ASPECTS

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Policy statement. The aim of social research in leprosy should be to assist in improving the policy and execution of leprosy control. At the same time, it should contribute to a conceptual framework which helps to understand the social, economic, and psychological problems experienced by leprosy patients, their relatives, and the health staff concerned.

Criteria for research.

a) Research should be scientifically sound, ethically acceptable, and cost effective.

b) Research should be carried out by interdisciplinary teams of social and medical scientists.

c) The active participation of local personnel (medical, paramedical, social workers) as well as patients and community members should be encouraged.

d) Research should whenever possible be undertaken by national researchers.

Research to date has concentrated on the following topics:

a) Knowledge, beliefs, and attitudes concerning leprosy and health-related behavior of leprosy patients and community members. Often research results are geared to health education.

b) Social, economic, and psychological consequences of contracting leprosy, i.e., stigma, and their relationship to rehabilitation.

c) Patient compliance: medical, social, economic, cultural, psychological, and leprosy service factors influencing case-finding and case-holding.

d) Management and functioning of leprosy control: health staff's knowledge of leprosy and leprosy treatment, and its behavior towards leprosy patients; organizational

bottlenecks in leprosy services; cost effectiveness (e.g., of vertical services, of integrated services, and of primary health care including leprosy control).

These topics have been elaborated in a number of meetings organized by WHO and national/international leprosy associations.

Research priorities. This workshop strongly encouraged a comprehensive approach to problems in leprosy control, paying equal attention to the factors related to the patient, the patient's near surroundings, and to the leprosy services. Research should ultimately concentrate on those areas where the problems are most obvious and where remedial action seems most feasible.

In addition, to continue the research above, the following topics were proposed for elaboration of previous research:

a) Definition by the community and by the patients of the concepts of illness and cure in leprosy:

- Terminology of different manifestations/stages of leprosy used by the community and by the patients

b) Consequences of contracting leprosy:

- Possible differences between the perception of stigma by community members, staff, and by patients, and the degree of stigma actually experienced
- Forces that make some leprosy patients stigmatize themselves (comparative research)
- Mechanisms that help patients to maintain and to regain their social and economic positions in society; determinants of self-acceptance and community acceptance of patients

c) Evaluation of:

- Acceptability to patients, community, and health staff of different types and ways of providing services
- Content and impact of health education
- Possible contributions of the community, leprosy patients, and social services to leprosy control, including care of the handicapped
- Economic and social consequences of reconstructive surgery

The following topics for new research were identified:

a) Participation in the planning and monitoring of trials with multidrug therapy (MDT); evaluation of the effect of MDT on the community and on the patient's perceptions of leprosy

b) Participation in the planning, monitoring, and evaluation of vaccine trials in the field

c) Investigation of the factors in human behavior which may be contributing to the transmission of leprosy, e.g., migration

Research methods. A combination of research methods should be used: the study of relevant documents; informal and formal interviews; questionnaires; observing systematically. It was noted that questionnaires as a single research tool may give superficial and misleading results.

Implementation of research results. So-

cial research should provide direction for possible solutions to problems and for action. The results should be made available and presented in terms which are understandable to the potential users (medical and social workers). Implementation of research results will be more effective if the social scientists who conducted the research are invited to participate.

In order to increase the quality and the quantity of social research and its impact on leprosy control, it was suggested that regional centers be developed as focal points for the collection and dissemination of research results. These centers would also develop training programs for social research in leprosy and carry out investigations. It was proposed that the existing informal international network of social researchers in leprosy should be used and strengthened with links established to the regional centers mentioned above.

The manual on *Social Dimensions of Leprosy* (ILEP, 1982) was discussed in the workshop. This book could be useful to paramedical teachers who have some training in the social sciences in order that they might adapt it for local use. However, for use at this field level, the theoretical section of the manual would need revision, focusing on the working situation of a field staff. The workshop made a number of suggestions for this purpose.