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XIII LEPROSY CONGRESS STATE-OF-THE-ART LECTURE

We are pleased to have the opportunity of publishing the full texts of the state-of-the-art lectures presented at the XIII International Leprosy Congress at The Hague, The Netherlands, 11–17 September 1988.

Social Science Research on Social Dimensions of Leprosy: Where Are We Going from Here?*

This paper attempts to offer a systematic review of research studies on the social dimensions of leprosy. However, a thoroughly systematic review must remain a task for the future because, at present, there are very few resources on this topic and those works that have been published to date have actually phrased the social and economic dimensions of leprosy very differently and are therefore not included in this paper. In order to offer a comprehensive state-of-the-art lecture on the social dimensions of leprosy, one would need a number of studies that address such issues as how allocations of local efforts and resources are used for the prevention and control of diseases, how leprosy impacts on the lives of individuals and on their households and communities, and consequently how the disease leads to economic costs and psychological dislocations in the households of patients. Unfortunately, there are very few studies addressing these questions. A look into recent literature reveals few materials on health education and community participation that relate to the disease but, again, these studies are excluded from this paper although I will be citing some issues derived from such materials.

The dearth of social science literature on leprosy reflects many other realities. For example, it shows the limited interest of social scientists in studying this particular topic for fear they will become personally isolated from the mainstream of contemporary issues being addressed by their professional peer group. It also reflects the existence of a barrier among social scientists, a barrier that has been more difficult to overcome than the existing gaps between social science and medicine, such that more power and higher status are accorded to persons who are considered specialists in development theories, political economy, and in power and industrialization. As a consequence of the "gap," many sociological associations in the less-developed countries do not have sections on medical sociology. Today, however, subjects on medical anthropology, medical geography, and medical ethics are being considered in the academic curricula, designed to attract students who some day may become influential in shaping wise policy decisions in health concerns at the national level.

Over the years many articles have been written on leprosy but few use the social science perspectives. However limited the available literature on the social dimension of leprosy, it still allows one to make some conclusions as indicated in the last section of this paper.

Leprosy: the disease

Leprosy is a disease which may lead to serious deformities and to premature social death among patients. The disease is perceived as one that uglifies not only the body but the soul; it turns, though slowly, a person into a "thing." It was, in fact, common practice in the past to tie a bell around the

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* Based on state-of-the-art lecture presented at the XIII International Leprosy Congress, 16 September 1988, The Hague, The Netherlands.

ankle of a leprosy patient so that as he walked the bell would ring to warn people of his coming.

Today, reports still indicate 11.5 million cases of clinical leprosy in the world. This means that these millions of leprosy patients, if neglected, might become disfigured and, as such, will become objects of pity and scorn by the others who are free of the disease. These patients are found mostly in the tropical and subtropical belt of the African, Central American, and Southeast Asian countries. Sadder still, most of these persons come from the lower income groups, an observation that gave rise to the hypothesis that it is the poor, the underprivileged, the depressed people of the world who contract the disease.

Another characteristic of leprosy, in addition to its capacity to disfigure a person, is its chronicity. The standard medical description of leprosy states that it is a chronic communicable disease mainly affecting the nerves, skin, and mucosa. The adjective chronic derives from the Greek word *chronos* (time), which means constant, prolonged and lingering. These are excellent adjectives for leprosy: it subjects one to suffering for a long time and to potential gross deformities. Again, because of these characteristics, the general response of others is negative. From this initial response results stigmatization, a process painful not only for the patient but also for those people living in his immediate social environment. It is during this process that people learn myths and beliefs surrounding the disease. It is also during this time that the patient learns to become a "leper." And so, throughout this period, healthy people forget what the disease is all about, but continue to traverse the social pathway of stigmatization.

At this point, however, it is important to emphasize that while leprosy is chronic, no deaths can be attributed directly to the disease. Patients die because of its prolonged course of infection and complications, but not because of it. However, there is increased morbidity due to impairment in the motor, brain and sensory functions and from severe skin conditions among patients. In fact, the World Health Organization (WHO) has reported that death rates are higher among leprosy sufferers than among nonafflicted individuals in the same population.[1]

Filling the gaps

What are the problems and what are the issues? A report from WHO[2] documents the two principal problems associated with leprosy: that of public health and that of the individual and his disease. These two problems are inextricably interrelated and pose concerns to leprosy control workers in their battle against leprosy. Usually public health administrators and the general public are concerned with both the preventive and curative aspects and, thus, their work is centered on the key elements for control, i.e., case detection, therapy, and the search for effective vaccination. It has also been observed that, among themselves, health workers use the concept of primary health care (PHC) to carry out control activities. There is, however, another domain associated with the treatment of leprosy which is not adequately handled by the PHC strategies. I am referring to the domain of fear that people have to face when confronted with a deformed patient because of their overall lack of accurate information on what the disease is all about. Their own ignorance breeds their own fear; fear and its consequences create more impact on health-givers than the disease itself. Therefore, any social studies on the disease must contend with this phenomenon of fear which is often cited as stigma. But what is stigma?

Stigma. Once a person is correctly diagnosed as a leprosy patient, his roles in society will be restricted and constrained. Many years ago, he would have been removed altogether from his place in the system, "exiled" into a colony and completely separated from ordinary social activities. In his new roles, he will soon become a "nonperson," thus starting his own premature "social death." Paradoxically, it is during

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[1] World Health Organization. Community involvement for health development. Report of Inter-regional Meeting, Brioni, Yugoslavia, 9–14 June 1985. Geneva: WHO, 1985.

[2] WHO Second Scientific Working Group on Social and Economic Research. Guidelines to assess the social and economic consequences of the tropical diseases, 22–27 October 1980. Geneva: WHO, 1980, p. 56. TDR/SER-SWG (2)/80.3.

this whole process of separation and segregation that the patient will dutifully accept his new role, his new place in the social structure. In addition to being treated as a social outcast, he will also be blamed for his own sickness. However, his willingness to assume a sick role does not mean that he will accept all the drug regimens prescribed for him. In this manner he will pose dilemmas to the healthy persons who may not understand him completely and cannot comprehend his refusal to take the prescribed medicine. The health-giver will judge the patient as being unreasonable. Our culture dictates that sick persons should take their medicine, because it will cure and free people from their diseases. Contradictory behavior such as patient noncompliance implies illogical illness behavior. It is not uncommon to find that PHC village workers will perceive patients in very negative ways but will not encourage patients to comply and will not reassure the patients that their disease is curable.

So, as in all clinical practices, when the patient shows no will to be well, the magic of medicine will go away. At the same time, the health-givers lose the motivation to cure, along with some of their compassion, and their drive to help. Instead, cynicism becomes part of their professional stock.

Who is spoiling whose identity? Empowering the patient. The classic theory on stigma, postulated by Goffman[3] and widely validated by subsequent researchers, suggested that the stigmatized individual will define himself as no different from other human beings, but those around him will define him as someone set apart. This implies a clash of perceptions between the patient and the beholders. This differential perception implies that someone other than the patient is clearly spoiling his image and, hence, his identity. This view holds that there are particular "spoil-sports" whose attitudes toward patients are mainly responsible for the community's general reaction to leprosy patients. Studies in The Philippines by Valencia, *et al.*,[4,5] however, seem to indicate a contrary viewpoint: the patient has an equal and shared responsibility in reinforcing the negative attitudes of others toward him. In effect, one may argue legitimately that patients themselves contribute to the process of spoiling their own images. Self-stigma is caused by the patients' inability to assert themselves in family and community affairs, by their willful consent to be denied access to places were nonaffected people can go, and by their quiet and passive acquiescence to actions directed toward them.

And because they have quietly agreed to stay in their special islands (accurate or illusory), they will cease to be significant people in the community. When a sick person is aware that his or her disease will persist over time and that the therapy offered may not control the disfigurement (the potential is always there), then it is almost logical to predict that the sufferers will experience a lowered self-image. An understanding of this phase of the dilemma being posed to patients is important for health-givers in the control program because this means that the most serious steps will be taken not in drug distribution or in the promotion of multidrug therapy (MDT) but in the process of returning to these patients part of their power to think again as persons, in effect empowering them so that they can enhance their own self-images. They should be taught to rethink their position in the community. The key message should be addressed toward transformation of positive ideas critical to their return to the folds of society, more specifically to their original family and group affiliations. I feel that before the patient can convince the outsiders that he is still a functioning individual he should first feel convinced of his own worth. But how do you go about doing this? How do you manage stigma?

Managing stigma. Stigma management is a general feature of society, a process occurring wherever there are identity norms. The same features are involved whether or

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[3] Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, New Jersey, U.S.A.: Prentice Hall, 1961.

[4] Valencia, L. B., *et al.* Society and leprosy: a Philippine experience. Philipp. Sociol. Rev. **34** (1986) 1–4.

[5] Valencia, L. B. Socio-economic research in The Philippines with special reference to leprosy. Southeast Asian J. Trop. Med. Public Health **14** (1983) 29–32.

not the differentness in question is of the kind traditionally defined as stigmatic. For years, Goffman's ideas[3] on stigma and on stigma management have been the dominant approach when one thinks of "differentness," for example, in mental illness. As a social scientist involved in understanding the leprosy patient, I began to feel that unlike persons suffering an impaired capacity for reasoning, a leprosy patient is, by the nature of his disease, never affected mentally. There is no basis to suspect that his capacity to think is ever affected by the presence of the bacillus in his body. From this viewpoint one may argue that it is critical to help the patient socially transform his roles from being merely an object of scorn to taking on a participatory role within the mechanisms of leprosy control structures. There should be affirmation of strength in key messages. But these affirmations must start from the patient and not from those responsible for his treatment.

Goffman[3] refers to stigma as an attribute that is deeply discrediting. He says it should be seen as a *language of relationship* (emphasis added). In this particular case, the relationship is between the patient and the health-giver, or the patient and the unafflicted people in the community. The basis of that relationship is how patient and nonpatient deal with the abominations of the body as displayed by the patient, and initially on how the patient will handle his own sense of personal worth. If he handles it impersonally and avoids calling attention to his "differentness," there will, I suspect, be increased respect for his courage.

But how can he, when fund-raising efforts by the many programs and missions harp on his differentness, when they work on the emotions of potential donors by emphasizing the deformities and displaying the most disfigured of them all? In this sense, the fund raisers themselves are guilty of failing to empower the patient.

Building positive self-images. In brief, in dealing with the stigma process one should take into account the patient's role as the initiator of the act. One's identity is not necessarily spoiled as the direct result of an outsider's negative perception of him. On the contrary, it starts with the patient. Goffman tried to explain the situation with his idea that "the stigmatized individual, at least the visibly stigmatized one, will have special reasons for feeling that the mixed social situations make for anxious unanchored interactions. . . ." [3] It is crucially important for key people in leprosy control programs to first address these "special reasons," in order to break down the protective capsules built by patients themselves, and to create positive pathways as the basis of social interactions. Self-stigma is also disease producing: although it may not produce a bacterium or microorganism, it will produce a pathogen of negative social reactions which will, in the end, inhibit an effective delivery system of services by control programs. Since it is difficult to measure stigma per se, it is even more difficult to even suggest how self-stigma may be quantified.

Measures of self-stigma: what are they? In this connection therefore one should begin to ask: What is self-stigma? What are the measures of self-stigma? What is the meaning of self-stigma? Today, the illness narratives of patients increasingly reveal meaningful parameters of self-stigma rather than stigma per se. Unfortunately for some of us, these have been incorrectly interpreted as patterns of stigma. We blame the outside world too much, because this time we are afraid to blame the victims. Our usual and conventional mode of thinking is to spare them because we believe they are already being punished enough. It is important that health providers learn to radically reorder the world values of patients from self-pity to thinking of themselves as well-adjusted people whose predominating attitude should be to transcend one's sickness. This idea, that the patient must be able to go beyond his disease, must be the central thrust of the messages addressed to him. While his physical sensitivity to varying degrees of heat and cold may atrophy, I believe his mind is never affected, let alone his memories of who he was before. If through the course of his sickness he has lost his personal identity, it is the duty of the health-giver to assist him in reconstructing a newer identity, to some extent one still allied to his former self.

Waxler[6] offered the hypothesis that a leprosy patient learns to be a "leper," that his

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[6] Waxler, N. E. Learning to be a leper: a case study in the social construction of illness. Cited by Mishler,

transformation from a chronically ill person to a "leper" is, to a certain degree, influenced by how society understands the meaning of the disease, by the nature of the organizational and social context in which care is given to him, and of the various medical missions and agencies that treat leprosy. For these reasons, we must briefly consider the historical conditions and the cultural and social matrix in which the disease is embedded.

This idea is not totally new, as documented by Meisels-Navon[7] who conducted studies in Israel, and documents the reality of self-stigmatization among patients. This process was enhanced, according to the author, by the legal institutions that were supposed to help patients cope. Meisels-Navon described using anthropological methods for several months and interviewing staff members in each study site, i.e., hospital. She discovered that the message the institution transmitted to the outside world about the patients enhanced the former's fear of the latter. Coupled with these clues is the fact that these institutions had kept the data but concealed the patients and their records from public consciousness. As a result, she said, of the successful application of this policy, "the stigma of leprosy in Israel appears today mainly in a symbolic form: the 'leper' has become a stigmatizing symbol, disconnected from actual reference to 'leprosy patients.' "

In sociology, we call this process social labeling; it has been successful in influencing the sick role careers of Indians and of Filipino leprosy patients, but it did not do much to stigmatize the Sri Lankans or the Nigerians. Today, Filipino leprosy patients are mainstreamed; they remain in their homes and carry on some forms of economic activities. This does not mean, however, that they are no longer ostracized and feared by the nonpatients in the community. Thus, to some extent, stigma still causes a decrease in the patient's own self-esteem over time.

Saylan,[8] writing about Turkish patients, provides us one final look at the problems posed by the personnel serving in various health institutions, clinics and health training establishments. He found that their ignorance on the subject, their incorrect knowledge of the subject, their undue fears, their complete lack of information about the preliminary symptoms of the disease—in short, their general ignorance of social behavior—all compounded their general idea of what the disease is all about.

Empirical Referents: What is Going on in Social Research in the Field of Leprosy?

There are many outstanding articles on leprosy but we need, in the context of this state-of-the-art lecture, empirical papers. They should at least be scientific field research papers which include the elements of experimentation and verification, and analysis based on testing and retesting of verifiable statements. This must be looked into because we need a body of literature-based research that will enable us to test great and contemporary ideas. The limitations of available resources on the socio-economic aspects of leprosy are such that they have remained as ideas still to be tested, still to be validated and to be systematized so that they become valid inputs to policies beneficial to leprosy control programs. Or take the theories of Waxler[6] whose postulates about learning to be a "leper" are sociologically acceptable. How do you translate these ideas into concrete programs for leprosy control in India, Nigeria, or Sri Lanka, or even in the western settings where cases of leprosy have been reported? Before I address this, let me first give you the salient ideas of this very provocative article on leprosy. Waxler says: a) The bacillus itself is only a minor actor in the drama of leprosy. Instead, surrounding the disease in many societies is a set of social beliefs and expectations that profoundly affect the patient's experience and the doctor's work. b) This cross-cultural variation in the stigma of leprosy had led us to conclude that the source of a particular response is in the social and cultural matrix in which the disease exists. c) The ideology surrounding leprosy pro-

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E. G., *et al.* In: *Social Contexts of Health, Illness, and Patient Care.* Cambridge: Cambridge University Press, 1981, pp. 169–192.

[7] Meisels-Navon, L. Summary of findings of the research conducted in Israel and of the research program referring to additional countries, 1984 (unpublished paper).

[8] Saylan, T. Social aspects of leprosy control in Turkey, 1984 (unpublished paper).

vides a map for the "leper." Moral definitions tell the "leper" how to "have" the illness. d) Finally, once the moral definition becomes established, it is often perpetuated for reasons having very little to do with the disease itself.

The last point is a very refreshing one. She puts it as follows: ". . . this moral definition of leprosy is often perpetuated by the very organization that the disease through a complex and circular relationship between the community's preference for removing deviant people and the leprosy organization's needs for society's support in order to survive. . . . To continue their work, then, the organizations that 'own' leprosy must sustain the stigma of leprosy." Somehow this same idea runs through this paper in the section on stigma. But what of it? How can we utilize this analytical thought to improve a control program? Waxler did her work on leprosy, I believe, in Sri Lanka. She studied a sample of leprosy patients from an outpatient leprosy clinic. But I am not sure whether she stayed long enough in the country to really follow up a career map for patients and how much of the shaping of this career map can be attributed to the many leprosy organizations working in the area.

A more recent example of empirical work in leprosy in Chen's work in Malaysia,[9] in which he attempts to qualify social interaction in terms of group dynamics, namely, the size of the groups formed in a given period and the duration of interaction of each group. The inherent assumption of this study is that the larger the group size, the greater the degree of social interaction. He also assumed that since groups are likely to form and reform, then the more groups formed, the greater the possibility for increased social interaction. Finally, he assumed that the longer the group persists, the greater the likelihood of social interaction.

Chen compared two varieties of settlements in Malaysia: villages of single dwellings and villages composed of longhouses and, of course, selected populations of equivalent size. Chen's project question was whether the prevalence of leprosy and tuberculosis—both transmitted through social contact—would be higher among tribes living in the longhouse type of dwelling or those living in single dwellings. His findings indicated a strong association between longhouse living and a higher prevalence of leprosy and tuberculosis as compared to those living in villages of single dwellings. This study demonstrates, among other things, that research questions can be measured and quantified using anthropological phrasing, thus "satisfying" the frequent criticisms of epidemiologists and economists who work in tropical disease research and, more specifically, in leprosy, that such research is "soft" and qualitative. Chen's study points to a direction for reorganizing collaborative efforts across cultures. He says it would be more interesting to conduct a similar study among longhouse dwellers in Indonesia and in Papua New Guinea to examine the extent to which social interaction among social groups can facilitate leprosy contacts and, hence, influence the prevalence of leprosy.

The lack of empirical work has also been noted by Adamson,[10] writing for the WHO Special Programme for Research and Training in Tropical Diseases (TDR). She listed nine research projects concerned with leprosy in The Philippines, Kenya, Tanzania, Malaysia, Brazil, and India. She said that most of these projects have been observed to be lacking in strong epidemiological components in their respective research designs because of what is called "considerable variations in the diagnosis of the disease" over time and place. This lack implies the need for a standardized criterion for the diagnosis of leprosy taking place in many parts of the world and at different time periods,[10] a challenge that should be within the domain of the medical scientists.

In addition to the lack of epidemiological inputs in their research designs, these research projects also suffer from what Foster[11] describes as an interest in subordinating basic problems to research decisions. His ob-

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[9] Chen, P. C. Y. Longhouse dwelling: social contact and the prevalence of leprosy and tuberculosis among native tribes of Sarawak. Soc. Sci. Med. **26** (1988) 1073–1077.

[10] Adamson, H. Socio-economic research projects to improve the control of tropical diseases: an overview. Paper prepared for meeting in Salvador-Bahia, Brazil, 3–8 August 1986.

[11] Foster, G. M. World Health Organization behavioral science research: problems and prospects. Soc. Sci. Med. **24** (1987) 709–717.

servations—the lack of epidemiological input and subjecting basic research problems to expected research decisions—are important to remember. We, after all, hope that the findings derived from these studies will be brought into disease control programs whose main task—among other things such as control of deformities and spread of infection—is to increase the number of early cases detected and to improve case-holding. Still, one may argue that while Adamson's[10] observation on the lack of epidemiological input is correct, the fault lies not in the inherent weakness of the social science perspectives but in the absence of research models and of themes that may be used as sources of hypotheses and, later on, for validation.

A similar sentiment was expressed by Spruit and Kromhout[12] whose review of themes in the 1985 volumes of *Social Science Medicine* also concluded that "medical sociologists are needed in epidemiologic research on the role of social and psychosocial factors in the etiology of chronic diseases, as much as other scientific specialists are needed for research on other types of risk factors."

In addition to Chen's work, there is the leprosy study by Pearson,[13] whose work is in distance and its meaning to different people. The study is set in Laimjung, and deals with stigma and the meaning of distance to travel to the treatment center. The author says that the basic assumption underpinning the leprosy control strategy was that the number of cases detected, and their subsequent attendance for treatment, would be improved by reducing the distance traveled for treatment. This assumption, however, was not exactly correct. It turned out that distance was not as meaningful to the patients as the quality of service offered. The conventional mode of thought, that the patient's problem in overcoming distance was the major factor impeding regular attendance, was debunked by this interesting study into the quality of service that will improve case-holding. This study further illustrates my basic assumption that the patient's capacity to make decisions is intact, and if he is provided with the correct framework for action, he will do so.

So, it is not stigma that prevents the patient from going for regular treatment; it is his own personal experience of poor service. Nevertheless, Pearson[13] suggests that leprosy is still feared and reviled in people's minds, if not in their overt actions. Continuing, she says that clearly, for leprosy cases, perceptions of space and accessibility vary with gender and ethnic group and are not synonymous with distance. While the elimination of stigma is a laudable long-term objection of all leprosy control strategies, the plans and policies must be realistic about current attitudes and flexible enough to incorporate gender and ethnic differences in mobility and attitudes.

Much earlier than Chen's and Pearson's studies is the 1981 interdisciplinary study by a group of social scientists (including a medical sociologist, health psychologist, linguist, and medical director) who tried to understand the etiology of Hansen's disease.[4] Very specifically, the study sought to: a) determine the respondents' levels of knowledge regarding the causation, transmission, diagnosis, and treatments of Hansen's disease; b) assess the intensity of feeling displayed by those afflicted by it and by the community in general about the disease; c) document the respondents' practices (both theoretical and real); and d) describe the respondents' coping mechanisms that over time have become those of an indigenous socioculture and psychological system of reactions. The setting for this study was the two most leprosy-endemic provinces in the northern part of The Philippines. The research project was designed using a mix of three strategies: survey questionnaires, linguistic analysis of interviews, and the administration of two psychological instruments. This study made some conclusions which can be utilized to improve the doctor-patient relationship as well as leprosy control programs. For example, the data show that the patient is often alone in his introspection as to what ails him; he is completely absent from his social world as he

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[12] Spruit, I. P. and Kromhout, D. Medical sociology and epidemiology: convergences, divergences and legitimate boundaries. Soc. Sci. Med. **25** (1987) 579–587.

[13] Pearson, M. What does distance matter? Leprosy control in West Nepal. Soc. Sci. Med. **26** (1988) 25–36.

takes and seeks control of his decisions and options through self-diagnosis.[4]

This finding implies that many cases go undetected since the patient finds the treatment meaningless and sees no possibilities for cure. The data also indicated that leprosy patients have, from the onset of the illness, evolved individualized personal systems of coping, for example, praying and dreaming (fantasies of cure), and consulting with herbalists first before going to a medical doctor at the skin clinic. The findings also indicate the devalued self-esteem of patients which implicitly contributes to the stigma of the illness.

This research was followed by an interaction study which was based on the premise that inside and outside the organization of a leprosy control program there is a degree of interaction among the people concerned that is worth examining. It[14] focused on a triad complex of the three types of actors involved in the leprosy control program. These actors are: p = leprosy patients; SP = service poorless; and SI = satellite informants. This triad complex and the complexity of interaction among them is considered a critical starting point for any attempt to assess the organization's structure and the effectiveness of service institutions such as medical clinics. It started by asking questions such as: How does one explain the process of interaction among the people involved in the control program in a micro-order setting like a village health station? Who are the people playing lead roles? How does one express the outcome of these relations? How do these forms of relationship determine the output of Hansen's disease control services? Is there any connection between high and low levels of interaction and medical services? Can one quantify the relationship between interaction and delivery of services at this point?

The blueprint view of social interaction became a very neat theoretical frame for understanding how people behave and why they try to behave according to a set of cultural rules. It seems, though, that the cultural rules that govern the social interaction of personnel inside the clinic are the very same ones that operate outside the clinical situation. More specifically, if one refers to a real world characterized by cultural homogeneity, there are no outstanding variant features that may affect an illness, especially when the illness is defined as chronic. The research design also addressed the interaction inside the clinical world and outside that world to find factors conducive to the formation of what can be termed "quality service."

It becomes clear that in studying the divergent structures of health care and chronic and even nonchronic diseases, social science and epidemiology must converge across scientific boundaries. In this case, each discipline can make legitimate contributions toward clarifying and even debunking relevant issues. For example, Kleinman[15] suggests that physicians should utilize social science approaches such as mini-ethnography, life history and socio-therapy, while the social scientists should assist in the interpretation of the data collected.

An interpretation that may again use Kleinman's words need not be overly solemn or gloomy, but there should be in it an ample place for wit, humor, and hope.

Another example of an empirical work is that of Paz, *et al.*[16] conducted in The Philippines using a qualitative approach to discuss the pain and suffering associated with the stigma of the disease.

What do these few studies say in general about research in leprosy? They say, in effect, that the human sciences of medicine, based on the traditional perspective of anthropology, sociology, psychology, history, ethics and of literature and the humanities, may be used by multidisciplinary groups of researchers to systematically conceptualize the meanings of leprosy as an illness among patients and nonpatients. Perhaps this is what Kleinman[15] is pointing out, i.e., the increased use of a framework that combines social and humanistic approaches to medicine, that sees the convergence of biological

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[14] Valencia, L. B. Psycho-social and environmental factors in the triad model for the management of control program: focus on leprosy. Southeast Asian J. Trop. Med. Public Health **17** (1986) 442–450.

[15] Kleinman, A. *The Illness Narratives: Suffering, Healing and the Human Condition.* New York: Basic Books, 1988.

[16] Paz, C., *et al.* Stigma. Report submitted to WHO/TDR, 1988.

and clinical services with the human resources of medicine.

But still, according to Andreano and Helmeneuk,[17] no tropical disease research has imaginatively moved beyond the present framework. Sadly lacking, they said, are studies that use microanalysis of the economics of households and the economics of risk-taking and avoidance. As a result, there are no findings which can be utilized for the making of policy decisions in health. Thus, they believe that for tropical disease research to be useful for policy making, it must be able to quantify the diseases' impacts on: a) health consumption effects; b) social interaction and leisure effects; c) short-term product effects; and d) long-term production/consumption effects.

However, with leprosy, which is a chronic disease, their suggested framework and methodologies for evaluation are simply not operational or feasible. They may continue to describe the available methodology of many of these tropical diseases as dubious and therefore limited. In addition, the sample of results of these studies are inadequate to establish confidence. I believe research on social dimensions of leprosy must be freed from these critical constraints. Foster[11] repeats similar statements but advocates more participant-observation techniques to collect data to make such studies acceptable. Foster[11] and Andreano and Helmeneuk[17] may contradict each other on the appropriate techniques of capturing the social dimension of this disease. These disagreements about methodologies and research are superfluous when they relate to leprosy because the disease has no impact on mortality calculations. No one dies from leprosy, and the number of persons afflicted is so small that even over time these people may not create a negative impact on production.

I repeat that studies on leprosy should not be evaluated against conventional criteria of research designs and methodology because leprosy has its own meaning. Leprosy means not only a disorder of body function, with its recognized etiologic agents, but it also has signs and symptoms that severely affect not only the patient but also his family and the community. In leprosy research the consistent view is: the patient is one of those interacting persons engaged in the production of a self-image within the context of a given social environment, and in the course of such an interaction process the participants are guided by a previously existing cultural system of ideas, values, and rules of action. It is the focus of leprosy research to understand this particular mode of interaction and to suggest the mechanisms of support for the patient to be responsible for coping with the perceived negative reactions usually said to be directed against him.

In 1974, a paper on leprosy in South East Asia (which includes Burma, Thailand, Malaysia and Singapore, Indonesia, Laos, Cambodia, Vietnam (North and South), and The Philippines) by Browne[18] stated that: ". . . despite local divergencies and differences in ethnic origins, local pigmentation, standards of living and culture, these countries exhibit some overriding characteristics that have a significant bearing on the dimensions of the leprosy epidemic and the measures that should be taken to contain and control it." Written almost 15 years ago, this particular insight is still true. The implication of such a statement lies in the fact that it points to the importance of cross-cultural behavioral research that will be of great use to control programs. If Browne's observation is correct (and I maintain that it is), then there is a need for a collaborative effect to study, for instance, stigma and/or patient compliance. Such a study would be a greater step toward the often discussed plans for standardizing instruments, protocols and the analysis of data. A data base can be established for the region that might be useful to decision-makers. I think this is one of the serious steps that funding agencies with shared research interests should look into. For what is happening today is that there are pockets of micro site-specific studies on leprosy with very limited sample sizes and with flawed theoretical perspectives. The results derived from these qual-

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[17] Andreano, R. and Helmeneuk, T. Economics, health, and tropical disease: a review. Paper prepared for WHO Special Programme for Tropical Disease Research, 1986.

[18] Browne, S. G. Leprosy in Southeast Asia; present position and prospects. Southeast Asian J. Trop. Med. Public Health **5** (1974) 65–68.

itative efforts are, of course, of limited value.

Trends and Directions: Where Are We Going from Here?

What are the prospects and the future of leprosy research in the field of social science? Andreano and Helmeneuk[17] suggest looking into the impact of disease (not necessarily leprosy) on household work adjustment in order to estimate production and impact costs. We need to know what activities are sacrificed, if any, in connection with the household adjustments. Are other productive activities abandoned, or only temporarily delayed by those who substitute? Or is production activity maintained at the expense of household chores, child care, school attendance, community activities, or valued leisure which might also have longer-term production impacts? These questions are relevant as socio-economic issues related to leprosy control.

In terms of methodologies in data collection and techniques, there should be by now some moves to duplicate the rarely done sociolinguistic analyses by Paz.[16] Interviews between leprosy patients and doctors and between leprosy patients and other health-givers all show how the health professional prevails; patients react to questions very succinctly. Most of the time, their responses are laconic, and during these discourses, patients are not encouraged to speak up and are often sadly summarily dismissed. While this technique is extensive, it is also expensive.

Paz' study is not new, considering that as early as the 1970s others were already documenting the use of archival materials in the analysis and interpretation of full data and in explaining their case study on the institutionalization of the myth of leprosy as "leper." So when similar approaches were being used by others in their works on the history of leprosy in The Philippines, they confirmed that such methodologies for collecting data on leprosy are still useful. But are they useful for leprosy control programs?

In the long run, the need for more professionals in the field of applied linguistics to do both the collection and analysis of data will be a source of constraint. While there is a potential wealth of information that can be empirically gathered, which when properly analyzed and evaluated may be useful to health education and community participation purposes, there is the problem of the dearth of professionals who can perform this disciplined scientific task. Therefore, the adoption of this particular technique of data gathering among researchers on the social dimension of leprosy may not be as quick as we hope, but this is one of the most outstanding innovations in the field of leprosy research. For it is in capturing the nuances of language that the dynamics of interaction are better explored and explained.

Lack of an organizing framework

The future direction of social science research in leprosy is faced with some problems. For instance, while both Hahn and Kleinman[19] see the need to integrate medical and anthropological approaches in interdisciplinary research in Western biomedical settings as well as to narrow the gap between social science and medicine, I see the need for the integration as critical, mainly in expanding our understanding of the suffering and pain which are more predominant among leprosy patients than among other types of patients. Max[20] sees a lack of relevance of economic theories to health policy and planning in general and, more particularly, to leprosy control programs, but feels there is a need for an organizing framework that may be useful in policy evaluation. He suggests that we look into economic theories.

Where should it be: in MDT or social science involvement?

The most significant trend in leprosy control programs, which may be used as the setting for increased involvement of social scientists, is in the encouraging results seen with multidrug therapy (MDT). The clinical and field trials of MDT so far have shown

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[19] Hahn, R. A. and Kleinman, A. Biomedical practice and anthropological theory: frameworks and direction. Ann. Rev. Anthropol. **12** (1983) 305–333.

[20] Max, E. Economics and the management of health: the case of leprosy control. Paper written for International Meeting on Leprosy, Pune, India, 20–25 March 1988.

the efficacy of the drugs. But the ultimate beneficiaries of these encouraging results must know, and be convinced of, the drugs' power and the community, together with the patients, must be involved in a program of persuasion. The techniques of social persuasion for increasing the number of MDT recipients are all well within the expertise of behavioral scientists.

I believe that a successful MDT program is now in the hands of social scientists. Social science must take the lead in formulating the basic rules related to detection of patient compliance and care. To do so, it must be involved, and must restructure its professional assumptions about social science paradigms.

Community participation in leprosy control programs

The trend also indicates not only the concerned involvement of the social scientists but, to some degree, the commitment of the community. The first unit that should be involved is the family.

The family. For the individual patient, the community can clarify the nature of his health problems and join in his struggles to cope with chronic pain and work out a program of self-help. This is, in essence, why we need the community to participate in the delivery of leprosy control services. But how do we help the care-givers, who are the most important constituents of the community, to transcend their own fears toward leprosy patients? How do we reduce fear among leprosy patients about their own chronic disease? This situation calls for a broker—a third party—who may be able to negotiate an order of meaning for both, and who may be able to equalize the situation for both concerned parties. I suggest the family as the third party, the immediate family of the patient working hand in hand with the health-care givers. Because these families are usually the recipients of the direct consequences of the disease, they are motivated more than anyone else to help the patients. The family is high on the motivation scale since it constitutes the patient's life-support system, especially during the early stages of the disease. While the patients somehow develop a sickness career, their immediate families consequently are responsible for a successful turn of events.

It is the family that can best handle the deformity which a patient may develop. The ability of a patient to deal with outsiders is influenced by his own kin's entire outlook. Actions of families in support of their sick members have been discussed in the literature but still have not been analyzed for leprosy in particular.

Women in the patients' lives and in the community. Within this proposition—that the family is a critical factor in leprosy control—is the inherent and inexplicable role of women as initiators of health activities in relation to leprosy in the community. Women constitute the most basic unit in the building of an infrastructure for an efficient leprosy control program. Together with nonpatients, with others familiar in the community and with care-givers, women can form a solid foundation for social support in the area of coping and in psychological rehabilitation, in the health education campaigns to increase understanding of the disease and, most critically, in the daily economic sustenance of the family. Ventura's study[21] shows that the women not only nurture their families, they also act as breadwinners when the husband-patient is no longer gainfully employed and when the likelihood of his future earnings is nil.

Community at large. The importance of the community at large is indicated in the literature on leprosy as well as in other health sectors. The pressure to use community participation as a control technique in the health sector is not new. For leprosy control programs, however, it may be quite innovative in the sense that because of the nature of the disease, people would naturally put some distance between those afflicted and their families.

Let us consider the implications of community participation on the allocation of material and nonmaterial resources to the community in question. Often, we find that department of health budgets do not cover extraneous expenses. To be able to carry out leprosy control may, in the long run, prove to be an additional burden, not only from

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[21] Ventura, E. R. Of hansenatics: health, psychology, insights. Unpublished Ph.D. dissertation, University of The Philippines, 1985.

the perspective of the bureaucrats, but for the primary health care village worker and the larger community. The degree to which the community exercises these "participatory" activities is taken as a direct measure of the involvement not only of the bureaucratic machineries, but of the entire social system. Until now, the desire to organize an ideology of participation among the residents of poor communities has not shifted from passive to active radical commitment to achieve the goals.

Most of the communities with leprosy have been characterized as poor, depressed and unstable. The lack of community participation in these endemic areas does not necessarily indicate insensitivity or "irrational cultural systems" among the nonpatients and in the social system, but is the result of complex socioeconomic-political forces. It is not the traditional values of the people that limit the desire to initiate, organize and follow through with community participation. Rather, the problems lie in inhibiting factors such as the peace and order situation, conflicting economic ideologies, etc., that lead to decreased production and small budgetary allocations.

Globally, especially early in the 1970s and 1980s, the concept of people's participation or, more popularly, community participation, had been invoked and, as expected, became one of the main elements of the primary health care program which was adopted worldwide.[22-24] What is new is community participation in the control of disease. Will it really work in leprosy control, considering how long it has been in use?

Health education and leprosy control programs

A technique useful in community participation is health education—seen as a vital aspect of leprosy control work.[25, 26] It is important to educate the patients, their families and the community as a whole in the nature of the disease, its prevention, and treatment, because most of the problems which pose barriers to leprosy control efforts, as already mentioned, are educational in nature.

Thus, the goal of health education in leprosy control is to provide experiences to help the patient and his family, the health workers, and the community as a whole to bridge the gap between what they know and do about leprosy and what should be done in order to prevent the spread of the disease; to undertake regular and sustained treatment; and to prevent deformities and disabilities.[26]

Health education is defined as that part of health care that is concerned with promoting health behavior.[27] By changing behavior, individuals can solve and prevent many of their problems. Health education should be differentiated from health information. Information or knowledge has an influence on behavior but there are many other things which affect behavior, e.g., culture. Health education uses, therefore, a variety of methods to help people understand their own situations and to choose actions that will improve their health. In health education, participation means that the person, the group or the community works actively with the health workers and others to solve their own problems.

Health education has been recognized to be of such importance, especially in the developing countries where the most common causes of morbidity and mortality are preventable, that it is one of the eight essential components of primary health care.[24, 28, 29]

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[22] Lundstedt, C., Pederson, K. and Milsen, V. Health for all in a Danish country. World Health Forum **8** (1987) 191–196.

[23] Alfiler, M. C. Primary health care in The Philippines: a closer look at a policy and a program. Paper prepared for the Commission on Audit's Policy Audit Seminar, Quezon City, 3–14 September 1984, pp. 1–20.

[24] Primary Health Care. Report of the International Conference on Primary Health Care, Alma-Alta, U.S.S.R., 6–12 September 1978. Geneva: WHO, Health for All Series No. 1.

[25] Mutatkar, R. K. and Ranade, M. G. Evaluation of health education in leprosy control programme: methodological considerations. Southeast Asian J. Trop. Med. Public Health **17** (1986) 437–441.

[26] Cudal, A. Health education in leprosy control. Philipp. J. Lepr. **3** (1968) 53–59.

[27] World Health Organization. *Education for Health: Manual on Health Education for Primary Health Care.* Geneva: WHO, 1984.

[28] Mahler, H. Health for all—everyone's concern. World Health April–May (1983) 2–4.

[29] Guinaratne, V. T. H. Health for all by the year 2000: the role of health education. Int. J. Health Educ. **23** (1960).

Health education aims to enable the people to define their own problems and needs, to understand what they can do about these problems and needs with their own resources and outside support, and then to decide on the action most appropriate to promote healthy living and community wellbeing.

The importance of health education in improving the health situation has already been proven in several countries.[30-32] For instance, in Sri Lanka, India, and Costa Rica, health activities, social and economic reforms, and educational improvements were initiated.[30] As a result, these countries have been able to increase their populations' life expectancy and decrease their infant and maternal mortality rates, all despite comparatively low levels of income.

Despite all of these encouraging experiences, we must also admit and recognize the limitations of health education in health activities.[29, 33] Foremost among these is the paucity of research about individual, cultural, societal, and health behavior and the nature, motivations and determinations of health learning and change in response to health education.

Another limitation of health education stems from a nation's failure in its health policy.[33] Policy has failed in that it has limited the concept of health education to the ideas that it is a tool in the service of specific disease programs. Health policy has also failed health education in that its support has been too meager to permit achievements to match the people's expectations. Another limitation is that it has not sufficiently taken into account the fact that in reaching health decisions, people are influenced by factors outside their control, e.g., working conditions, the general educational level of the community, social norms and customs. Although health education is intended to help people assume greater responsibility for their health, it should not lead to the belief that their behavior alone is responsible for their state of health.[33]

Today, because of changing disease patterns, rising social expectations, and a new relationship between community members and health-care providers, health education is now placed in a broad perspective in which information and education are seen as elements on the same continuum. This continuum involves activities ranging from advocacy, arousing health consciousness and reaching out to large numbers of the population through the media, to an approach involving interpersonal relations in dealing with specific individual community aspirations and problems.

The question now arises as to how to evaluate the impact of health education, for example, in leprosy control. Mutatkar and Ranade[25] reported on the following qualitative and quantitative indicators of goal achievement: people's participation in case detection-voluntary reporting; regularity in treatment/deformity rate reduction; social acceptability of patients; use of civic facilities by patients; no divorce/separation on grounds of leprosy; and viable places for leprosy clinics and residences for leprosy workers.

Future research topics

Determination of factors of compliance and noncompliance. While epidemiological and clinical issues are supposed to be best left to physicians, the underlying behavioral themes of disabilities and MDT acceptability represent unfinished tasks for the social scientists. For example, 90 countries (about 2.1 million leprosy cases) are on MDT or have completed MDT. There is no doubt that medical expectations of its success are great, but there is also the element of nonacceptance and noncompliance with the regimen that may cut its success rate in half. This is where the collaborations of human sciences—of medical sociology, medical anthropology, medical geography, health psy-

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[30] Hammad, A. E. B. Intersectoral cooperation in primary health care. World Health (1986) 3–5.

[31] Pribadi, W., Muzham, F., Santoso, T., Rasisi, R., Rukmono, B. and Soeharto. The implementation of community participation in the control of malaria in rural Tanjung, Pinang, Indonesia. In: Social and Economic Research in Tropical Diseases in Southeast Asia, Seameo-Tropmed, Bangkok, 16–19 June 1986, pp. 371–378.

[32] Rajagopalan, K. and Joo, L. K. Problems in leprosy control and the need for human behaviour and socio-economic research. Southeast Asian J. Trop. Med. Public Health **17** (1986) 486–488.

[33] World Health Organization. New policies for health education in primary health care. In: Report of the Technical Discussions, 13 May 1983. Geneva: WHO, 1983, pp. 1–19.

chology, medical history and medical ethics—with medicine will be greatly appreciated.

The problem of patient compliance is one of the most critical areas of concern in leprosy work. Patient noncompliance is so prevalent that several authorities now regard it as one of the most significant problems facing medicine today. And leprosy is no exception. Strategies to improve communication and compliance include explicit directions, explanation of purpose or importance, written reinforcement and supplementation, explicit categorization, simplification, consistency of advice, and the use of multiple strategies.

As early as 1981, Zola[34] called patient compliance a neglected area of research that is closely tied with the lack of scientific attention to what people do to and for themselves to prevent, help, and cure a vast range of physical and psychosocial conditions. Zola does not believe that noncompliance is almost entirely a patient issue; he feels it is equally attributable to the physician's overwhelming "uncooperativeness" and his beliefs about his own importance in the doctor-patient relationship scenarios, which he describes as an "unwitting process of intimidation." In the larger majority of leprosy patients seeking medical help, the stage of noncompliance and how it can affect the acceptance of MDT need to be systematically documented.

Like others, Zola believes that the phenomenon of noncompliance is more difficult with persons with chronic diseasè. Zola writes: ". . . the patients will, in the course of their disorder, inevitably have more questions, more troubles and more doubts. They must not be 'guilted' for things that are just starting to be better for them now." Zola hypothesized that a change in communication patterns with patients can mean a greater likelihood of patient medical compliance. This assumption must be tested and must be operationalized, both to improve clinical encounters and to clarify information given to patients.

Patient compliance in taking prescribed drugs is still not well known despite numerous studies. WHO, through Rosenfeld,[35] undertook to find out why some communities and their people develop antipathies to some drugs which may explain the phenomenon of noncompliance. Although a total of 87 studies were compiled, there were no specific studies on the problems of noncompliance among leprosy patients. Most of the studies dealt with hepatitis, renal problems, hypertension, and blindness. The literature review ranged from efforts to relate frequency of dosing and specific influences of patient compliance in taking medication. For instance, Greenberg's review[36] of the literature on patient compliance indicated that: a) Once-a-day and twice-a-day regimens were associated with significantly better compliance (73% and 70%, respectively) than were three times daily and four times daily (52% and 42%) regimens. b) Compliance is not related to income, social class, occupation or educational background, and it cannot be accurately predicted by physicians. c) Unintentional errors in taking medication are made by 50%–90% of patients. Although the respondents in these studies on patient compliance are by no means different, they still offer many hypotheses and insights that need to be tested and possibly validated to produce a more holistic understanding of why leprosy patients are or are not complying with medical treatment. An example of this hypothesis is seen in the question of what is the role of drug dispensers in the whole set of problems affecting patient compliance? Has the limited understanding of the drugs shown by the patients and their relatives determined, to some extent, the phenomenon of noncompliance by leprosy patients?

In Wartman, *et al.*'s study[37] of 1367 patients, compliance was found to be posi-

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[34] Zola, I. K. Structural constraints in the doctor-patient relationship: the care of non-compliance. In: *The Relevance of Social Science for Medicine.* Eisenberg, L. and Kleinman, A., eds. Dordrecht, The Netherlands: I. Reidel Pub. Co., 1981, pp. 241–252.

[35] Rosenfeld, P. Social science research in relation to rehabilitation of leprosy patients: notes for discussion. Unpublished paper for Consultation on Disability Prevention in Leprosy Control Programs, Geneva, 9–11 March 1987.

[36] Greenberg, R. N. Overview of patient compliance with medication dosing: a literature review. Clin. Ther. **6** (1984) 592–599.

[37] Wartman, S. A., Morlock, L. L., Malitz, F. E. and Palm, E. A. Patient understanding and satisfaction as

tively correlated with the understanding of the drug instructions but negatively correlated with the satisfaction with communication. Their findings also suggest that satisfying doctor-patient interactions do not necessarily reflect effective communication about drug regimens. Overall, their study indicates the need to test the following variables as they relate to compliance: a) psychological factors, such as patients' levels of anxiety, motivation to recover, and the attitudes and beliefs of significant others in their environment, and b) reasons for noncompliance, such as occurrence of adverse reaction, lack of symptoms, too many drugs, and forgetfulness. It would be interesting and important to validate or reject these reasons in future studies.

Wartman, *et al.*'s study[37] suggests that satisfying doctor-patient interactions does not necessarily reflect effective communication about drug regimens. Evans and Spelman[38] state that "contrary to beliefs of many doctors, his study does not support the view that drug non-compliance is a deviant from behavior influenced by patient characteristics." Conclusions on the role of doctors vary[37, 38] and therefore must be repeated at some other times and places. On the other hand, the studies confirmed that educational measures are required to increase patient participation in the therapeutic process[39] because patient education is often insufficient; physicians tend to blame the failure of a treatment regimen on the patient's lack of compliance. It is very clear that what we have here are studies which show varying conclusions depending on what methodologies were utilized and what reasons were invoked by the researchers. Considering that our efforts are simplified by the fact that we have to deal only with one disease and with one problem (noncompliance), we may discover some more useful clues for understanding leprosy and its attendant problems, i.e., noncompliance. Our efforts may be blocked by the fact that so far there has been no well-developed theory or model of compliance behavior except health-belief models on compliance. If we can address this problem of noncompliance using data obtained among leprosy patients and develop an alternative perspective, perhaps our efforts to improve leprosy control services will be facilitated.

Determination of roles of health-givers and effectivity of strategies. There is also another area of concern related to the issue of compliance. The efforts of health-care givers to improve compliance must be studied and intervention efforts documented. For example, use of: nurse intervenors and pharmacists to increase patient response to drugs; quality medications to influence patient use of drugs; tangible rewards—e.g., provisions of pill dispensers and use of clinical and drug counseling; after-care visits or home visits by doctors when possible; simple medication routines if possible; family as support; educational measures to increase patient participation in the process; post-card reminders as "cues"; drug monitoring; patient-held records; and integrated surveys (as was done in Wardha district, India, in 1976).

All of the above intervention strategies were found to be moderately successful in improving compliance among patients suffering from illnesses such as blood pressure, renal problems, cardiac diseases, and vision loss. Will these be equally useful in leprosy control work? The challenge will be to discover whether these approaches work in leprosy, and to understand the phenomenon of noncompliance among leprosy patients.

Not all the attention should be put on the patients, for it is especially important that the health-givers are understood in the context of their work. They should be motivated by the use of formal awards and benefits from restructured incentives. So far, the significant role of the health-care givers or leprosy personnel has been understated and the perceived potential of the community has not been fully realized.

Determination of disease impact on children. Another area of research that is potentially helpful to leprosy control programs, provided it is accomplished correctly, is the determination of the impact of the

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predictors of compliance. Med. Care **21** (1983) 886–891.

[38] Evans, L. and Spelman, M. The problem of noncompliance with drug therapy. Drugs **25** (1983) 63–76 (99 ref.).

[39] Levy, M., Mermelstein, L. and Hemo, D. Medical admissions due to noncompliance with drug therapy. Int. J. Clin. Pharmacol. Therap. Toxicol. **20** (1982) 600–604.

disease on children. Ramasoota[40] writes: "In the general population in endemic areas, 50% of individuals may be lepromin positive. Meanwhile, about 90% of them may be lepromin positive after puberty. Children, therefore, seem to be more susceptible than adults and have more chances for close exposure and direct contact with infectious cases. It would seem that children are more susceptible, for where children are at risk because of leprosy—in the family up to 60% develop the disease as children or young adults after an incubation period of 2.7 years (usually 3–5 years). Exposure to known cases cannot be established in an appreciable proportion of leprosy cases, even in young children, in part because of the long incubation period."

It would therefore be useful to determine from a sociological point of view what happens to these children with leprous fathers and mothers, in the school and in the playgroup.

Determination of effectivity of community-based rehabilitation. Research must be conducted to determine the viability of community-based rehabilitation for disabled patients. Community-based rehabilitation uses primary health care principles in action. The most immediate goals are to find out how to actively link the disabled patients, family and community members with the rehabilitation experts in the training efforts, in the use of single methods and techniques for the prevention of more serious deformities.

Research into acceptability of a vaccine for leprosy. There is also the possibility that a vaccine will be available in 5 years' time. A study involving 30,000 contacts of leprosy is underway in Venezuela, where subjects have been given a vaccine of killed *M. leprae* with BCG. The second large-scale trial involves about 120,000 persons in Malawi. It is clear that a vaccine is in the scenario of leprosy control programs. However, the acceptability of such a mode of treatment is a still bigger issue, for the patients must be informed as to its efficacy and the community must be encouraged to participate in the task of social persuasion. How to socially prepare the patient to accept it must be determined now, not after the vaccine becomes available.

Determination of measures of stigma. Chauhan, *et al.*'s study[41] of the experiences of identification and differentiation as a function of leprosy, personality, and age provides an example of a study on stigma. The study proceeds with a good research design that will satisfy some of the criticisms of other social scientists. How to use its conclusions for a leprosy control program is another issue. There should be more studies on stigma, studies whose findings can easily be translated into practical input to control programs.

CONCLUSION

Need for more scientific papers

The importance of social and economic factors in the spread of leprosy as well as in its control has long been emphasized,[42] but empirical studies on leprosy have been limited mostly to health education. In brief, most studies have not been approached or phrased sociologically, nor have their perspectives been strictly behavioral and social science. Similar statements were expressed by Noordeen[42] when he noted that "progress in approaching the subject at a scientific level has been limited either to identifying social and economic factors that promote the disease or to social and economic interventions that could contribute to a better control of leprosy."

A careful review of studies on leprosy should be postponed until there is sufficient empirical work to evaluate the items that provide clues to the dynamic changes and events in leprosy work. Exciting things are happening, such as the occurrence of dapsone resistance and the promise of MDT.

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[40] Ramasoota, T. Epidemiology and control of leprosy. Unpublished paper, Department of Communicable Disease Control, Ministry of Public Health, Thailand, 1984.

[41] Chauhan, N. S., Dhar, U. and Singh, Y. Experiences of identification and differentiation as functions of leprosy, personality and age. Indian J. Lepr. **56** (1984) 292–300.

[42] Noordeen, S. K. The changing nature of leprosy control: a global perspective. Address, Opening Session, International Meeting of Social and Economic Factors in Leprosy Control, Pune, India, 22–25 March 1988.

On the whole, there are fewer and fewer leprosy patients with severe deformities and complications. New knowledge about the disease is leading to the breaking up of myths surrounding this pathology.

Erasing the "multiple burden"

In 1986, Dr. Ramalingaswami[43] spoke about the developing countries carrying a "double burden." He meant the burden of diseases arising out of the malnutrition-infection complex and the evolving burden of disease associated with increasing affluence, microchemical pollution of the environment, changing life styles, and new health problems consequent upon economic development, including migrant worker populations. Any community with leprosy patients carries not only a "double burden" but a "multiple burden" and, therefore, needs all the support it can muster.

Moving toward a synthesis of social science, technology, and medicine

I believe that it is in the study of leprosy that the full application of biobehavioral sciences is best provided. It is a disease and an illness and, therefore, an excellent object of study by medicine and by social science, and an excellent case study for technological application. This is what is in the "art of the possible," and again I quote from Ramalingaswami: "The art of research is the art of making difficult problems soluble, not merely to grapple with them. I would say that the art of the possible is the art of dealing effectively with existing problems, with existing knowledge and technology, be they in the field of health or any other against the backdrop of all human experience."[43]

In conclusion, this paper on the social dimensions of leprosy is not all-encompassing. I have simply attempted to give you in a more integrated fashion what, to my mind, are some of the salient issues related to leprosy research. I would also like to stress that there is not too much data to describe the specific situations around the communities where leprosy patients are living and, therefore, much further acceptable research is needed in this area.

Where are we going from here?

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[43] Ramalingaswami, V. Health in the tropics: a saga of missed opportunities. Soc. Sci. Med. **22** (1986) 1097–1103.