

SOCIAL ASPECTS OF LEPROSY

By

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Leprosy is known as a 'great disease' by common people. Scientists interested in leprosy find it challenging. Medical practitioners find it uninteresting. Social scientists do not consider leprosy as their domain. Administrators are interested in the prevalence and incidence rates. Social workers try to focus on the rehabilitation of patients. Men of religion treat leprosy with compassion. Leprosy is thus differently perceived, but least understood. People are afraid of it since it brings social death and changes the identity of a person. Leprosy control programmes are greatly concerned in developing technology to prevent transmission and ensure cure with a view to reduce the pool of infection. But the situations connected with delivery of technology to people lead to various problems such as drug resistance. People are more concerned with clinical manifestations of the disease than with bacteriological condition and they are mortally afraid of deformity.

Social aspects of leprosy have been conventionally understood as dealing with socio-economic and rehabilitative problems of leprosy patients. Humanitarian work of sheltering leprosy patients in leprosy villages has been designated as great social work and is lauded as service to God. Till the International Congress of 1984, sessions on Social Aspects used to be concurrent sessions and the workshop was designated as on Human Aspects relating to treatment of leprosy patients. Shift in the emphasis from patient to community emphasizes the role of social sciences in preference to humanitarian social work. Researches presented at the Social Aspects session at the XII Congress related mainly to the need and methods of health education, the role of

migration of people, the burden experienced by families of leprosy patients, the problem of drop-outs, attitudes of people about leprosy, problems of rehabilitation, and self-developed colonies.

These types of researches have been attempted by (1) those social science students who have no understanding of the medical problem of leprosy, and (2) the para-medical staff in leprosy control establishments to seek solutions to the problems of compliance.

Health education has also been misunderstood, in practice, as a tool to ensure compliance of people with leprosy control strategies.

The social aspects thus continue to be misunderstood as dealing with the rehabilitation of patients and socio-economic reasons for non-compliance. For people the disease threatening social death continues to be dreaded and stigmatised. They do not understand:

- (1) Why one gets it. Knowledge of immunology does not reach them through health education programmes.
- (2) How does it spread?
- (3) Why their doctors do not confidently diagnose it but refer them to places like leprosy clinics which are 'haunted' places.
- (4) Why long treatment is given which does not bring about any perceptible change in a reasonable period and usually no duration of treatment is prescribed.
- (5) Why one gets deformities.

Answers to some of these questions are not known to anybody and if they are tried to be explained to common people, it may put more fear in their minds, knowing more uncertainties about the disease. In spite of widespread literacy programmes, people occupying decision-making or opinion-making positions such as law givers, administrators, teachers, religious leaders are equally ignorant about leprosy and nurture prejudices handed down by tradition.

The scientists, on the other hand, are engaged in developing better drugs and vaccine against leprosy in order to control the disease. DDS is still considered an effective drug but the problem of compliance has led to drug resistance issues. MDT is now considered effective but how would its delivery to people be ensured when DDS could not be delivered to the people? Smallpox vaccine has taken 200 years to produce results; polio vaccine is still ineffective in the sense that most orthopedic disabilities are due to polio.

Thus, tools developed under laboratory conditions may be ideal, but unless their use by people is ensured, they are ineffective. Common people, whose perceptions of organised and disorganised life are culturally patterned, do not possess enough motivation to take care of their health, particularly in case of chronic ailments like leprosy which do not require immediate attention. Those illnesses are cared for by people who hinder their playing of effective social roles, who hinder their efforts in fulfilling social obligations. In leprosy, that stage is reached when a person's identity as a member of a social group is threatened and when remedial action is difficult.

The term social aspects used in leprosy should actually include, in social science terminology, social, cultural, economic, political, psychological and religious issues. It would thus refer to the interplay of forces that act on the patient, the family, the community, health workers and the drug industry. This broad understanding of social aspects would give better insights into the role of these aspects in the transmission and control of leprosy.

The crux of leprosy control programmes, from the people's point of view, should aim at preventing deformities. People are afraid of leprosy because of deformities. Deformity threatens personal identity by threatening social death. The close association of the word leprosy with deformity prompts a person not to accept the diagnosis, since its acceptance threatens social rejection. However, nerve damage research has so far not produced any preventable solution. The success of the programme can therefore be measured in terms of deformity rate.

The problems of case finding and case holding have been identified, and solutions have been suggested through health education, community participation and better management techniques.

A policy statement about health education adopted at the Post-Congress workshop on Health Education spells out the broad objectives: "Health Education refers to the process of assimilation of scientific health knowledge, attitudes and behaviour in the health culture of people. Health Education in leprosy aims at ensuring community participation in leprosy control programmes. Health education therefore addresses itself to the patients, their families, to the community and all components of health services".

The importance of listening to people and discussion is being more realised now in preference to one-way talk from the health education worker to pass on 'wisdom' to the people. Community participation is also getting its due importance, which would mean (i)

involvement of the community in the utilisation of services, (ii) participation in decision-making to meet the objectives: (a) increase the social acceptability and effectiveness of leprosy control, (b) increase cost effectiveness. Indicators of success of community participation would mean (i) deformity rate reduction, (ii) voluntary reporting, (iii) utilisation of services, and (iv) rehabilitation.

Although the transmission process is not conclusively known, transmission from one human to another calls for an understanding of the cultural habits of the people. Environments producing respiratory infections and the habits of spitting and sneezing by people are relevant for understanding droplet infection. Habits like tobacco-chewing need to be understood for their relevance. Contacts in all cultural groups are socially defined and are related to caste, class and kinship affiliations. Large-scale migrations and settlements in industrialised cities or at development sites have relevance for epidemiological studies. In cities like Bombay, the prevalence rate has become high due to migrations. The intensity of interaction in both sexes needs to be studied by variation according to sex.

In every society, the rules of endogamy and exogamy regulate mating patterns. These rules, having been followed for centuries, coupled with varying food habits and other cultural patterns, must have given rise to varying genetic compositions in various ethnic groups. Studies in population genetics may therefore be relevant in leprosy transmission. It is felt that not enough attention is given to strains amongst human beings as amongst strains in bacteria.

Multi-drug therapy has been liked by people since it has shown quick results in the clinical manifestations of the disease. The disappearance of nodules and change in skin colour have helped to regain the social identity which was being lost. Studies of the impact of MDT on the attitudes of patients, their families and health workers would be useful in a situation where MDT has been administered only to lepromatous and where it has been given to all patients.

Needed Research

The social sciences possess tools for quantitative as well as qualitative research. Usually a judicious combination of quantitative and qualitative methods is recommended for valid and reliable results. Research areas in social aspects could be broadly divided into (a) those

having a direct bearing on control programmes, and (b) those supporting epidemiological and immunological studies. This classification is, no doubt, arbitrary and not mutually exclusive, but it may give some guidelines for providing priorities or forming research teams.

In the first category, the following research areas could be included:

(1) Operational problems in case finding. Comparative study in high and low prevalence zones could be attempted from the standpoint of people and health workers.

(2) Case holding. Studies of absenteeism in high and low endemic areas. Case studies of regular people to understand motivational forces are necessary.

(3) The perception of leprosy by health workers at different levels.

(4) An evaluation of the effect of MDT on patients, and its relevance to Health Education, community and health workers.

(5) Action research or participatory research in community participation.

(6) The role of community health volunteers and traditional birth attendants in leprosy control and rehabilitation in the context of Primary Health Care.

(7) Studies in migration and leprosy, with special reference to ethnic groups from endemic areas.

(8) The perception of stigma by the community and patients and the degree of stigma actually experienced.

(9) Studies of cured persons accepted back by the community to understand the reversibility of stigma.

In the second category, the following research areas could be included:

(1) Contact studies with reference to extended kin group, including consanguineal and affinal kin.

(2) Correlation studies of leprosy with crowding, personal hygiene habits and environmental sanitation.

(3) Attitudes of people about other vaccination programmes.

(4) Studies in social structure to understand mating patterns, rules of endogamy and exogamy, patient interaction with other members of the group, and rules of physical proximity.

(5) Studies of local physical environment with special reference to micro-environment of patients in terms of daily mobility, eating, drinking and sleeping habits, etc.

(6) Relevant studies about morbidity, with particular reference to skin, nervous and respiratory disorders.

It would be necessary to associate social scientists as members of multi-disciplinary research teams giving them equal status. This would also ensure understanding of relevant research issues by social scientists. Social scientists are good in evaluation research. They are also good at providing background social and economic information about the community as well as about the perceptions of people which is necessary before planning MDT or vaccine trials.

The traditional cultures of people do not equip people for precision management. Sophisticated tools require precision and a high degree of motivation. Life styles of various groups vary and keep changing, which may add to variables in immunology and epidemiology. Unless people are equipped to accept and use tools, they by themselves do not come forward. It is thus the business of social sciences to understand the process of culture and social change in the context of leprosy. Health education has a big role to play in changing people's responses, provided it is done with the help of community participation. The social aspects of leprosy thus involve the understanding of social, cultural and economic forces which have evolved historically and which keep on changing under the impact of technology.