

**WORKSHOP 9: CONSUMER AND COMMUNITY PARTICIPATION IN
CARE AND REHABILITATION PROGRAMS FOR
PERSONS WITH LEPROSY**

Chair: Maria Leide W. de Oliveira
Co-Chair: Anwei Skinsnes Law
Rapporteur: Judith Justice

Participants

Z. Bakirtzief	R. Mutatkar
M. Bly	R. Ngatimin
A. T. D'Souza	F. V. Nunes
M. U. Ekekezie	M. Prado
E. Faria	P. B. Predaswat
P. K. Gopal	B. Punikaia
S. Grino	A. Samy
E. Ishihara	R. K. Shrestha
S. K. Jung	J. Sircar
J. Lew	H. Smith
V. P. Macaden	S. Solomon
M. Malo	H. Srinivasan
S. G. Mariam	A. Style
J. Mehta	E. Taferi
K. Mutatkar	L.-H. Yang

J.-S. Yoo

The Workshop on Consumer and Community Participation in Care and Rehabilitation Programs for Persons with Leprosy combined three Workshop topics from the XIIIth International Leprosy Congress including Social Aspects, Health Education and Rehabilitation.

The emphasis of the Workshop was on the individual who has the disease, the community as consumers, and the leprosy control program as the production process which encompasses all aspects of care, extending beyond chemotherapy and the reduction of prevalence rates. The Workshop emphasized the social and economic aspects of leprosy without ignoring the biomedical aspects. In keeping with this approach, social science research needs to provide the appropriate theories and methodology for studying the leprosy control program, with special efforts to include perceptions of individuals with the disease and the community.

The following invited formal presentations were made by Workshop participants: a) "Status of Health Education in Leprosy Control" by Dr. R. Mutatkar (India), b)

"Physical Rehabilitation and the Community" by Dr. H. Srinivasan (India), c) "Socioeconomic Rehabilitation" by Dr. J. Lew (Korea) and Mr. S. K. Jung (Korea), d) "The Priorities of Social Science Research in Leprosy" by Dr. Judith Justice (USA), e) "Case Study of Economic Rehabilitation in India" by Dr. Jal Mehta (India), f) "Hawaiian Storytelling" by Makia Malo (USA).

Discussion

The Workshop participants were divided into three groups for discussion: Health Education, Rehabilitation and Social Science Research.

Health Education. The Health Education Group addressed the following questions: How can leprosy treatment (in its present short-term form) be managed so that the individual's life, work and family relationships will not be interrupted? Has MDT really altered the social isolation felt by persons with leprosy? What can be done to lessen social isolation? How can individuals with leprosy be brought into the public health education process?

Rehabilitation. The Rehabilitation Group addressed the following questions: Can leprosy rehabilitation programs be successfully integrated into the general health care system? If so, how would this be possible? Is this always desirable? How can persons who have had leprosy, and have been living in colonies or other isolated situations, be empowered to participate in community activities? How can they be re-integrated into the community and what can be done for those for whom integration is not possible? How can persons with leprosy improve their socioeconomic status in order to become fully accepted as productive members of the community? How can fund raisers be brought into the public education process?

Social Science Research. The Social Science Research Group addressed the following questions: What should be the priorities of social science research in leprosy? How can the results of the projects in social science research be applied in order to improve the efficiency of leprosy control?

Recommendations

For Health Education.

1. The management of leprosy treatment can be successful at the individual and family level without interrupting normal life, work and family relationships. To achieve this, drug delivery and other services should be combined with personal and family counseling and appropriate health education for the individual, his family and the community.

2. A combination of MDT and health education has lessened the social isolation felt by individuals with leprosy.

3. Health education efforts should be evaluated periodically and updated to include the latest scientific information.

4. As leprosy programs are increasingly integrated into the general health care system, the number of leprosy workers and health educators is often reduced. Serious consideration should be given to training individuals with leprosy to fill these positions so that health education efforts are not diminished.

5. Networks should be devised whereby information can be distributed to individuals with the disease.

6. It is recognized that each country has

its preferred terminology for the disease. However, the use of derogatory terms such as "leper" should never be used.

7. In integrated programs, community participation becomes even more necessary. Organized community groups, such as youth groups, women's groups and service organizations, should be utilized to help disseminate information on leprosy. Information provided should take into consideration sociocultural factors of the people.

8. Religious leaders also should be encouraged to be health educators to educate the community about leprosy.

9. Every effort should be made to ensure that the mass media does not give incorrect information which perpetuates stigma and fear.

10. Ultimately, the responsibility for health education should be transferred from health providers to the community.

11. Health education will help to achieve the stated goal of elimination of leprosy, but it must be continued even after leprosy is no longer considered "a public health problem."

For Rehabilitation. Multidrug therapy has brought great benefits to a large number of people, and future development in chemotherapy promises simpler and shorter treatment. These changes suggest a possible shift in emphasis and increased allocation of human and financial resources to the physical and socioeconomic rehabilitation of persons who have leprosy-related handicaps. The participation of persons with such handicaps in the delivery of rehabilitation services at all levels is seen not only as a response to their demands, but also as a beneficial contribution. In view of such future developments, the participants of the discussion group on Rehabilitation made the following recommendations:

1. Each country should develop a national policy suited to its requirement to deal with leprosy-related problems other than chemotherapy. Such a policy should make a political commitment to deal with the massive problems of physical and socioeconomic rehabilitation, allocate necessary funds, generate the needed infrastructure, and ensure the participation of people with leprosy-related handicaps in the efforts of governments and nongovernmental organizations (NGOs).

2. Action plans for physical, socioeconomic and psychological rehabilitation of the persons with leprosy-related handicaps need to be prepared and adequate budgetary allocation ensured.

3. It is strongly recommended that, wherever possible, physical rehabilitation and disability prevention programs operate through the general health delivery services. With MDT, contact between providers and persons with the disease is lessened, increasing the risk of negligence of disability prevention. To achieve the effective implementation of programs, appropriate training should be given to all connected personnel.

4. It is recognized that leprosy and poverty are inter-related. Therefore, stigma associated with the disease can be eliminated more easily through improving the individual's economic status rather than through education of the community. As confirmed by experiences in Korea and India, the large-scale initiation of programs designed to improve the socioeconomic status of persons with leprosy-related handicaps can be very successful and are needed urgently in other areas of the world.

5. In countries such as Japan and the U.S.A. where economic well-being is not as serious a problem as in developing countries, persons with leprosy still encounter problems of self respect related to society's attitudes. For example, Japanese laws require persons with leprosy to inform officials every time they travel, even within the country. The Workshop, therefore, recommends that discriminatory laws such as those in Japan and India be removed and that persons with leprosy-related handicaps be respected.

6. Socioeconomic projects have a greater chance of success if they are planned and controlled by the beneficiaries. Modes of control, format and management may vary, e.g., handicraft subcontractors, agro-based groups, cooperatives, registered small-scale industry, etc., depending on the situation in each country, with the common factor being full participation of the beneficiaries in the decision-making process.

7. "Leprosy colonies" need not always be viewed as a negative development but one that fulfilled a need and, therefore, the situation must be utilized to the best advantage. An extreme example is Korea,

where the nondisabled moved into such villages because of their economic prosperity. Brazil provides another example where people in colonies are free to leave, and those who choose to remain must be allowed to live undisturbed. However, it must be strongly stated that no new colonies or segregated hospitals or settlements should be created.

8. In countries where special privileges are given to persons with hearing, visual and orthopedic disabilities, similar privileges should not be denied to those with leprosy-related social disabilities.

9. The use of photos and pictures depicting poverty, deformity and deprivation that shock people, promote pity and appeal to the emotions should not be used in fund raising. The information provided today should depict reality and appeal to the intellect. In practical terms, earlier appeals were for grants for charitable purposes. Appeals should now be based on the need for investment in development and how this investment would provide relief in the short term and eliminate dependency in the long term.

For Social Science Research. Recommendations were made taking into account the individual, community, health services, technology, and social science theory and methodology.

1. The group endorses the definition of the case of leprosy as given in the Sixth WHO Expert Committee Report on Leprosy. Social science research, therefore, should address all aspects of leprosy including epidemiology, chemotherapy, deformity prevention and rehabilitation.

2. Social science research should document and evaluate the process of integrating leprosy control programs into the general health services.

3. Social science research should address the concept of cure including the perceptions of patients, community and health workers, particularly related to the implementation of MDT at the global level.

4. Social science research methodology workshops should be held for leprosy workers who are interested in social science inputs in leprosy control work.

5. Training materials should be developed for medical officers and other health workers for looking at problems of individ-

uals with the disease and the community which result from problems of disability, ulcers, the threat of social isolation, and dehabilitation.

6. Social science research should be used for empowerment of individuals with leprosy.

7. A recording system for nonmedical work needs to be developed, including qualitative and quantitative parameters.

8. Funding for social science research in leprosy needs to be generated from international and national agencies including the international organizations, such as WHO, UNICEF, ILA, ILEP, ALM, national and international NGOs, and national social and medical research councils.

9. Social science research should be used for research, documentation and evaluation of community participation programs designed to share responsibilities of the health services in leprosy control.

10. Social scientists should study social, economic and political issues related to the decline of leprosy colonies.

11. Participatory research approaches involving persons with leprosy, community and health workers should be encouraged.

12. Social scientists should give special attention to identifying research problems and implementation of studies in collaboration with individuals, the community and health care providers.

13. Research results should be disseminated in accessible forms, including publication in international and national scientific journals, particularly in countries where research is conducted, and made available to patients, communities and leprosy control programs.

14. Because it is not possible for many social scientists to attend international meetings, national and international networks of social scientists should be formed to enhance the training of social scientists, to increase social science research, and to ensure the dissemination of research results. Social scientists should be recognized as one of the scientific groups of the International Leprosy Association with specialized meetings at the International Congresses.