

SOCIAL DIMENSIONS OF LEPROSY IN RELATION TO CONTROL

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This paper discusses the importance of understanding the social dimensions of diseases, particularly of leprosy, in relation to control. Before a productive, efficacious and humane control program can be designed, health providers must realize that all diseases have bio-medical as well as social dimensions. The control of illnesses should not be left to clinicians alone. Socio-cultural specialists should also get involved. This means that a medical model is not sufficient. There is yet a need for a socio-biological model of treatment which takes into consideration the patient's entire socio-cultural milieu, his individual perspective and the social context of the disease.

Social dimension is the extent and scope of whatever relates to, or is affected by, the general structure of a society. The term involves three basic levels of organization, namely, interpersonal, group, and societal.¹ The interpersonal level refers to relations between two or more persons; the group level, families or such highly structured groups as clubs, associations, and bureaucracies; the societal level, the general organization, or pattern of the social order. On the societal level, the patterning of the social order is often, although not exclusively, based on religion, kinship or a combination of both. These components, however, are useful only for theoretical and pedagogical purposes because, in reality, these levels of organization are closely interconnected. For instance, the smallest and most basic unit of individuals grouped together is the family. Groups of families in a common area constitute the basis of a given social order. An understanding of this "given social order" is crucial for any serious attempt at introduction and application of social inventions and interventions.² In the case of leprosy control, it is imperative for health providers to have extensive knowledge of enormous resources of creativity in the community. Health providers in the area of leprosy control must be socio-cultural specialists in order to design

reasonably efficacious and humane services in endemic areas. Literature on the subject indicates that socio-cultural variability is one of the most studied topics in the area of health and social science (Kegeles 1976), but has received scant attention with regard to leprosy. The major contribution of sociologists toward the understanding of health behavior is, according to Matteus (1976), a better knowledge of (1) the social and cultural processes which influence the perceptions of illness; and (2) the influences of group structures on the use of professional services. The statement encapsulates what is significant in understanding the social dimensions of disease in general, and of leprosy control, in particular.

The Social Dimensions of Disease

Let us describe examples of how some culture brokers proceed and how they are able to determine disease etiologies and design health programmes. Unfortunately, socio-cultural descriptions usually have not been taken into consideration in the development of health policy. Only recently have health providers and policy makers begun to address such a social issue, as the influence of culture, in the utilization of skin clinics for leprosy control.

One such study (Matteus and Jesudasan 1978) reports the results of a survey of knowledge and attitudes of the general public towards leprosy. The results of this survey have become the basis for a health-education project. An interesting finding is that the patch observed among leprosy patients is not perceived to be related to leprosy, and therefore those with patches do not seek early medical diagnosis. They will however utilize allopathic (traditional) treatment – this being more culturally acceptable to the people of the village.

Occupation as a social factor in the treatment process among leprosy patients was studied by Kuppusamy and Salvapandian (1979). They interviewed one hundred and sixteen patients, consisting of 54 males and 62 females, all engaged in agriculture and deprived of employment owing to their deformity. In a related study, Dogleotti (1979) concluded that "in almost all cultures, the predominant attitude is marked by emotion, disgust and rejection towards persons suffering from the disease."

The community usually reacts very strongly to disfigurements and deformities exhibited by leprosy patients. One consequence is that patients lose their jobs. Strong emotions, fear and rejection are universal cultural predispositions to deformity but specifics vary from culture to culture. Still, according to Dogleotti, a program of destigmatization can be outlined. The forms of rejection take on unique cultural features, and all efforts aimed at the control of Hanseniasis (leprosy) are doomed to failure unless the significance of stigma and associated social and economic factors are given adequate consideration.

Dharmalingan (1982) observes that education, as a social factor in the diagnosis of leprosy patients, is an area which is greatly overlooked. The study stresses the need for improved educational tools in leprosy control programs.³

Another study which demonstrates the relationship of culture to disease deals with the so-called "*latah paradox*" among Malays.⁴

Latah is a Malay condition precipitated by sudden fright and involves compulsive obscenity. Donn V. Hart (1978) observed a similar cultural phenomenon among the Samaritan peasants in the Philippines and described it as *lanti*.⁵ Both *latah* and *lanti* are culture-specific reactions to a neurophysiological potential, and have to be understood in context so that they are properly managed.

A study on the comparison of health locus of control belief among low-back patients from the U.S. and New Zealand (P. Tart and others 1982) focused on sex and ethnic variables. G. M. White's (1982) study of the role of cultural explanation in somatization psychologization made causal inferences about illness and behavioral difficulties from samples of Americans (Caucasian) and Hongkong Chinese students at the University of Hawaii. The Americans showed a more psychologized model of illness, as contrasted with the situational explanation of the Hongkong Chinese. All these examples demonstrate the interaction between culture and disease. The failure to realize this interaction results in the underutilization of mental health services, family planning clinics, cancer services, and so on.

Rural or urban residence, as a social dimension of health care alternatives, was a significant variable in D. H. Weisberg's (1982) study. In the study conducted in Thailand, the individual Thai strives to preserve a secure social environment by controlling the course and choice of treatment during an illness crisis. Two types of medical technology which govern the utilization of health-care systems were classified into urban-rural and modern-traditional. The Thais offer alternative systems of explaining illness because of the presence of local practitioners, and the validation of their practices by the local people. This study showed that the nature of social interaction between the healers and the people (who sought their help) strengthened the predominance of traditional healing.

It is necessary to have a knowledge of styles of illness-management in rural settings if we are to promote a productive leprosy

control program. Illness-management systems are culturally transmitted and constitute a vital part of a family's reactions to control. As well, experiences, mood-states, performances, religion, and political ideologies are all culturally determined.

These examples illustrate the importance of understanding the social dimensions of leprosy and other diseases in order to control it. After all, medicine is also a social science (Kark 1982).

Discussion

All diseases have a social dimension; all illnesses have clinical, and therefore biological, attributes. One cannot categorically suggest that the social aspects of disease be left to social scientists and the bio-medical problems of disease to clinicians and epidemiologists. In the design of socio-biological-medical models of treatment, that which gives pain and suffering to man must be given the highest priority. First of all, certain questions must be asked and answered. For example, how do we improve patients' acceptance of their condition? How do we reduce patients' anxiety about their future? The answers to these questions seem to lie in our understanding of the patient's entire sociocultural milieu, i.e., his family, friends, peers, community, and his network in the larger social system. To achieve this understanding, we recommend the following:

1. Gather a patient-profile, including the patient's goals, beliefs about Hansen disease, life-style, occupation, and social status;
2. Make a community-based assessment or community diagnosis;
3. Develop educational strategies based on operational knowledge. Identify the role of patient behavior in affecting health-outcomes. One example is the teaching of management stress-reduction through filmstrips or teaching aids (Padilla and

others 1981). Another is decision-story strategy (Smith 1981), a powerful tool for health educators in assisting patients to make and evaluate health care decisions. We can draw some serious lessons from these models and teach patients to decide for themselves, to continue treatment and to seek prompt diagnosis. At the same time, our own reaction to patients is based on our understanding of them as individuals;

4. Conduct a continuous evaluation of recommendations 1-3; and
5. Develop health-maintenance organizations and activities for patients. These include income-generating activities, improvement of water supply, continuous medicine supply at cheap cost, and the formation of organizations, e.g., a service club to oversee how patients discuss their fears, hopes, needs, and future in the community.

In summary, an understanding of the social dimensions of a particular disease, such as leprosy, is dependent on an understanding of the patient's perspective — his/her personal behavior and attitudes, family and community ties, and cultural experiences. Each individual operates in his own world — where he is the main actor. There is a need, therefore, to penetrate this world without destroying it. However, this point poses ethical problems. The skills of medical anthropologists are valuable as they are trained to elicit and interpret people's expressed ideas about sickness and health. Some recent literature, however, has been critical of medical anthropologists (Good 1981 and Young 1981). Nevertheless, the skills of medical anthropologists combined with those of social psychologists are sorely needed to improve leprosy control programs. Medical anthropologists can develop an ethnographically-informed, social context model of skin clinic utilization.

The social context of the disease needs to be analyzed. Data should be gathered on:

(a) demographic and social characteristics (including migration, religion, ethnicity, language, education and occupation); (b) customs in the area; (c) language; (d) public-health status of the community (including water supply, nutritional status, morbidity, transportation system and housing); (e) political structure of the community; and (f) media availability.

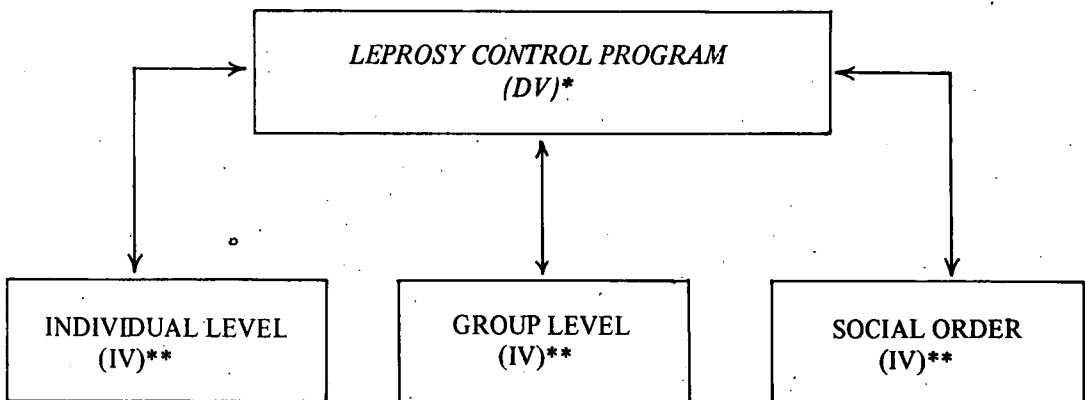
Demographic and social variables can be collected through surveys. The skills of a social anthropologist are needed in data analysis. The political factor may be a problem in areas where the politics of the country tends to shape the ideology of health-care systems. The discourse on the relationship between political networks and the provision of health-services is oftentimes more emotional than rational. But the political factor as Variable X in the scheme of health care systems cannot be overlooked. A socio-medical model in leprosy control service should definitely include a description of the constraints posed by the national and local political structures.

Conclusion

This paper discussed what elements

constitute the social dimensions of leprosy in relation to control, and the variations that should be studied before an efficacious, productive leprosy control program can be designed. It did not adequately consider the role of culture and language through which people organize their experiences and perceptions with regard to diseases and illnesses. Those in the leprosy-control programs need to realize that they are not merely health educators, nurses, or doctors, but also expert culture brokers and linguists. Based on a discussion of the literature, it is obvious that a medical model alone is not sufficient to make a program successful. Therefore, it is proposed that a socio-psychological-medical model should be an area of concern for us. If such a model should prove effective, it may be applied to other health programs.

The schematic diagram below (Figure 1) shows the linkages of the individual actors to the larger social system with regard to leprosy control. It is imperative that the empirical evidence of such linkages be examined as soon as possible.



*DV – Dependent variable

**IV – Independent variable.

Figure 1. *Social Dimensions Model in Relation to Leprosy Control.*

Notes

1. Some behavioral scientists would call this "from micro to macro approach."

2. According to William Foote Whyte (1982), these two terms have different meanings. For him, an intervention is something brought into an organization or community from the outside. An invention is a new creation which may and often does emerge in a community or organization, without any direct outside influence.

3. Most of the leprosy endemic countries are characterized by low-scale economic features, and in these areas, persons affected have very little or no educational attainment at all.

4. The *latah* paradox was studied and restudied by Simmons, then by Kenny. Kenny (1983) concluded that "latah-like conditions" are best considered in terms of their local meaning and that biomedical approaches to the question seriously affect the nature of the phenomenon and potentially distort clinical practice in relation to it.

5. *Lanti* is a Visayan term which describes the mental state of the persons who after being exposed to some traumatic experiences proceed to act in "peculiar" ways (Hart 1978).

6. This factor is not so crucial to Philippine experience since the country is predominantly Roman Catholic. But for some countries, this variable is significant.

7. For example, the Ministry of Health of the Philippines will soon embark on an integration scheme and one result is that the Leprosy Control Program will become part of the Primary Health Care. The skin clinics will now be a part of its services. What effects this type of incorporation may bring are difficult to determine at this point.

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