

SOCIETY AND LEPROSY: A PHILIPPINE EXPERIENCE

Luzviminda B. Valencia

*Department of Sociology,
University of the Philippines*

Elizabeth R. Ventura

*Department of Psychology,
University of the Philippines*

Consuelo J. Paz

*Department of Linguistics and Asian Languages
University of the Philippines*

Adelwisa Ortega

*Institute of Public Health,
University of the Philippines*

Leprosy is viewed as a chronic disease which involves stigmatization and leads into a "disruptive experience" particularly on the part of the person afflicted with the disease. With this in view, this research work seeks to understand and present the complex set of social factors involved. The Ilocanos of Northern Philippines were chosen as the subjects of study with emphasis on three major characters: leprosy patients (P), Critical Informants (CRI) or those who serve as his social support, and the Key Informants (KI). The research utilizes a multidisciplinary approach in eliciting and analyzing data, i.e., this includes sociological, psychological and linguistic tools. Data on knowledge, attitudes and practices of Ilocanos on leprosy as well as data on the coping mechanisms developed by these people were determined. On the basis of the findings, this paper proceeds to present a new model of action which calls for the strengthening of the bonds among Ps, CRIs, and KIs and gives due recognition to the indigenous aspects of coping with a chronic disease.

This paper is a multidisciplinary effort to understand the social etiology of Hansen's disease. It is directed, specifically, by the following goals: (1) to determine the respondents' level of knowledge regarding the causation, transmission, diagnosis, and treatment of Hansen's disease; (2) to assess the intensity of feelings displayed by those afflicted and by the community in general about the disease; (3) to document the respondents' practices (both "theoretical" and real); and (4) to describe the respondents' coping mechanisms that over time have become part of an indigenous socio-cultural and psychological system of reactions. The settings for this study are the provinces of Ilocos Norte and Ilocos Sur, the two most leprosy-endemic provinces in the Philippines. In turn the respondents are out-patients Hansenites who never experienced institutionalization and who, at the time of the study, resided in selected municipalities of the two Ilocos provinces.

Methods

The research project was designed in such a way as to be able to use what Patton (1980) calls "triangulation mixes" — a triangulation of data gathered from three different independent strategies, namely: the use of survey questionnaires, the linguistic analysis of interviews, and the administration of two psychological instruments for in-depth interviews — the Rorschach and Philippine Thematic Apperception Tests (PTAT).

The choice of study sites was purposive: it was determined by the highest rate of leprosy prevalence at the time of the project. In 1982, Ilocos Norte had a prevalence rate of 477 and Ilocos Sur 379, making these two provinces the most leprosy-endemic areas in the Philippines. Once these two provinces were selected, the municipality within each province with the highest prevalence rate was chosen. In Ilocos Sur, Bantay has had the highest incidence of

leprosy for the past six years while Guimod, the barangay chosen as the study site for Phase I, had a prevalence rate of 57.32 in 1982. San Nicolas in Ilocos Norte shares the same problem in that two of its barangays, Barangays 8 and 9, have very high prevalence rates.

The initial survey questionnaire used in this study consisted of two structured interviews. This questionnaire was pretested three times before it was finally administered to the sample.

The inductive linguistic strategy used in this study followed this procedure. The interviews of the Hansenites (P), Critical Informants (CRI) and Key Informants (KI) from the study sites (Guimod and San Nicolas) were taped. The tapes were then brought to the Department of Linguistics and Asian Languages for transcription — a free-flowing, literal translation from Ilocano into Pilipino, and then into English. The informant's choice of linguistic structure was then analyzed in order to educe the state of social interaction between P and CRI — and sometimes among P, CRI, and KI — and to determine the psychological factors which come into play when making choices on mood, emotion, motivation and attitudes. The data obtained were subjected to both lexical (vocabulary) and syntactic analysis to elicit the following information: attitudes, beliefs, local terms for the disease, knowledge, transmission cure and symptoms. Later, the linguistic devices used by the informants to convey the information on these topics, were classified as either syntactic or lexical structures, or as modes of code switching, loans or metaphor.

The study also employed the following techniques of eliciting data: a) the Philippine Thematic Apperception Test; b) the Rorschach test; and c) In-depth interviews revolving around perceptions, feelings, reactions, problems, dreams and experience. The use of the Rorschach and PTAT tests circumvented the problems of language and the respondents low literacy level. These tests were easily administered using standardized instructions in Ilocano. Local norms for the Rorschach, previously established in a study by Floro,

were referred to in the analysis. In turn, the PTAT, developed by A.V. Lagmay (1965), consists of 25 cards (including one blank card) showing various scenes depicting Philippine conditions. This test was developed from Lagmay's original pool of 64 cards. In the present study, however, only five cards were used, namely: Cards 1, 3, CG4, 7 and 10. They were chosen by two psychologists with extensive experience in using the test, because they suggested situations similar to those found in the setting of the study. They have been proved effective in pretests conducted at the Vigan Skin Clinic.

Actual field work commenced after this and other preliminary activities. Since the study concentrated on out-patient Hansenites who had never experienced institutionalization, the research instruments were designed to gain an understanding of their phenomenology within the context of disease-related stresses. Respondents who were given psychological tests were randomly chosen based on their being physically able to see and talk normally. In Guimod, introductions were made by personnel from the Skin Clinic who told the patients that the interviewers were conducting a study on Hansenites and sought their cooperation. Rapport was quickly established since the interviewers spoke the dialect and tried to minimize the physical distance between themselves and the patients. Then, too, instead of the usual formal question-and-answer format with the interviewer as interrogator, the researchers encouraged a mutual exchange of ideas between them and the respondents, thus creating a freer, more relaxed atmosphere for a more natural interaction to take place.

Respondent Profile

The total number of respondents was 213. 125 Ilocos Norte and 88 from Ilocos Sur. The Ilocos Norte (San Nicolas) sample had 40 were P's (patient respondents), 40 CRI's (critical informants) and 45 KI's. (key informants). The Ilocos Sur (Bantay and Guimod) sample had 35 P's, 23 CRI's and 30 KIs.

Of the 213 respondents, 70 were given psychological tests, 31 of whom were from San Nicolas and 39 from Guimod. For linguistics analysis, 61 interviews were taped, 35 of which were from Guimod and 26 from San Nicolas.

Of the total number of respondents, the highest percentage of incidence belongs to the age group between 20-29, followed by the group between 40-49 years for San Nicolas and 50-59 for Guimod. Majority of the patients belong to the 10-19 age group which indicates that more young people are afflicted with leprosy in both sites. The greatest number of CRI for San Nicolas belongs to the 40-49 age bracket while for Guimod, majority belong to the age bracket 20-29. Finally, the highest percentage of KI's belongs to the age group 20-29 for the two sites.

Of the 125 respondents in San Nicolas, 25 P's, 19 CR's and 6 KI's reached the elementary level of education, while in Guimod, 33 P's, 18 CRI's and 4 KI's achieved the same level of schooling.

Among Guimod patients 57.3 percent are married, 39.6 percent are single and 3.1 percent are either widows or widowers. In San Nicolas, 55 percent of the patients are married, 43.4 percent are single and 7.8 percent are widows.

There are more single than married patients in San Nicolas because the stigma attached to their disease make them apprehensive of having relationships with the opposite sex. Afraid of being rejected to some such consequence, they shun intimate relationships.

There are slightly more females (55.7 percent from San Nicolas and 58.3 percent from Guimod) than males (44.3 percent from San Nicolas and 41.7 percent in Guimod) among the respondents. As for the CRI's, 5.2 percent are males as against 20.9 percent females in San Nicolas. This shows that women are closer to the ill-fated members of their families and feel more responsible for their care.

Farming is the predominant occupation among the Ilocos Sur respondents. Hence, most of the Guimod patients and CRI's interviewed were farmers. In contrast, because San Nicolas has a monopoly of the pottery

industry, most of the Ilocos Norte patients and CRI's interviewed are potters, the rest are either deepwell diggers or metal workers. In both sites, KI's are either teachers or office employees, which is to say that they occupy a higher socioeconomic status.

Most of the barrio people speak Ilocano, the mother tongue of both provinces. Majority claim to understand, if not speak the national language, Pilipino, proficiently. The Ilocano spoken in San Nicolas, is quite different, however, from that spoken in Ilocos Sur, a fact which illustrates dialectical differences in the Ilocano language.

Hansenites, (Ps), CRI's and KI's living in the study sites were studied for a 34-month period, during which a great number of local terms indicating the symptoms or describing the state of the illness surfaced. All terms are indigenous and the list of symptoms elicited from San Nicolas reveal how the informants regard the symptoms of the disease, how they feel physically and how the informants feel after medication.

Folk Beliefs and Traditional Knowledge of Leprosy

The local terms for leprosy are *kamanaw* (tinea flava), *kamuras* (measles), *gudpud* (scabies), *supotsupot* (rash), *kurad* (ringworm), *budobudo* (itches), *kamuro* (pimples), and *kating* (yaws). The respondents also used other terms such as *kukutil*, *leprosi*, and *ketong* — all of which means "leprosy". Since there are several local terms for the disease, it is possible to say that people in the study sites are more or less knowledgeable about it. The term *leprosi* is used in both sites while *ketong* is used only among the natives of San Nicolas. However, both words are loan words from English and Tagalog respectively, and are considered taboo. Ilocanos, like other Philippine groups, refrain from uttering names of diseases for the fear that to do so would be to expose themselves to the sickness. Thus, instead of using the above listed words, they call those afflicted with it *tuko* (lizard).

All of the terms encountered in San Nicolas are native words, mostly verbs, which show that the informants' perceptions of the disease are not static but progressive in nature. Respondents describe some of the symptoms by comparing them to commonly known sicknesses, i.e., like a pinching or squeezing sensation, skin stains or measles. Descriptive phrases like "stretching of skin" or "cauliflower ear" are also used.

The respondents' description of symptoms such as bodily changes, especially on the skin, reveals a certain degree of knowledge which they articulate in descriptive terms. However, the respondents tend to equate the symptoms with a skin disease. They insist on describing the skin changes while denying the possibility that these changes are indicative of leprosy. In their view, leprosy does not exist, only some kind of skin problem which is not serious but uncomfortable. Respondents have often convinced themselves that these skin changes were simply rashes, ringworms, pimples and the like, and would disappear in due time.

All respondents know that the risk of contracting the disease comes from skin contact (with wounds) over a prolonged period of time. Because of the close family ties of Filipinos, the chances of getting infected through contact with commonly used household items cannot be avoided. The intimate relationship of husband and wife is a suspected vehicle of transmission. Thus, it is obvious that the respondents have ideas regarding the transmission of *M. Leprae*, although other findings (Gupte 1983) have raised doubts about the skin being the exclusive route of entry. Doctors believe that the micro-organisms enter the body by inoculation into the skin and not by passive contact. Apparently, such knowledge is not new to San Nicolas respondents who identify insect bites as the disease's medium of transmission. But Guimod residents do not make the same connection — a disparity which seems strange because mosquitoes, flies and cockroaches infest both study sites on account of the poor environmental and sanitary conditions, and of the climatic conditions which encourage the rapid breeding of these

insects.

Although there is no direct scientific evidence to show that leprosy is transmitted through ingestion, the respondents claim that one contracts the malady by eating one of the following foods: octopus, fresh water shrimp, small prawns, eggs, beef (especially its fat), pork, lentils, chicken, fish sauce made from very small shrimps, monosodium glutamate, and the combination of chicken and squash. They also believe that swallowing a certain "venom" found in drinking water makes one susceptible to infection.

Some data indicate that the respondents may have some knowledge about the transmission of the disease through inhalation or the respiratory route. Among the respondents, the term "respiratory" is equated with the lungs. They believe that the lungs should be protected from unnecessary stress and that sudden changes in the weather affect the respiratory system of the "lungs" and predispose people to the disease. But since most of the respondents are farmers, fishermen, and potters, their exposure to the heat of the sun or to the kilns in pottery factories cannot be avoided. Another aggravating factor is the respondents' practice of soaking or swimming in the river after work which is also believed to increase susceptibility to the disease.

Scientifically, the causative agent of Hansen's disease is the *M. Leprae bacillus*, discovered by a Norwegian physician in 1971. Hansen's bacillus is a red-shaped microbe, non-motile, 1" to 8" long by 0.2" to 0.5" wide, and is straight or slightly curved.

To the majority of the respondents in Guimod and San Nicolas, however, the disease is caused not by bacteria but by curse, witchcraft or fate. While there is some knowledge about *M. Leprae* among the San Nicolas respondents, the dominant explanation still lies in supernatural phenomena, enticement and envy. Clearly, the majority of the respondents do not make clear distinctions between causative agents of the disease (in this case, *M. Leprae*) and the different modes of transmission previously discussed in this paper,

a conclusion empirically validated in previous studies (e.g. Valencia 1983).

Knowledge on Prevention, Diagnosis and Treatment

Technically, the term "prevention" means "to stop something from happening or prompt action to avoid serious aftermaths." One therefore takes precautionary actions to ward off disease or illness. Today it is assumed that the diagnosis of leprosy should be based upon clear bacteriological, immunological and pathological findings. This implies the necessity of employing special tests and using other laboratory aids for diagnostic purposes. Patients start to have their cases diagnosed when they begin to see visible changes on their skin. In this case, P will begin seeing a "real doctor" or herbalist.

The obvious dermatological conditions are usually called "allergy" by the patient and sometimes by personnel of the skin clinics as well. When diagnosed as such, no further comments are made except by the Public Health Nurse, and when P comes back to the clinic he or she is oftentimes lightly brushed off. Instances such as these account for decreased case handling. However, these difficulties do not arise in the diagnosis of advanced cases. More cases are lost because they are misdiagnosed during the early stage.

Diagnosis in the study sites is done by a single skin clinic specialist who is not even a leprologist; thus, the chances of a greater number of definite misdiagnosis of leprosy are very real. It may be said that the majority of the respondents resort to diagnosis which are usually based on observed skin changes and describe these dermatological conditions as tinea flava, measles, scabies, rashes, ringworm, and itches.

But leprosy demands careful and prompt attention. Theoretically, the leprosy patients in the study sites are given the triple chemotherapy and are even supposed to take some of the medicine under the supervision of the skin clinic personnel, at least by the nurse. However, in practice, treatment protocol is

not observed at all. For instance, the patients are not prepared for anti-leprotic treatment. Neither are they given a thorough physical examination, routine blood count, hemoglobin reading, and urinalysis.

The data on treatment in the study sites reveal definite social action processes, as follows:

- a. Self-diagnosis — a treatment process where P is the focal actor.
- b. A treatment process within the primary group relationship where the CRI plays a strong influencing role (CRI and P in "connivance").
- c. Treatment linked with the structure found acceptable by the community health agencies and "non-acceptable health agencies" such as the clinics of herbalists and other traditional healers. (This last process has local settings that are known but quietly ignored by health staff). The first two processes listed above could be integrated, but the third type of treatment process might be taken as a "recourse process completely untapped." Patients readily confessed that they had stopped taking medication altogether but had not ceased going to the herbalist. Going to the traditional doctor for treatment was also a way to make P finally accept his disease.

Traditional Practices

The life of the Ilocanos in the study sites revolve around their belief in witchcraft, voodoo magic, spell-binding, fatalism, malediction and the negative force of hatred and envy. Hence, they define illnesses that befall them in terms that new closely to these beliefs. This facilitates acceptance of the notion regarding the multiple etiology of disease in general (not only of leprosy), i.e., the notion that no illness can be due to any single final cause.

As a result, Ilocanos consult the herbalist. The term herbalist is used here to indicate not only one who cures the sick by means of natural materials such as roots, herbs and oil, but also one who treats illnesses or dispels evil

spells by means of rituals. Practically all communities in the Philippines, most especially in the rural areas, have at least one such person. The belief in the herbalist's power is still prevalent and widespread.

While leprologists and other medical people believe that the bacillus *M. Leprae*, causes leprosy, the Ilocano respondents insist that leprosy is brought about by the "unexplainable in nature", the undefinable spirits roaming around in their environment. For this reason, they consult herbalist of all types when anyone contracts the disease. These traditional healers dispense common folk remedies for skin disease in general and give treatment along with prayers.

But other treatment practices abound: many Ilocanos wear black clothes when the skin eruptions appear. Others wear earrings as this would counteract any attempt to cast spells that would result in leprosy. Similarly, Ilocanos are also careful not to be critical when they see or speak about a Hansenite; if they do, the disease would afflict them, too. Neither should anyone loudly speak the word *leprosi* for the same reason. These prescriptions are consistent with observations that most respondents repeatedly make use of substitute terminology in referring to leprosy such as *kasdyayen* (like that already), *nga sakit nga kasdiay* (like that sickness), *nga kua daydiay* (that is that one), *adda tao nga kasdiay na* (have one like that) or *daydiay tao nga kasdiay* (that person like that) when referring to Hansenites.

Prayers and Dreams: Forms of Stress Management System

Medically, leprosy is a chronic disease with high infectivity but low pathogenicity. For this reason, the disease is dreaded and persons suffering from its debilitating effects are stigmatized, though subtly. Aside from the stigma attached to the disease, its victims have to suffer its crippling effect on their resources and of those indirectly associated with them (CRI's and the KI's). Immediate

family members who are involved in patient care were included in the study to elicit their stress and coping reactions in their daily social interaction with the Hansenites. To some extent, the community also shares the stress of providing support to those afflicted. By and large the stress has been found to be socially and emotionally contagious; that is to say, the larger social system usually suffers together with the patients and their families, a fact which is not surprising because Filipinos tend to be clannish. This herdish cultural trait oftentimes becomes a source of difficulties.

The data makes possible a summary of the mode of development of leprosy and the patient's typical response to it in chronological sequence.

The patient's final confrontation of the problem varied. In the Guimod sample, everyone reported negative feelings — varying degrees of worry, fear, shame, depression and anger. The victim also imagined the perceptions of others and their responses to him. Sixty-two percent of both male and female patients inferred negative reactions from their relatives, friends and neighbors. These included shock, worry, fear, loathing, pity and disdain. Thirty-eight percent of the Guimod patients, however, reported no change in the reactions of their families and friends.

In the case history of a P, it is indicated that stress builds up from the first to the last step, with the CRI suffering equally. For P, one way of coping was going to the hospital, taking the medicines prescribed, and seeking traditional healers. For the CRI's, nothing was mentioned except helping P in "asking for Gos's help." At the same time both respondents (P and CRI) expressed fear, shame, anger and despair. Being Catholics, however, their main coping mechanism is to pray for Divine help. The importance of the role of the CRI, therefore, should not be ignored. They serve as a support system; they are part of P's life-sustaining mechanism. Oftentimes, we find P coping because the CRIs live in the same household. But because they share and live in the same household, the CRI's risk of catching the disease is increased. Thus,

praying is a coping mechanism, and one of illusion.

Dreaming (night and day dreaming) is another mechanism used by Hansenites who are overcome with feelings of frustration, unhappiness, worry, shame and rejection. Using the documentary method of interpretation which treats utterance as documents (Gerhardt 1979), the researchers have given meaning to these dreams and illusions which make up the social realities of the Ps and the CRIs.

Around 29 percent of Guimod respondents and about 19 percent of San Nicolas respondents dream of being healed through a magic potion, oil or saliva applied all over their bodies. More male victims (31.5 percent) report this type of dream than females (16.7 percent).

Even the non-patient respondents of Guimod reported generally negative dreams compared to San Nicolas respondents. This lends significance to the inference that life in Guimod may indeed be generally harder than in San Nicolas. More female non-patients reported negative dreams, which is again consistent with the Rorschach data on this group.

Thus, it appears that sex is an important variable in determining adjustment to and coping with the chronic nature of Hansen's disease. Since males in a traditional society, like that of the rural areas of the Philippines, are expected to be breadwinners and protectors of the family, it is understandable why the male Hansenite is more resentful than his female counterpart (who is expected to be passive and dependent).

The non-patients, both male and female, are more active in their effort to counteract particular problems they find themselves in. But there are problems as well. The presence of one male member of the family suffering from Hansen's disease may increase parental protectiveness over the "healthy" sons. Similarly, the negative attitude of female non-patients may lie in the over-burdening of the mother or sister with household duties and responsibilities. The additional task of attending to a handicapped Hansenite may contribute to their resentment and hostility.

However, whatever personal relations are

among the P, CRI, and the KI's in this study, the P's outlook can still be described as "normal". The P still thinks about holding a job and if unmarried, still wishes to marry.

In general the Hansenites want to get well. But they are emotionally affected by the disease and are hopelessly bewildered at times. The helplessness may explain the apparent neglect of their conditions or the discontinuation of their medication in many cases. These respondents seem to have simply accepted their plight as hopeless.

The community as a whole does not react negatively to the Hansenites. However, the data gathered from the language informants show adverse reactions, especially to the lepromatous cases.

Perceptions and Attitudes

Hansenites are called *tuko* (lizard) by non-Hansenites. They are likened to the reptile, because the Hansenite's skin, thickened with whitish spots, is leathery like the animal's and similarly scaly. These skin deformities are usually the basis of some of the very negative perceptions of the non-Hansenites towards the disease or the patients. The KI's (representing the community) express their general reaction to the disease as well. Among the San Nicolas respondents, for instance, negative reactions such as humiliation, cruelty, avoidance, disdain and pity predominate.

In both study sites, the non-patients (usually CRIs) consistently described their Hansenite relatives as sad and worried about their condition. Their own reported feelings likewise reflect the perceptions of the patients. Thus, feelings of pity, sadness, disbelief, embarrassment and shame have been reported.

When asked about their perceptions of other people's reactions toward the patients, 50 percent of the CRI respondents confirmed the observations of the Hansenites. One of CRIs also mentioned that even if these people feel queasy about the conditions of their sick relatives, they try not to show this to him. The rest claim that their own feelings have not changed and observe that neighbors still interact with the patient.

Furthermore, the CRIs (who can very well be representing the community too) have the same prevailing attitudes that can be described as confused and ambivalent. These feelings range from a certain degree of expressed sympathy for the P to extreme anger and hostility. The fact that the CRI is someone very close to the patient (a spouse, a relative or a friend) and knows him well makes the CRI physically and emotionally involved with the patient and sees him during his best and worst moments. Proximity to the P puts the CRI in a very distressed state, full of feelings of pity and/or unexpressed anger toward no one in particular.

The P's attitude toward his affliction is described as "something to be ashamed of." The results of the PTAT test strongly indicated that "shame" is the dominant feeling, but at the same time P expressed the need for help and understanding (succorant attitude) from God, other people and his fellow Hansenites. The Hansenites patients dwell on their disease constantly and generally in a highly negative manner. These perceptions are projected into the characters of their stories and dreams. For example, male patients reported dreams of falling all the way down a ravine, being chased by a ghost, bitten by a snake, unable to move because a monster sat on a patient's stomach, or chased by two men and getting killed. Thus, when asked about their "happiest experiences", 47.3 percent said "none" (one was never happy). They could not identify a single happy experience. A good 50.3 percent perceived themselves as forever in a "state of deprivation." But sometimes there are some more pleasant dreams, almost magical and wish-fulfilling in nature, e.g., dreaming of being completely healed by applying lotion all over the body, seeing God, talking to God which makes their disease more bearable, and being informed by others about a doctor who can really cure leprosy.

The attitude is one of despair and a desire to be healed. The data obtained through direct inquiry, the in-depth interview, as well as the logical and syntactic analysis are all descriptive of the depressing effects of the chronic nature

of Hansen's disease. The P's look at their disease as the primary source of their unhappy experience (consistent across study sites, 47.6 percent for Guimod, 68.8 percent for San Nicolas and across sex, 63.2 percent for males and 50 percent for females). The male patients in both study sites show negative attitudes marked by a destructive orientation,

The Hansenites are engulfed by hopelessness and despair owing to loss of eyesight, and by ill-feelings owing to the side effects of their medicines. Fear of the disease and of its consequences result in the strong determination to avoid harm (pain, physical injury, illness and death) and the need for affiliation and security instead of being alienated from the CRIs and the community.

P's complaints range from weariness, weakening of the blood, lightness of body, dizziness, chills, feeling low, nasal speech, aging, not to mention the discomfort owing to visible skin changes. They suffer pains associated with some physiological changes and soon after, depression, moodiness, and anger set in. Hansenites can still socially, though segmentally, interact with non-Hansenites, and welcome visits from the medical team as indicated by 94.3 percent of the patients from Guimod and 75 percent from San Nicolas. This clustering of negative sentiments result in a so-called "myth making" which in effect breeds alienation (Kaufort: 1148:1979).

Knowledge, Attitude and Practice

To determine the correlation among knowledge, attitude and practices, scores were computed for each respondent. The knowledge score is based on the responses to these questions: What do you see or observe in a person sick with leprosy? What causes leprosy? Is leprosy contagious? How? Who are the most susceptible to this disease? Can you avoid getting sick with leprosy? How? Have you known or heard of some beliefs pertaining to the following activities: eating, sleeping, taking a bath, dressing, etc.?

The enumerator checked any of these choices given on the questionnaire or they wrote down their own answers to the questions if they were different from any of the given choices. Points ranging from 2 to -2 were assigned to each answer.

The attitude score is based on questions about (1) the respondent's reaction to seeing a Hansenite, (2) how he would feel about a relative, a friend or co-worker, contracting leprosy, and (3) whether he should be ashamed to tell others if one member of his family is afflicted with leprosy.

In addition to the three questions, the respondents were asked to react to a series of statements regarding leprosy by indicating the extent to which they agree or disagree with any one of them. These statements are as follows:

1. I like to associate with Hansenites.
2. I feel that Hansenites face a bleak future.
3. I don't mind sitting side by side with a Hansenite in a public transportation.
4. I feel that Hansenites should be treated with more compassion.
5. I believe that leprosy cannot be cured.
6. I cannot imagine myself working with a Hansenite.
7. I panic when a Hansenite approaches me.
8. I believe that Hansenites should be kept in an institution.
9. Leprosy can be cured.

Each of the four-point scale attitudes "strongly disagree", "disagree", "agree", and "strongly agree") was given a corresponding score of either +2, +1 or -1, -2 depending on the statement. The total score for these nine statements and that for the preceding questions are added together to form the attitude score.

Practice scores (only in the San Nicolas sample) are derived from answers to the following questions:

1. Have you known or heard of some practices of Hansenites pertaining to the following activities: eating, sleeping, smoking.
2. In your perception, can a Hansenite continue working, marry, continue school-

ing? Have sex with mate? Have children?
Live with his family?

Each one of the correct practices mentioned by the respondent is scored 1 point while each of the wrong practices mentioned is scored -1 point. All no answers are scored -1 point. However, a no answer given for the right reason also scored 1 point.

The patient-respondents were ranked according to their knowledge scores 1); that is, the lowest score is ranked 1 and the highest score, 40. They were also ranked according to their attitude scores 2). and practices scores 3). To determine the extent to which these three rankings converge, Kendall's coefficient of concordance (W) was computed. To test the significance of W, Friedman's χ^2 was used.

A similar ranking of knowledge, attitudes and practices scores was done for the CRI and KI respondents, and the coefficient of concordance computed for each group of respondents. Table 1 shows the results of the computations, together with Friedman's r , the corresponding critical value (C) of the chi-square distribution for the specified degrees of freedom at the .05 level of significance.

Table 1. Rank Correlations among Knowledge, Attitude, and Practice Scores by Sample Sub-group

Sub-group	W	d.f.	r	C
Patient	0.50	39	51.57	54.10
CRI	0.43	29	25.32	42.56
KI	0.47	44	37.00	60.48

Since the obtained values do not reach the required critical value, it is concluded that the ranking for attitudes, beliefs and practices across the three types of respondents, while moderately correlated, are not statistically significant. This finding implies some independence among the three variables: one's knowledge may be perfect, but this is not necessarily consistent with practice. As an intervening variable, attitude may negate or emphasize the effects of knowledge. Furthermore, other variables (such as convenience or social

pressure) may, in fact, determine actual practice.

Comparison of Respondents

Since the data on knowledge was elicited from all types of respondents in the two study sites, it is possible to compare the responses of the three groups of respondents through the use of the Kruskal-Wallis Test.

Table 2 shows the results of the computations for both the San Nicolas and Guimod respondents.

The Kruskal-Wallis H' knowledge scores of the respondents in San Nicolas reveal that the knowledge of the patients, CRI's and KI's respondents of San Nicolas about leprosy differ significantly. The same conclusion may be said to apply to the Guimod respondents.

Table 2. Comparison Among the Three Groups of Respondents Using the Kruskal-Wallis Test

Scores:	N	C	H'
<i>San Nicolas</i>			
Knowledge	12.977	.998	12.997*
Attitude	28.052	.996	28.155*
Practice	30.854	.966	31.929*
<i>Guimod</i>			
Knowledge	9.70	.990	9.78
Attitude	3.72	.996	3.73
Practice	—	—	—

*p < .05.

Conclusion and Recommendations

The findings support a model for leprosy control with the following as significant inputs: first, the recognition of leprosy as a chronic disease which results in a very disruptive experience for the afflicted; second, the role of social supports from the CRIs which can lead to the development of a greater and more vigorous coping capacity among the patients;

and third, increasing the participation of the herbalists as paramedical personnel in the community after appropriate training at the skin clinic. In sum, the central basis of this model consists in strengthening the bonds among the Ps CRIs and KIs, as well as linking the work of the herbalists with the skin clinic. This model recognizes the indigenous aspects of coping with a chronic disease which is perceived as an expansion of the usual biomedical model utilized by physicians.

There are some "givens" in this model. One of these is the notion of a patient as "one who is acted upon." The data indicated the presence of CRIs who, as social support, oftentimes "act" upon the patient; the KIs, sometimes through "indirect action", also act upon the patient. These people can be made to act as powerful agents for "community involvement activities" which are designed to reduce the dependency of the Ps. The data also show that the patient is alone in his introspection over what ails him; he is completely alienated from his social world even as he tackles and seeks control of his decisions and options through self-diagnosis. For leprosy control programs, this means an increased number of undetected cases. The patient finds other forms of treatment meaningless, especially those provided by the skin clinics, and sees no logical possibilities for cure.

But the data indicate that the Hansenites have evolved individualized systems of coping such as prayers and dreams, and seeking cures by consulting with herbalists and medical doctors. We shall call these systems of coping in response to leprosy more psychological (praying and dreaming) than social, except the attempts to seek the herbalists' advice.

The study's findings raise many more questions worthy of more research such as:

1. How do we shift the Hansenites' coping reaction from the usual psychological mechanisms to social action coping?
2. How do we shift the P's choice of treatment from the herbalist to the medical doctor? In other words, how do we encourage greater utilization of medical clinics for better diagnosis and increasing

case detection? The data indicated that we need to do the following for control purposes:

- a. To understand what the skin clinic means to the Ps so that its functions will become more relevant to them.
 - b. To evaluate the skin clinics as they exist today.
 - c. To understand why the effectivity of the skin clinic as a delivery system is low and why the present skin clinics are not perceived as the main source of health care among the Hansenites.
3. How do we bind the three types of respondents (Ps CRIs, KIs) so that they can work together and be more appreciative of their respective roles in controlling leprosy?
 4. How do we incorporate a system whereby the Ps, CRIs and KIs can work together to reduce P's alienation from his social world?
 5. How do we introduce viable socio-economic activities in the community to facilitate the entry of Hansenites into the mainstream of community life?
 6. What accounts for the social stigma attached to leprosy, subtle though its forms may be?

The data indicate the social pressure arising from social stigma, a negative factor brought about by what Goffman (1963) calls, "abominations of the body various deformities which are particularly affected by cultural definitions." The research findings disclosed that among our respondents, "stigma" is conceptualized not only in terms of individual characteristics but also through the "language of relationships". Thus, P fears others (but not as much as others fear him) because of what he is, something which he cannot understand himself. The stigmatized individual (Respondent-Patient) exhibits fear of visiting and being visited; fear of going to the clinic for medical advice; and fear of social interaction, all of which contribute to a lowered self-esteem. Social stigma arises from membership in a "devalued group" with a minority status. The problem, therefore, is how

to formulate intervention programs to desensitize the community so that it can fully accept the presence of the Hansenities. Ultimately, the community's continuous support will be prospective control programs.

References

- Brown, Theodore H.
1969 *The Use of Statistical Techniques in Certain Problems of Market Research*. Cambridge: Harvard University Press.
- Bury, M.
1982 "Chronic Illness as Biographical Disruption." *Sociology of Health and Illness*, 9: 167-182.
- Conrad, Peter
1979 "Types of Medical Social Control," *Sociology of Health and Illness*, 1: 195-225.
- Galang, Zoilo M. (ed.)
1950 *Encyclopedia of the Philippines*, 3rd ed. Vol. 16, New Jersey: McCullough Print Co.
- Gerhardt, U.
1979 "Coping and Social Actions: Theoretical Reconstruction of the Life-event Approach," *Sociology of Health and Illness*, 1: 195-225. pp.
- Goffman, Erving
1963. *Stigma*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Guinto, Ricardo S.
"Epidemiology of Leprosy: Current Views, Concepts and Problems." Unpublished paper.
- Gupti, M.D.
1983. "Review of Present Knowledge in Epidemiology of Leprosy." Working Paper presented at Geneva, LEP/SG/WP/83.2.
- Kaufort L.
1968 "Statistical Significance in Psychological Research," *Psychological Bulletin*.
- Lagmay, A.V.
1965 *The Philippine Thematic Apperception Test* Social Science and Humanities Research Council, University of the Philippines, Diliman, Quezon City.
- Patton, Michael G.
1980 *Qualitative Evaluation Methods*. New York: MacMillan Press.
- Tupas, F.
1978 "The World View of Iloko Folklore," *Ang Pandaigdigang Pananaw ng mga Pilipino*. PRTH.
- Valencia, L.B. with Aida Lu
1983 "The Social Aspect of Filariasis in the Philippines," *Southeast Asia Journal of Tropical Medicine and Public Health*, 14: 43-46.