# Social and Economic Research Project Reports

Society and Leprosy: A Study of Knowledge, Attitudes and Practices of Philippine Ilocanos

Luzviminda B. Valencia Elizabeth R. Ventura Consuelo J. Paz Azucena C. Darvin Adelwisa R. Ortega Antoinette S. Rosel

College of Social Sciences and Philosophy University of the Philippines

Final report of a project supported by the TDR Social and Economic Research Component



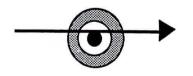
UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR)

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## Foreword

The UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR) is a globally coordinated effort to bring the resources of modern science to bear on the control of major tropical diseases. The Programme has two interdependent objectives:

- To develop new methods of preventing, diagnosing and treating selected tropical diseases, methods
  that would be applicable, acceptable and affordable by developing countries, require minimal skills
  or supervision and be readily integrated into the health services of these countries;
- To strengthen -- through training in biomedical and social sciences and through support to institutions
   -- the capability of developing countries to undertake the research required to develop these new disease control technologies.

Research is conducted on a global basis by multidisciplinary Scientific Working Groups on the six diseases selected for attack: malaria, schistosomiasis, filariasis (including onchocerciasis), the trypanosomiases (both African sleeping sickness and the American form, Chagas' disease), the leishmaniases and leprosy. Scientific Working Groups are also active in the "trans-disease" areas of biological control of vectors, epidemiology, and social and economic research. The training and institution strengthening activities are limited to the tropical countries where the diseases are endemic.

The Social and Economic Research Project Reports series represents a new communication venture undertaken by TDR's Social and Economic Research (SER) Component. This series has been launched to facilitate and increase communication among social scientists and researchers in related disciplines carrying out research on social and economic aspects of tropical diseases and to disseminate social and economic research results to disease control personnel and government officials concerned with improving the effectiveness of tropical disease control.

Research reports published in this series are final reports of projects funded by TDR and usually include more material than ordinarily published in peer review journal articles. TDR considers this material to be valuable both for investigators involved in the study of social and economic aspects of tropical diseases and for professionals involved in training programmes in the social sciences, economics and public health. The series should acquaint those working on similar problems with approaches undertaken by others, in order to test new approaches in different settings, and should provide useful information to personnel in disease control programmes and related agencies.

In the interests of rapid dissemination of social and economic research findings, supporting material, e.g., tabulated data, has not been included in the present report. This material is, however, available upon request to interested researchers. All requests for such material, citing in full the number, title and author(s) of the SER Project Report, should be addressed to: Dr C. Vlassoff, Secretary, Steering Committee on Social and Economic Research, TDR, World Health Organization, 1211 Geneva 27, Switzerland.

Tore Godal, Director

Special Programme for Research and Training in Tropical Diseases TDR

## Preface

Since 1979 the Social and Economic Research (SER) Component of the UNDP/WORLD BANK/ WHO Special Programme for Research and Training in Tropical Diseases (TDR) has been supporting research aimed at improving the effectiveness of disease control programmes through the incorporation of social, cultural and economic factors into the design and implementation of control programme activities. In aiming towards this overall final objective, two intermediate objectives guide TDR's social and economic research activities:

- To determine the impact of social, cultural, demographic and economic conditions on disease transmission and control.
- To promote the design and use of cost-effective and acceptable disease control programmes and policies.

The study undertaken by Dr Valencia and her team falls directly within the framework of SER's first intermediate objective. The team studied leprosy-related knowledge, attitudes and practices of the Ilocano population in the Philippines with the objective of improving leprosy control and rehabilitation. Research methods used to collect data included: psychological tests for patients and family members; a social linguistic survey for use in the design of health education material; and a study of social structures in the affected communities. Vignettes were used to obtain better understanding of the role of the leprosy patient in the community. Close contact was established with the Philippine leprosy control programme.

This innovative project was followed by a further study of the interactions among Hansenite patients, service providers and the community at large. The results of the follow-up study are contained in *Social and Economic Research Project Reports No. 3*.

Patricia L. Rosenfield, Former Secretary, Scientific Working Group and Steering Committee on Social and Economic Research

> Special Programme for Research and Training in Tropical Diseases TDR

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### ABSTRACT

The integration of the social sciences and pure sciences has long been a global interest but very few have attempted to work on this existing gap in the field of research. This limitation is the predisposing factor behind the conceptualization of this ongoing investigation. This paper seeks to correlate the medical aspects (causation, transmission, symptomatology and treatment) of leprosy with the psycho-socio-linguistic facets (beliefs, knowledge, attitudes and practices) of the disease. The respondents for this study are divided into three sets, namely, the patients, the critical informants (who are close to the patients) and the key informants (who are unrelated to the patients but are occupying key positions in the community). Of the 213 respondents, 96 come from Barangay Guimod, Ilocos Sur, while 117 come from Tala, Novaliches. An analytical comparison of the data have, so far, yielded results stressing poverty-related circumstances as the major cause of leprosy prevalence in these areas. It has also been shown that the respondents have overlapping notions of causation and transmission, and of prevention and treatment. These, and the rest of the preliminary findings suggest that the present leprosy control programmes be equipped with a stronger, concrete psycho-social foundation for greater efficacy.

## I. INTRODUCTION

The UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases has focussed on the major objective of increasing the effectiveness of disease control programmes through the integration of human behavioural factors in programme design and management. In this context, behaviour was defined to include social, cultural and economic factors.

In connection with the above objective a multi-disciplinary team, all coming from the University of the Philippines, College of Arts and Sciences and the Institute of Public Health, sought to consider the following:

- 1. To describe folk beliefs and traditional knowledge about the causation, transmission and symptomatology of leprosy;
- 2. To assess the existing attitudes towards the disease and stress perceptions of afflicted patients in the locality;
- To describe the cultural definitions of the disease and the social practice of the people relating to the transmission, treatment and prevention of leprosy; and
- 4. To utilize the data to be able to formulate recommendations for the management and control of leprosy in the Philippines.

#### A. The Setting of the Study

The study site was Barangay Guimod<sup>1</sup>, one of the 34 barangays in the town of Bantay, Ilocos Sur. The total population of Bantay, as of the 1980 census, was 22,282. The study site, Guimod, has a total land area of 490 hectares, 489 of which are privately owned. At the time of the survey there were 500 people living in the area. This constituted 120 households, and of this number, only very few had declared an income of over P1,000.00 per annum; in fact only 3 households reported that they had P10,000.00-20,000.00 at least per annum. The rest of the 120 households indicated "no income", saying that they were unemployed. Included among these unemployed people or those earning the lowest income were 36 families whose family members are in the active list of patients of the Vigan Skin Clinic.

Generally, their means of livelihood included farming, livestock raising, cottage industries, private employment, government employment, skilled labor, unskilled labor, transportation and commerce.

#### B. <u>Method</u>

The design of the project called for a triangulation of data gathering and analytical techniques using three different independent strategies, namely the use of survey questionnaires, linguistic analysis of taped interviews and the administration of two psychological instruments, the Rorschach and Philippine Thematic Apperception Tests. The survey questionnaires consisted of two structured interviews which were pre-tested three times by the team before they were finally administered. Basically, these interviews contained two major parts: one part is designed to elicit data from the patients who were in the active list of the Skin Clinic at the time of survey and the other set of questionnaires was used to gather data from the Critical Informants (CRIs) and the Key Informants (KIs). The survey also included patients as well as CRIs and KIs living in Tala Leprosarium in Novaliches and around the area of Caloocan City. The reason for including them was to compare the responses of these patients who are institutionalized, as well as of urban CRIs and KIs with those of the rural out-patients living in their domestic milieu and CRIs and KIs who are living in the rural areas.

The critical informant or CRI is a person who is closest to a leprosy patient. This person may be the patient's spouse, a relative, a friend, or even just a neighbour so long as this person has a direct knowledge of the patient. This type of informant usually takes care of the patient and more or less knows the history of the patient's sickness. Above all, he is a confidante of the patient. Sometimes a CRI is an ex-patient himself<sup>2</sup>.

Through the CRI, we are afforded an intimate glimpse of how the disease has brought about changes in the patient's outlook on life and in his interactions with others, whether he has adjusted easily or is having a hard time accepting the fact of his illness. From questions asked of the CRI, we learn whether the disease has brought any problems to his family and relatives and if so, what the effects are or were.

A key informant (KI), on the other hand, is someone who is not related in any way to a patient but has some knowledge of leprosy. In this case, the field interviewers contact various members of the community, such as teachers, doctors, nurses, municipal or barangay officials, social workers, priests or ministers.

Information gathered from the KIs provide us some insights on how the community reacts to lepers, especially from the economic standpoint. Among the questions asked of KIs are whether they are willing to employ a person whose leprosy has been cured and conversely, whether they would dismiss an employee found suffering from leprosy.

The interview sessions were taped and brought to the Department of Linguistics and Asian Languages for language analysis. The same applies to the data gathered through the administration of the Rorschach and Philippine Thematic Apperception Tests to the respondents. The subjects for the psychological testing were drawn from the same list, i.e. the list of active patients of the Skin Clinic at the time of the survey. Usually, the members of the research team were introduced to the respondents by the personnel of the Vigan Skin Clinic. After the usual amenities, the Philippine Thematic Apperception Test was administered first; then the Rorschach was given. The psychologists also did indepth interviews on the subjects; they asked questions on dreams, best and worst experiences, knowledge, feelings, attitudes and coping reactions. Later on, card-by-card content analysis was used to interpret their results. Thirty-eight respondents participated in this portion of the study, 18 of whom were relatives (CRIs) being included as a comparison group. They were considered to be a good source of data as they shared with the patients similar social and physical environments.

The linguistic approach was chosen as the best source of information concerning man or any aspect of human endeavor. It is through language that man reports his experience, imparts his knowledge and makes known his inner-most feelings and thoughts.

The lexical or vocabulary choice one makes in reporting an experience, reacting to a situation or in imparting information is the obvious means of knowing and understanding the message one wishes to impart. But one's choice of syntactic structures and signals, though not consciously made and not as obviously identifiable as vocabulary choice, is just as effective a means of knowing and understanding the different nuances of a message. These structures allow the listener to feel and react to what has not been said outright, for whatever reasons the speaker may have.

The objectives of this linguistic study were to elicit, classify and analyze the linguistic structures used by Ilocanos in order to gather information regarding their knowledge of leprosy and their beliefs, attitudes and practices concerning the disease.

These objectives were considered in the light of sociolinguistic and psycholinguistic factors. The analysis took into consideration not only the different types of structures used by the informants but such social factors as place, socio-economic status and occupation that influenced the informants' choice of structures and the psychological factors such as mood, emotion, relationships and motivations which influenced this choice.

The study is inductive or empirical in nature, hence the results reported here have arisen from the gathered data.

The procedure for the linguistic study began with transcriptions of 27 taped interviews representing 15 Hansenite patients, medical personnel, relatives and other informants. These interviews were translated first into Filipino and later into English. Since Filipino and Ilocano are closely related Philippine languages, it was possible to make a one-to-one translation from Ilocano to Filipino. This made typological verification possible, which in turn facilitated the checking and counterchecking of the Ilocano material. The Filipino translation also facilitated the

actual analysis of the material. A one-to-one translation followed by a free translation in English was then made. But for the purposes of this paper the Filipino translation is not included. What is given are the samples in Ilocano with a one-to-one translation in English followed by a free translation. The data was then carefully examined qualitatively for lexicon and syntactic structures to ascertain direct or implied information. They show how the informants made use of the different devices, whether consciously or unconsciously, to set a mood, reveal an attitutde, impart an opinion and convince the listener of its merits, and emphasize, play down, or avoid a topic.

Two folktales in which a character was suffering from a skin ailment were also examined. However, some of the interviews were not included in the analysis since the informants gave curt answers or were not responsive, possibly due to shyness, embarrassment, ignorance or fear.

The Tala (N = 117) respondents representing the urban sample were excluded from the linguistic survey and the psychological testing. As they represented various ethnic groups with different local dialects their responses were tabulated only for the sociological component of the study. At best they were used to compare rural and urban reactions to the disease; and to describe the behaviour of the non-institutionalized and compare it with that of the institutionalized in the city leprosarium. The Tala samples were also Ilocanos and were comparable in age to the Guimod group. All in all there were 41 patients from Tala and 34 patients from Guimod<sup>3</sup>.

## C. <u>Sampling</u>

Basically, a multi-stage cluster, purposive sampling design was used. From among the municipalities of Ilocos Sur, one municipality was chosen and within this, one barrio was selected as the primary (sub-sample) area. From this we drew three major sets of respondents in the study: the patients themselves, the CRIs and lastly the KIs. The selection of Bantay as the municipality from which barangay Guimod was drawn was based on the fact that Bantay has had the highest incidence of leprosy for the past five or six years (but lately only second highest) in Ilocos Sur.

The CRIs were drawn from the families of the patients and the sub-sample of KIs were chosen by type of occupational groupings and their assumed knowledge of the community etc.

As a kind of control variable, a sample of 37 institutionalized patients at the Tala Leprosarium in Novaliches, Quezon City was drawn by quota sampling.

#### D. <u>Review of Literature</u>

There is very little scientific literature on leprosy. The fact is that from the years 1952-1981 issues of the <u>American Journal for Tropical</u> <u>Medicine and Hygiene</u> have come up with merely 33 titles of experiments on leprosy<sup>4</sup>. Volumes 1 to 15 of the periodical, <u>Social Science and</u> <u>Medicine</u>, published from 1967 to 1981 have been reveiwed but have produced no articles on leprosy. Soldevilla<sup>5</sup> similarly notes that advances in leprosy research have indeed been slow.

However, it can be said that the quality of the information gathered over the years more than makes up for the small quantity of research done. Still, some authors e.g. Kato<sup>6</sup> claim that what needs primary consideration is not really the number nor the kind of studies done but rather, whether the current trends are moving in the right direction, which is, toward obtaining more effective control and consequently eradicating leprosy.

We can classify the literature on leprosy as medical, psycho-social and cultural in approach. Of the 126 articles reviewed for this study, 94 (74%) are classified as medical in approach, 28 (22%) as psycho-social, and 4 (4%) as cultural.

Research, both foreign and local, has more output in the medical than in the two other academic disciplines. Over the years, greater concentration has been given by the man to the area of sciences so that with out knowing it, he has been proceeding under his own narrow vision of the leprosy problem. <u>The Medical Viewpoint</u>, as expressed in the literature had focussed on leprosy as a chronic and infectious disease and as caused by a micro-organism called <u>Mycobacterium leprae</u>. A hundred years after the discovery of this causative agent by Hansen, all attempts made to cultivate this acid-fast bacilli (AFB) in artificial media failed. This is one major obstacle to the efforts of finding the complete panacea for this disease.

<u>M</u>. <u>leprae</u> is an intracellular bacilli, known to be basically harmless, devoid of toxins and incapable of causing tissue damage<sup>7</sup> They become destructive only when reactional complications develop due to adverse host immunological responses.

For a long time, it was believed that leprosy is specific only to humans. The view was that human cases discharging <u>M</u>. <u>leprae</u> constitute the only sources of infection<sup>8</sup>. However, in his article Rodriguez<sup>9</sup> mentioned a very important and unusual discovery by Dr Binford<sup>10</sup> and co-workers who found armadillos naturally infected with <u>M</u>. <u>leprae</u>. This is significant in assessing the danger that the bacilli pose not only to the human race but to lower forms of life as well.

Furthermore, the literature on the medical aspect of the disease revealed varying schools of thought regarding its communicability. For example, many leprologists insist that leprosy is the least communicable of all communicable diseases. One proponent of this is Dr C.B. Lara<sup>11</sup> of the Culion Sanitarium in the Philippines. In Lara's study, which took 28 years and involved 2,000 children born and living in the Culion Leper Colony, it was shown that the risk of contracting leprosy, even under maximum exposure in children, was less than 25 per cent. The other school of thought propogates a different theory. Conflicting reports exist. For instance, S.R. Lang said that leprosy has apparently become a disease of high infectivity but low pathogenicity; hence, no longer can it be maintained that prolonged close contact is necessary for infection to take place. However, the dissemination of bacilli from infected nasal septa may not necessarily be via the airborne route alone but it may also be through the heavy contamination of objects that subsequently come in contact with unhealthy skin<sup>12</sup>. The present team feels inclined to adhere to this theory because of the empirical evidence/observations in the study sites where it is not uncommon to find a single household with 4-6 members afflicted with the disease.

Although many authors (such as Muir and Rogers:  $1946^{13}$ , Marchoux: 1934<sup>14</sup>, Olsen and Porritt:  $1947^{15}$ , Lara and Nolasco:  $1956^{16}$ ,) are in support of the cutaneous route as the mode of leprosy transmission, there is an increasing opinion rejecting the skin as the most usual or the only portal of entry of the <u>M</u>. <u>leprae</u>. In addition, a number of studies undertaken by Dungal ( $1960^{17}$ ,) and Munos Rivas ( $1942^{18}$ ,  $1958^{19}$ ,) suggest that since it is partially certain that the bacillus is incapable of penetrating intact skin, then biting or <u>blood-sucking insects</u> may be the logical and even obligatory transmitting agents of the disease. Despite all these assertions, nevertheless, many scientists and leprologists believe that much uncertainty still surrounds the exact manner of leprosy transmission.

It seems, however, confirmed by the scientific literature that appropriate exposure is the key to the transmission of leprosy and that the degree of resistance of an individual determines the fate of the <u>M. leprae</u> that he has contacted. Other factors that could effect successful transmission would be the <u>duration</u> and <u>intimacy</u> of the contact.

That leprosy is hereditary is considered an old and wrong notion by many authorities in the area but then a number of researchers continue to harbour the idea of a genetic susceptibility to leprosy. They suspect that some have an inherited predisposition to the disease and that this could very well account for the concentration of leprosy in certain families aside from the more accepted theory of increased exposure.

The medical literature on leprosy agrees upon the fact that leprosy is generally a very chronic disease and that the severe forms tend to be progressive and last for life, if untreated. The studies have also confirmed that this disease is not only crippling and disfiguring, it also shortens a person's life expectancy by a few years. The disabilities caused by leprosy affect mainly the limb extremities and the face, including the eyes, making leprosy a grave threat to the working capacity of its victims.

The medico-legal definition of a <u>disability</u> is the loss of function or earning power and is graded only by the extent to which it interferes with a person's ability to earn his living or to enjoy a normal life. On the other hand, <u>deformity</u> denotes a change or alteration in the form or shape of a part of the body<sup>20</sup>. In the study by Reyes<sup>21</sup>, it has been found that the involvement of the sensory component of the nerve is more severe in degree and occurs earlier than that of motor fibers for those afflicted with leprosy. Furthermore, they observed that the upper and lower extremities were generally affected equally in the lepromatous type whereas the peripheral nerves in the upper extremities were more severely involved in the tuberculoid type. This peculiar predilection of <u>M</u>. <u>leprae</u> for the peripheral nerves has also been given emphasis by Binford<sup>22</sup>, and others.

The medical studies have to this date agreed that no preventive technique has yet been devised or discovered and disease control is merely based on the proper and timely treatment delivery. Poor and inadequate treatment often leads to drug resistance and such resistance is presently a growing world problem<sup>23</sup>.

A case in point is the use of Dapsone in treatment. Studies have revealed that this drug has a slow effect in the serious forms of leprosy<sup>24</sup>. Yet many Third World nations, the Philippines included, still continue using this drug to treat even the critical forms of the disease. Furthermore, it must be understood that treatment can only be possible through recognition of the symptoms associated with Hansen's disease.

Prevention of drug-resistance requires a combined therapy for multi-bacillary types maintained at a full dosage. This method of treatment more or less ensures that should the occurrence of mutant organisms make one drug fail then the other drug would still be effective.

Another complicating factor in the treatment of leprosy is the incidence of <u>relapse</u>. Waters has defined relapse as the renewed multiplication of <u>M</u>. <u>leprae</u> resulting in the appearance of new lesions in Lepromatous leprosy (LL) or Borderline leprosy (BL) patients who have been responding favourably to chemotherapy where the disease was becoming or had become quiescent or even arrested. A relapse may also be due either to the emergence of drug-resistant <u>M</u>. <u>leprae</u> or to multiplication when chemotherapy is stopped<sup>25</sup>. Increased drug intake without the doctor's prescription due to the patient's over-confidence on the beneficial effect of the drug may likewise lead to a reaction or a relapse.

In view of these medical findings, it is therefore imperative to study control over the leprosy predicament.

## 1. The Psycho-Social Viewpoint Components of the Disease

The layman's term for leprosy is Hansen's disease. Articles reviewed showed that the disease is very much a psycho-social issue that the world cannot choose to ignore. As G.H. Ree has professed, "No other pathological state has led to such psycho-social reaction as leprosy, affecting both the patient and the community in all aspects of their cultural and social life. Psycho-social reactions to leprosy are obviously of importance in epidemiology and control<sup>26</sup>." This viewpoint has been confirmed by other researchers like Fasal, <u>et al.</u>, who asserted that traditionally and historically, the modern social face of leprosy finds separation from the clinical faces of leprosy difficult<sup>27</sup>. This can be explained by the fact that from the roots of the leprosy problem to its yield, socio-psychological factors and implications abound.

A clear-cut example of a psycho-social implication of leprosy is the birth of the so-called "leprophobia" or fear of leprosy. Sociologists in leprosy claim that education will destroy leprophobia. However, education as a cure for leprophobia was found to have definite limitations.

Only in very few cases, if there are any at all, can education completely assure people of the harmlessness of leprosy and thereby erase their fear and hesitancy toward anyone or anything that has to do with the disease. The stigma associated with leprosy has existed ever since man can remember. The stigma seems as old as the notion of time itself, so that it is almost impossible to think the world will ever be without it.

As Fite has written:

"I find it difficult to believe that a broad educational plan in leprosy would not create several times the general amount of leprophobia it dispelled. The assumptions that educational procedures would eliminate leprophobia are inadequately founded; that they would have an ameliorating effect among many men is true, but when one examines what has happened with respect to other educational effects in other diseases the grave doubt is aggravated<sup>28</sup>."

In other words, there exists the possibility that learning about the frightening truths of the disease could only enhance the negative attitude that most people have towards it. This social insensitivity accorded to many of the lepers is a blow to their psycho-social make-up and mental health.

Since the leprosy patient is usually aware of the negative attitude of the community to the disease and eventually to those afflicted by it, it does not seem unthinkable if he develops a warped personality from the anguish that his depressing condition is causing him. This change in his psychological state and perceptions may finally result in his adoption of anti-social attitudes. Such reactions of the leprosy patient serve as his coping mechanisms to salvage the dwindling dignity that he actually has, even if he may no longer feel it. After the panic and the depression comes the withdrawal from the world that once acknowledged him like any other human being.

Most, if not all of them, learn to destignatize the situation. Thus, many take up permanent residence at the center or in a leper community where they can identify with someone else, work, marry and perhaps have children. In the words of Alexander and Moulun<sup>29</sup> they protect themselves by "colonizing". They create a world of their own where they feel accepted and perhaps, needed. It is thus suggested that care is the basic attitude that must accompany the treatment and rehabilitation of leprosy patients. Cure without care makes us rulers, controllers, manipulators and prevents a real healing community from taking shape.<sup>30</sup>

Most of the literature on leprosy therefore proposed that treatment and rehabilitation of lepers be made the responsibility not only of people in the medical field but of the whole society. How can this be realized? the idea is quite simple but the task involved is not. Despite the doubts clouding the effectivity of education as the agent of social change in this respect, researchers still see the need for health information/health education in counteracting the fear and prejudice directed toward the leprosy patient.

Fritschi defines rehabilitation as a cooperative enterprise involving the medical team, the patient and society at large and requiring faith in one another and hope for the future. In such a relationship, the community is taught to extend help naturally when it is needed without patronizing or pity while the disabled accepts the help he needs without self-conciousness, resentment or self-pity. In Bauru, Sao Paulo, Brazil the SORRI (Sociedade para a Reabilitacao e Reintegracao do Incapacitado), an integrated vocational rehabilitation center, is continuously proving that a useful and normal life still awaits leprosy patients.

Health education, on the other hand, is based on the behavioural sciences and applies insights from these sciences to change people's behaviour in a way that is beneficial to their health<sup>31</sup>.

In the Philippine scene, Dr Mita Pardo de Tavera blamed poverty as the socio-economic factor for the prevailing decline of health among Filipinos. Approximately 80 percent of the Filipino population are bereft of the satisfaction of the basic human needs and are, therefore, in no position to resist the easy breakdown of their bodily defenses to the rising leprosy prevalence. Diseases such as tuberculosis, schistosomiasis, polio, rabies and malaria are likewise increasing tenfold. Hence, although immunity to leprosy is largely inborn, the Filipino's susceptibility to the disease, may be heightened by environmental circumstances like improper nutrition, pregnancy and co-existing disease.

## 2. <u>Cultural Viewpoint</u>

The other set of literature on leprosy expresses the culture perspectives. Culture is an all-encompassing word that traces the entire way of life of a people. However, it has not clarified the most potent cultural facet that concerns the problem of leprosy.

In 1952 Frederick Lendrum hinted at language as that cultural facet when he wrote that "in no other disease is nomenclature a major hazard for public health<sup>32</sup>". From thereon, startling discoveries have been made on how the many "connotations" of the term leprosy could have paralyzing effects on public health measures, effective treatment and control of the disease, rehabilitation and social acceptance of the diseased.

For many centuries now the mere mention of the term "leprosy" elicited great fear in many parts of the world. In fact, in the State of Hawaii the law has imposed as official only the use of the term "Hansen's Disease" to neutralize the wave of terror associated with "leprosy" that the Bible has helped to propagate. Data gathered in this ongoing research has similarly shown how practices and beliefs or superstitions have compounded the problems of case finding and management of the disease.

There are many articles on leprosy, but being mostly medical in perspective, they did not deal directly with leprosy as a social problem. The numerous foreign studies especially are on disease experimentation, clinical tests, etc., and indeed reveal significant facts from which man can truly benefit. However, it is disillusioning to note that in both the local and foreign research institutions there still exists a wide gap in research between medical and psycho-social-economic dimensions of the disease. The present study on leprosy intends to fill this gap.

## II. DATA

## A. <u>Social and Economic Profile of the Respondents</u>

The total respondents to the survey questionnaires were 213. Ninety-six or 45 percent were from Guimod while 117 or 55 percent were from Tala.

For the sociolinguistic data only 35 taped interviews of the 96 Ilocanos, 15 of which were Hansenites, were analyzed. The remaining taped interviews were those of the CRIs and KIs (relatives, barrio officials, doctors and nurses and some towns people who claimed not to have had contact or who have had no personal knowledge of Hansenites) and also of the 96 respondents, 38 subjects participated in the psychological aspect of the study.

## 1. <u>Age</u>

Most of the patients (Guimod) belong to the age group of 10-19, younger than those taken from Tala, who were in the age bracket of 20-29.

## 2. Educational Attainment

The majority of the patient-respondents and critical informants in Guimod finished some grades in the elementary level. The same applies to the respondents from Tala.

In both sites, the majority of key informants had finished their education and were practicing their profession. There are 18 elementary schools in Bantay, all of which are public schools, but no school for the secondary level. As for tertiary education, there is only one private and one public school. This is also one reason why the patient-respondents and the critical informants of Guimod only reached the elementary level.

No secondary school is located in the municipality of Bantay. They have to go to the neighbouring municipalities if they want to continue with their education. Most people find this travelling to the neighbouring municipalities taxing. They would rather stay home and do their household work. They see this as more rewarding than finishing their education. Most of the time poverty is associated with their inability to proceed to secondary education.

In the case of respondents in Tala, a school right in their vicinity caters to the educational needs (from elementary to tertiary level) of the patients and their relatives. In this school, they are also taught some vocational and technical skills.

#### 3. <u>Civil Status</u>

The majority of the respondents were married (61.0%), while 73 out of 213 or 34.4% were single and 3.7% are classified as widow or widower. Only 2 respondents were separated from their spouses.

#### 4. <u>Sex Distribution</u>

There were more female than male respondents except in the case of the key informants of the Tala group. The distribution of patients for Guimod, however, represents the population of all its active cases. Hence, no sampling for the set of patients was necessary in Guimod unlike the patient population in Tala where quota sampling was done for comparison purposes. The big difference between the number of male and female critical informants could be proof that the traditional role attributed to women all over the world concerning the caring of the sick still exists to date.

## 5. <u>Occupations</u>

The three occupations with the highest frequencies in descending order are doing domestic jobs (storekeeping, animal husbandy, laundering etc.), farming and teaching. Most of the Guimod patients and critical informants interviewed are farmers while the majority of the Guimod key informants are teachers. In Tala, on the other hand, most of the patients and critical informants are employed in domestic jobs whereas many of Tala key informants are in the teaching profession.

## B. <u>Native Theory of Causation of the Disease vs. "Germ Theory"</u>

In the assessment of the respondents' knowledge about the causes of leprosy, the data indicated the following: unclean surroundings, poor helth, not obeying doctor's advice and handling or smoking tobacco which is not well-cured. Eight Guimod respondents and nine Tala respondents, mostly key informants, mentioned bacteria as the cause of the disease.\* Some other causes mentioned by the respondents are prolonged contact with a leper, too much liquor, frequent "galis" or scabies, bad or unclean blood, "pasma" or exposure to extreme change of temperature, and fate or will of God. The majority (53%) of the respondents considered poor health or lowered resistance as the cause of leprosy. Unclean surroundings is the most frequently mentioned cause. Kendall's coefficient of concordance was computed for six types of respondents: for patients, critical informants and key informants of Guimod and Tala Leprosaria. There was general agreement among the six types of respondents as to knowledge of the causes of leprosy. The rank correlation coefficient which has been computed showed agreement in the ranking of the possible causes of leprosy.

In effect, all the types of respondent agree that there is a common set of determinants of leprosy. This commonality of poverty-circumstances produce the disease. That the root cause of leprosy is not from the action of the bacteria found but it is in the consequences of unclean surroundings, poor health, malnutrition and then lowered resistance.

The linguistic data supplementing the survey responses revealed aspects of the prevailing beliefs system surrounding food/diet of the people and causes of Hansen's disease such as the eating of chicken with squash, beef or pork; other causative factors are using the things of someone sick with "it", or not having toilets so that chicken (finally eaten by men) could eat human excreta, or skin ailments that have been left untreated.

From the data gathered, it was shown that certain myths concerning the cause of leprosy continue to thrive. The correct response, which is Mycobacterium Leprae (a microorganism), did not turn up even among the patients of Tala Leprosarium whose greater knowledge of the disease was anticipated.

## C. <u>Modes of Transmission</u>

In this survey, a question was asked to determine the respondents' beliefs on how leprosy is passed on. Some choices were provided for in the questionnaire e.g. through skin contact, inhaling "some things" which are airborne, using things used by lepers and through skin contact with open wounds, which the respondents could check if they agree. Then, they were asked to add some other modes of transmission which they perceived to be true as verified by their experiences. Among those mentioned are "through flies and insects, through sweat or sputum and sexual contact". Skin contact is the most frequently mentioned mode of transmission by the Guimod residents but skin contact with open wounds is the most frequently

\*It is safe to hypothesize that as the respondents' educational attainment rises, so do their knowledge and perception of existing bacteria and/or germs as causative factors of the disease. mentioned mode of transmission by the Tala residents. This implies that the Tala residents may be better informed. Evidently, transmission through flies and other insects is neither well-known nor accepted by most of the respondents. Again, Kendall's coefficient of concordance for the six types of respondents was computed and indicated to be equal to .82 which is highly significant. This shows that the respondents agree more or less upon the differnet modes of transmission. Even the rank correlation coefficients computed for Guimod and Tala patients, for Guimod and Tala CRIs and for patients, CRIs and KIs of all areas combined are all significant, showing no significant difference in ranking.

While urban respondents (Tala) were more correct than the rural respondents in specifying prolonged skin contact with open wounds as the mode of transmission, the finding still indicated that both are not aware what can be transmitted during the contact. It is definitely unknown among the respondents that bacteria can enter through the open lesion and that this is probably the cause of the disease.

Analysis of the language structure of the respondents indicated that the people perceive the mode of transmission for leprosy as follows:

- 1. Rubbing one's skin against one who has the disease. In other words, this meant that they knew that direct skin contact could be contagious.
- Unsanitary conditions the lack of proper waste disposal of both humans and livestock could cause transmission of the disease through food contamination.

The respondents' answers indicated their ambivalence or lack of knowledge regarding the concepts of causation and transmission. The two are not clearly defined terminologies as far as language is concerned. This lack of terminological differentiation between causation and transmission validates Lendrum's (1952) concern that the "many connotations of the disease have paralyzing effects on control measures". A study on Filariasis by Lu <u>et al</u><sup>33</sup>. contained the same findings. Bacteria is an unknown concept because people do not see it in tangible forms, hence, it cannot be cited as a possible cause of disease nor can it be the villain in the spread of the disease.

#### D. <u>Prevention of Leprosy</u>

Repondents' concepts with regard to preventive measures against leprosy show similarity with their responses on the treatment of this disease. It is established that patients cannot recognize early signs of the disease and if they perceive some changes in their skin they usually call it allergi, or "curad". They have many terms to describe these skin conditions.

The survey questionnaire included a question as to how the respondents can avoid getting sick with leprosy. The choices provided in the questionnaire are: "To have the right amount of sleep, to eat the right kind and amount of food, to have clean surroundings, not to mingle with lepers, to obey medical advice regarding the disease, to avoid exposure to tobacco-curing processes and to avoid activities which necessitate exposure to soil or clay." Some respondents gave other answers like avoiding lepers with open wounds, observing proper hygiene, avoiding much stress or tension, avoiding worry and exhaustion and avoiding the use of a sick person's belongings, avoiding liquor and alcoholic drinks, avoiding smoking and avoiding activities that will expose them to sunlight or heat.

However, according to some, leprosy cannot be prevented. This sentiment was expressed by one Tala patient who exclaimed: "How can you prevent it when it is the will of God? Why, even leprologists can't establish its mode of transmission and now you are asking us if it can be prevented?" Another said: "Nakakatawa naman, yang tanong mo. Eh, kung alam ko lang na maiiwasas di sana hindi na ako nagkasakit."\* (This is roughly translated as: Your question is funny. If I knew that it could be prevented then I don't think I would have got sick.)

In general, obeying medical advice is the most popularly known method of preventing leprosy. This response showed that the patient is only aware of the disease when its visible signs are already rampant all over the body; when it is already too late to do anything to prevent its debilitating effects and only more serious complications can be avoided if they start "obeying medical advice". But at this stage, it may be quite late. On the other hand, the Tala patients and CRIs ranked the right amount of sleep and the right kind and amount of food as the most popularly believed method of prevention. The coefficient of concordance is computed to be at 0.66 for the six types of respondents, showing that the different types of respondents do not differ significantly in their knowledge with regard to prevention of leprosy. Their level of knowledge regarding prevention of leprosy is as low as their knowledge of some aspects of its etiology. This is significant also under the Chi-square test showing concordance of opinions with regard to leprosy prevention.

However, some informants indicated that they ask or consult the following for advice when there is an "allergi", or when they are convinced that there is something more than the rashes; their advice is sought to prevent the advancement of the perceived skin ailment to leprosy.

- Doctor. The informants used the terms doktors or mangangagas. (The former is a loan word and the latter means roughly "one who cures".)
- 2. Herb doctor. The data revealed six terms for herb doctor. Four are loan words and one a descriptive phrase. Three terms: otellana, particular and mangalubria could not be translated literally into Filipino or English but were used to indicate a herb doctor.

\*Taken from the field notes of C. Reyes, 21 April 1982.

Since they consider the disease a result of curse, voodoo, fate they usually resort to seeking a local healer, e.g. as in the cases below:

#### Manang Maria, 20 April 1982

"Manang Maria is a herbolario. Three of her children are afflicted with leprosy... Started with Roberto, because the boy kept going to the river for a swim right after playing in the fields. He started to itch - it is called 'agbudo-budo'. Then started to have 'supot-supot'. Then he went for consultation."

### Manong Domingo, 25 April 1982

"Two of his children got the disease searching for 'mangangagas' (local healer). Red spots on his two ears - when he was still a young boy; red spots appeared when he took a bath in the river with bamboo soaked in it. Applied oil of 'Good Friday', the spots disappeared. Children's disease not leprosy - it is the work of 'manggamud'. They went to another barrio to escape."

#### Marina Palapala, 21 April 1982

"Skin disease not leprosy. Appeared when she gave birth to her third child. Neighbours told her it was only 'curad'. Consulted brother-in-law who treats. Applied oil of Good Friday but it became worse. Went to skin clinic for consultation."

## E. <u>The Correlation between Attitudes and Knowledge</u>

To assess the existing attitudes and then to determine its correlation with knowledge, the following questions were asked:

- 1. What do you feel when you see a leper?
- If one of your relatives, friends or co-workers got sick with leprosy, what would you feel about him?
- 3. If one of the members of your family got sick with leprosy, would you be ashamed to tell others?

For the convenience of the respondents, choices were provided in the questionnaire like "scorn, loathing, feel sorry, annoyed", for the first question above. The respondent could check any of these choices or add any other reactions. He could give multiple answers. Each answer is scored 1 point if it shows a positive attitude towards the leper and it is scored -1 point if it shows negative attitude. For example, "scorn" is scored -1 point while "feel sorry" is scored +1 point. The scores for each of the three questions are added algebraically.

In addition, the following statements were given in the questionnaire:

I like to associate with lepers.

- I feel that lepers face a bleak future.
- I don't mind sitting side by side with a leper in a public conveyance.
- I feel that lepers should be treated with more compassion.
- I believe that leprosy is an incurable disease.
- I cannot imagine myself working with a leper.
- I believe that leprosy can be prevented.
- I can really get in a panic when a leper approaches me.
- I believe that lepers should be kept in an institution.
- Leprosy can be cured.

The respondents were asked whether they disagree or strongly disagree, agree or strongly agree with each of the above statements. The responses were given equivalent points. For example, for the first statement, "strongly disagree" is equivalent to -2 points; "disagree" -1 point: "agree" 1 point; "strongly agree" 2 points. For the second statement, scoring is the other way round: "strongly disagree" is equivalent to 2 points; "disagree" 1 point; "agree" -1 point; "strongly agree" -2 points. The equivalent points for all the 10 statements are added algebraically. The total score for these 10 statements and the above mentioned questions are added together to form the attitude scores(Y). Likewise the knowledge scores were computed. The knowledge score is based on the responses to the following questions:

- 1. Are there some beliefs about leprosy that you personally believe in?
- 2. Do you know how leprosy looks?
- 3. What can be the causes of leprosy?
- 4. Is leprosy contagious: If yes, how?
- 5. Can you avoid getting sick with leprosy? If yes, how?
- 6. Who is easily susceptible to leprosy?

There were choices given and the respondent could answer by checking one or more of the choices or give his own answer if his answer is different from any of the choices. Correct choices or answers are equivalent to 1 point each, but wrong choices or answers are equivalent to -1 point each. For example, in the first question above, if the answer is, "this is a curse", then the respondent gets a score of -1 for that answer. If one's answer for the third question is "bacteria", then he gets 1 point for that answer. The total number of points for all the six questions are added algebraically to get the knowledge score (X) of a respondent.

A test of normality was administered to each of the resulting distributions of knowledge scores and attitudes scored for Guimod and Tala respondents, separately. This to determine whether the coefficient of linear correlation is a valid instrument in determining the independence of the knowledge and attitude scores.

Since the result shows normality of the distribution of knowledge scores (X) and attitude scores (Y) at 5% significance level, Pearson's coefficient of linear correlation r between X and Y was computed. For the Tala respondents, r = -.08 which is not considered significant based on the t-test. Therefore, the knowledge and attitude are not correlated. For the Guimod respondents, r = -.20 which is considered significant at 5% significance level. This implies that knowledge and attitude are interrelated. However, at 1% significance level, this coefficient of linear correlation is not significant, implying that knowledge and attitude are independent of each other. For all respondents, Guimod and Tala respondents combined, r = -.15, which is considered significant at 5% significance level but not significant at 1% level.

Since the conclusion differs for different significance levels, Spearmen's rank correlation coefficient  $r_R$  was computed also. For the Tala respondents,  $r_R = -0.046$ , which is not significant based on the t-test. Thus, knowledge and attitude are independent of each other. For the Guimod respondents,  $r_R = -.218$ , which is considered significant at 5% level but insignificant at 1% level. For all respondents combined,  $r_R = .17$ , which is considered significant at both 5% and 1% significance levels. Thus the conclusions do not vary very much if the rank correlation coefficient was used instead of Pearson's r. Apart from the attitudinal statements, the linguistic analysis also showed the level of reactions and attitudes among those studied. Again, both types of data demonstrated almost similar perceptual bias in relation to the disease. In many cases their skin problems were considered not disabling; they were not aware of the seriousness of the disease.

Several informants did not recognize the sickness as leprosy until it was positively identified. For many of them, they like to think of it as skin ailments, for which the Ilocanos have, in fact, many terms. Terms for Skin Ailments:\*

Ilocano	<u>Filipino</u>	English
Kukutel	Ketong	leprosy
taramiding		
supot-supot	tagulabay	rash
kurad	buni	ring worm
kamuro	taghiyawat	pimples
kamanaw	anan	tina flava
gaddel	galis	itch
abbudobudo	pantal	rash
kating	bakukang	yaws
gudgud	galis aso	scabies
labba-it		

\*These terms will be useful in packaging health education materials.

The data further showed that the respondent Hansenites were often hesitant, evasive or indirect. This indicated their caution in making statements or comments about their state, hence consciously or unconsciously revealing their anxiety and feeling of insecurity.

Some of the Hansenites expressed the belief that their sickness was curable and did not despair of their state but expressed anxiety over their predicament. Some of the informants expressed the belief that those afflicted with the disease should be segregated to avoid its spread.

From the comments of the relatives of Hansenites it could be gathered that they expressed concern and tolerance towards those suffering from the disease. At the same time the data showed the relatives as keeping a distance, indicative of caution and uncertainty. In general, the informants who were not related to Hansenites showed very little knowledge of the disease itself or related aspects of it. Nonetheless, they expressed sympathy for those afflicted with leprosy.

#### III. STRESS AND COPING PATTERNS AMONG HANSENITES

The psychological aspect of the project sought to discover the types of psychological stress and coping reactions among Hansenites and their families. That leprosy is a dreaded and stigmatized disease appears to be a well-known fact and it is therefore expected that a Hansenite's life would be marked by stress. Apart from making this general observation, however, there has been no attempt to systematically study the exact nature of the stresses experienced by Hansenites. Earlier studies on psychological stress pointed to the amount of stress experienced by Hansenites prior to and after institutionalization. Thus, patients experienced the greatest amount of stress, first, upon learning that they had the disease and second, when they were released as outpatients. These findings suggest the time during which psychotherapeutic intervention could possibly take place.

The present study, on the other hand, concentrates on outpatient Hansenites who have never experienced institutionalization. It is therefore geared towards understanding their phenomenology within the context of disease-related stresses. Immediate family members who are involved in caring for the patient are likewise included in the study in order to place the patients' stress perceptions in proper context. It appears just as important to understand their stress perceptions and coping patterns because they provide the daily social interaction open to the Hansenites and to some extent share the stress of a chronic and stigmatized disease. Relatives also appeared to be a good comparison group as they share with the patients similar social and physical environments.

This report summarizes data from twenty patients (10 males, 10 females) and eighteen non-patients (8 males, 10 females) who are all registered with the Vigan Skin Clinic in Vigan, Ilocos Sur. The females have a mean age of 35 and the males of 33.

The subjects were chosen at random based on their being adults and being physicially able to see and talk normally. Introductions were made by personnel from the Vigan Skin Clinic. Prior to the interviews, rapport was establshed by the interviewer who spoke the dialect and tried to minimize the physical distance between herself and the patients. The Philippine Thematic Apperception Test was then administered after which the Rorschach was given. Finally, an in-depth interview including dreams, best and worst experiences, knowledge, feelings, attitudes and coping reactions was undertaken. Ending the session involved conversing with them casually and maintaining a friendly atmosphere.

The data generated from the interviews are very extensive and encouraging, suggesting various types of analysis. Case studies as well

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as group profiles could be done but for this report, a card-by-card content analysis is made for the projective tests and frequency counts and descriptions will be made for the rest of the data.

Table 1.

	Thematic Apperception Test (PTAT)
CARD NO	ТНЕМЕ
1	A girl ashamed about her disease A girl cooking/doing household chores
3	A sick man helped by others or through God's mercy
. 6FM	Two men trying to avoid a girl with leprosy Leprosy patients thinking about their disease
7	People praying attending mass Praying for God's help over illness (Leprosy)
10	An old couple with grandchild Sick people (leprosy patients)

Dominant Themes of Hansenites on the Philippine

The above thematic analysis indicated that the Hansenites dwell on their disease repeatedly and generally in a high negative manner. Their feelings of shame and worry are easily projected onto the characters in their stories. These came very naturally with minimal prodding and for some, it was a cathartic experience as they went from the story they created to their own personal lives.

The characterization of the heroes in the stories are uniform for both males and females: sick people, mostly with leprosy, who are overcome by feelings of frustration, unhappiness, worry, shame and rejection. The dominant needs expressed are those of succorance and harm-avoidance and the positive notes in these protocols appear to be in the story-endings. Although negative feelings and thoughts dominate the stories, they generally end with some hope for a better life.

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The tone of negative feeling is repeated in the dreams, especially those of the male patients who reported dreams of falling all the way down a ravine, being chased by a ghost, being bitten by a snake, being unable to move because a monster was sitting on their stomach, as well as two men chasing a patient and killing him. The positively toned dreams are almost magical and wish-fulfilling in nature: for instance, dreaming of being completely healed just by wiping a potion once, all over the body. The females have more positive dreams but those who have bad dreams report the same type as the men's - falling, being bitten and seeing something frightening. The positive dreams include seeing and talking to God thus making their disease more bearable and being informed by others about a doctor who can really heal leprosy. These positively-toned dreams suggest simultaneously the despair and desire to be healed: only a magical process or God's intervention can heal them of their leprosy.

From the content analysis of the subject's responses to the Rorschach the following inferences may be made: for both males and females, there is an expression of generalized negative attitude, a passive-receptive orientation, an indication of immature, inadequately developed personality, fear of bodily harm, a real concern about their bodies and attitudes of guardedness and evasion. The findings from the Philippine Thematic Apperception Test and dreams are thus further reinforced by the foregoing content analysis.

Part of the interview involved questions on their happiest and worst experiences. Five of the patients claim not having any happy experience at all (Awan ti amok nga pinagragsakak. I don't know of anything that made me happy. I was never happy.), while others point to their childhood when they did not yet have leprosy and to their present state. Their financially deprived condition can also be seen in their reports of happiness when a little money or food comes their way. (Naragsakak, basta ada masidak, uray no anya dita. I am happy as long as I have something to eat, anything at all.). The need for affiliation, on the other hand, determines their happiness: recalling walks with a boyfriend, reminiscing about dancing parties, the birth of the first son and Christmas Day. Worst experiences are mostly associated with their illness. Thus they report: getting sick with leprosy or feeling that their disease was getting worse, people avoiding them because of disease, feelings of shame, worry and sorrow about their disease and people teasing them about leprosy. Be it a projective or direct injury, the in-depth interview yielded data descriptive of the depressing effects of the chronic nature In describing their initial reactions to the of Hansen's disease. discovery that they had leprosy, both males and females reported being worried, afraid, depressed, sad and ashamed. They perceived their families as being worried and depressed too but that their neighbours feared them and some showed loathing for them. Their first coping behaviour involved going to the "arbularyo" who made them drink some potion, healed them with saliva and betel nut or who rubbed them with various kinds of leaves. At the same time, they isolated themselves from other people. Only when their condition seemed to get worse did they attempt to go to the Skin Clinic.

It seems clear from the foregoing analysis that there is a need to provide therapeutic counselling sessions for Hansenites.

#### Counselling and Stress Management among Hansenites

The results of the present study indicate the extent and intensity of stress experienced by Hansenites and the basic fact that people involved in their care (relatives and skin clinic personnel) have to be sensitive about the psychological impact of the disease on the patients. Skin Clinic personnel and relatives of the Hansenites can be a source of support as well as of stress for the patients. Thus, although the target beneficiaries for this proposed intervention are the Hansenites themselves, the strategy basically involves the education and training of skin clinic personnel and patient's relatives on the psychotherapeutic handling of the Hansenites.

That psychological stress and disease are closely associated is no longer a matter of debate. Research now links stress with disease as an antecedent, consequent or concurrent factor. For instance, Rahe <u>et al.(1964)<sup>34</sup></u> have evolved a scale which allows some degree of measuring the impact of life events on the individual and their work indicates that as life events become more stressful the frequency of illness also increases. In this context, therefore, the amount of stress present in the lives of Hansenites which the present study documents can not be overemphasized. Although no specific studies have been made on stress as an antecedent of Hansen's disease, it can be hypothesized from the present data that, as an accompanying factor, it could aggravate the physiological condition of the Hansenite.

#### IV. <u>RECOMMENDATIONS</u>

This section of this paper is the most important because it contains the recommendations for improving the leprosy control service in the Philippines to which serious consideration should be given.

## 1. <u>Suggested Strategy for Patients</u>

1.1 Relaxation training. Jacobson's technique should be utilized. Each session should last from 15 to 20 mintues, focusing on relaxation training.

1.2 Cognitive behaviour modication. The most stressful experience of the subject should be determined and a) an explanation of how conditions are aroused by one's thoughts will be made; b) practice in controlling arousal by means of relaxation and breathing should be introduced; and c) practice in rehearsing self-instructions to cope with stress situation should be encouraged. 1.3 Self-management and self-control.

2.

1.4 Group discussions and group conselling on common problems (patients are met in homogenous groups, e.g. males or females of a particular age group).

#### Suggested Strategy for Clinic Personnel and Family Members

2.1 Sensitivity training designed to make personnel more sensitive about the impact of their knowledge and behaviour.

2.2 Training sessions on the impact of preparatory communications in reducing fear and anxiety. Frankness, honesty and genuine concern for the patient will be emphsized.

2.3 A three-month intensive training and supervised practicum on the technique outlined for patients.

### 3. Suggested Strategy in Packaging Information on Leprosy

3.1 Packaging information about leprosy in Ilocano should use the very terms and linguistic forms Ilocanos are familiar with. Posters should not be in English.

3.2 Make targets of information aware of their state.

3.3 The language used in educational material should avoid hurting the sensibilities of those whom the message should reach in order to avoid negative reactions. For example, supernatural causes of leprosy may be included among legitimate ones to make those who believe in curses or voodoo relate to the educational material prepared for dissemination.

3.4 Significant dialectal differences for terms and for folk beliefs should be noted and included in the material to be disseminated.

3.5 The material gathered in the study could be used for training personnel involved in the prevention and control programs.

3.6 The results of the study should be incorporated and used to modify and elicit new material for a more extended study on leprosy in the Ilocos.

#### NOTES

1.

Cuimod is the study site while Tala serves as the control site. There is a need for a control site so as to have a basis for comparison of the study site. Tala Leprosarium is in Metro Manila, the National Capital Region of the Philippines (or simply, Region IV). It is an hour's drive from Manila, on average. Tala Leprosarium is located in Tala, one of the barangays in the municipality of Novaliches, comprising the City of Caloocan. The patients in that Leprosarium usually come from Luzon, most particularly from Central Luzon and Metro Manila since it is very accessible and very near the place. Only a few come from the Visayas and Mindanao.

There are 35 patients all in all but two are also CRI aside from bring patients because one is the sister and the other the husband of another leper (in both cases, the CRI/P got sick later than the patient corresponding to them). In one questionnaire, most questions were not answered because the 7-year old child could not comprehend the questions. From a quota of 38, we lack 3 but if we cancel that of the boy, we lack 4. There are 30 critical informants technically but only 21 questionnaires for single CRIs were answered. In 4 cases, the CRI is answerable for 2 patients each. In one case a CRI is answerable for 2 patients each. Ine one case a CRI is anserable for 4 patients - her sons (3) and a sister-in-law who is living with her. We lack 8 CRIs. There are 38 KIs and with a quota of 36 there is an excess of 2.

- 3. These 41 patients were derived (or taken) from the list supplied by the Central Administration of Tala. They are active cases and their characteristics were matched with the 34 patients from Guimod.
- 4. Taken from the field diary of Ms. Carmina Reyes dated 30 April 1982, page 12. Ms. Reyes was the field interviewer in Tala, Caloocan and Guimod, Bantay, Ilocos Sur for this research project.
- 5. Soldevilla, J.R., "Maximizing Resources of Assisting Agencies in Leprosy Problems in Leprosy Case Assistance", <u>The Philippine</u> <u>Journal of Dermatology and Leprosy</u>, Vol. VI-IX (January 1974-June 1979), pp.78-83.

 Kato, L., "Trends in Leprosy Research. Cultivation of the Neglected priority", Leprosy Scientific Memoranda, Leonard Wood Memorial (American Leprosy Foundation), L-1151 (September 1982), p.2.

2.

- Tranquilino Fajardo, Jr., "Immunology Therapy of Leprosy", <u>The Philippine Journal of Dermatology and Leprosy</u>, Vol. VI-IX (1974-1979), p.38.
- R.S. Guinto, "Epidemiology of Leprosy, Current Views, Concepts and Problems", p.26.
- 9. Rodriguez, J.N., "Problems in the Cultivation of <u>M</u>. <u>Leprae</u>", <u>The Philippine Journal of Dermatology and Leprosy</u>, Vol. VI-IX (January 1974-June 1979), pp.20-3.
- 10. Binford, C.H.,, "Predilection of <u>M</u>. <u>Leprae</u> for Peripheral Nerves", <u>Leprosy Brief Transactions</u>, Vol. 13 (1962).
- 11. Lara, C.B., "Leprosy Incidence and Age or Duration of Exposure at Onset in Unvaccinated and Vaccinated Contact Children", <u>The Philippine Journal of Leprosy</u>, Vol. 2, No. 2 (July-December 1968), pp.13-14.
- 12. S. R. Lang, "Leprosy in Auckland", <u>New Zealand Medical</u> <u>Journal</u>, 92 (8 October 1980), p.272. This has been validated by our observations in the study sites. In fact, the research team is beginning to suspect that the process of contamination is greatly enhanced by the very close contacts of family members. This system explains why there are many cases of all family members being sick at the same time. That contamination of things used by lepers is a very easy means of disseminating the <u>M. leprae</u> should be emphasized as well in health education. What happens is that only "prolonged skin to skin contact" is the most accepted and stressed mode of transmission by present health educators and leprologists in the country.
- Muir, E. and Sir L. Rogers, <u>Leprosy</u>, 3rd ed., Baltimore, Williams and Wilkins Co., 1946.
- 14. Marchoux, E. "Un cas d'inoculation accidentalle du bacille de Hansen en pays nonleprius:", <u>International Journal of</u> <u>Leprosy</u>, Vol. 2 (1934), pp.1-6.
- Olsen, R.S. and R.J. Porritt, "The Simultaneous Cases of Leprosy Developing in Tattoes", <u>American Jounal of</u> <u>Pathology</u>, Vol. 23 (1947), pp.805-17.
- 16. Lara, C.B. and J.O. Nolasco, "Self-healing or Abortive and Residual Forms of Childhood Leprosy and their Probable Significance", <u>International Journal of Leprosy</u>, Vol. 24 (1956), pp.245-63.
- 17. Dungal, N., "Is Leprosy Transmitted by Insects?", <u>Leprosy</u> <u>Review</u>, Vol. 31 (1960), pp.25-34.

- 18. Munos Rivas, G., "Algunasssss Observaciones Relacionadas con las pulgas y la transmission de le lepra", Rev. de la Fac. de Medicina Bogota, Vol. 10 (1942), p.635.
- 19. Munos Rivas, G., "La transmission de la lepra", Bogata, Vol. 8 (1958),
- F.L. Sahagun, "Physical Rehabilitation of Leprosy", <u>The</u> <u>Philippine Journal of Dermatology and Leprosy</u>, Vol. VI-IX (1974-1979), p.61.
- Reyes, T., "Nerve Conduction Velocity Studies in Filipinos with Leprosy", <u>The Philippine Journal of Dermatology and</u> <u>Leprosy</u>, Vol. VI-IX (January 1974-June 1979), pp.46-59.
- 22. See Note 10.
- 23. S.R. Lang, "Leprosy in Auckland", op. cit., p.272.
- 24. H. Johanse, "Prospects for Leprosy Control in the Eighties", <u>The Nursing Journal of India</u>, 71, 9 (1980), p.252.
- P.R. Tantiangco, "Problems in Chemotherapy and Recommendations", <u>The Philippine Journal of Dermatology and</u> <u>Leprosy</u>, <u>op</u>. <u>cit</u>., p.35.
- 26. G.H. Ree, "Psychosomatics of Leprosy", <u>PNG Medical Journal</u> (1980), p.51.
- 27. P. Fasal and G.L. Fite, "The Several Faces of Leprosy", <u>International Journal of Leprosy</u>, 47, 2 (1979) Suppl. Abstract VI, 212, pp.401-402. In fact, the present study seeks to understand the social face of leprosy.
- G.L. Fite, "Leprosy, Society and Hansen's Disease", <u>International Journal of Leprosy</u>, 24, 4 (1956), p.461.
- 29. Alexander, J.B. and R. Moulun, "Psychological Stress in Leprosy Patients", <u>The Philippine Journal of Leprosy</u>, Vol. IV, No. 2 (July-December 1969), pp.1-10.
- 30. G.A. Gonzales, "Psycho-Social Aspect of the Rehabilitation of Hansenites", <u>The Philippine Journal of Dermatology and Leprosy</u>, <u>op</u>. <u>cit</u>., p.75.
- M. Jesudasan <u>et al.</u>, "Health Education and Leprosy", <u>Leprosy</u> <u>Review</u>, 51 (1980), p.167.

F. Lendrum, "The Name Leprosy", <u>American Journal of Tropical</u> <u>Medicine and Hygiene</u>, 1, 6 (1952), p.999. The present study under the supervision of Dr C.M. Paz of the Department of Linguistics and Asian Languages seeks to document the importance of language analysis in understanding the illness. Hopefully, she might come out with certain recommendations regarding health education materials.

Aida G. Lu <u>et al</u>., "Filariasis: A Study of Knowledge, Attitudes and Practices of the People of Sorsagon", <u>Social</u> <u>and Economic Research Project Reports</u>, No. 1 (1988) UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR).

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33.

Rahe, R.H., M. Meyer, M. Smith, G. Kjaer and T.H. Holmes, "Social Stress and Illness Onset", <u>Journal of Psychosomatic</u> <u>Research</u>, Vol. 8 (1964).

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# APPENDIX I

# LIST OF BARANGAYS OF BANTAY, ILOCOS SUR

B-012903 - Code for Bantay, Ilocos Sur

CODE BARANGAY

(As of July 1982)

POPULATION

001	Aggay	510
002	An-annam	1,300
003	Balalang	2,073
004	Banaoang	368
005	Barangay 1	480
006	Barangay 2	1,210
007	Barangay 3	513
008	Barangay 4	848
009	Barangay 5	480
010	Barangay 6	400
011	Barangay	2,940
012	Buguig	390
013	Cabalangan	300
014	Cabaroan	389
015	Cabusligan	490
016	Capangdanan	420
017	Guimod	500
018	Lingsat	720-
019	Malingeb	886
020	Mira	388
021	Naguidayan	347
022	Ora	1,010
023	Paing	1,288
024	Puspus	388
025	Quimaraya	386
026	Sagneb	125
027	Sagpat	297
028	Sallacong	198
029	San Isidro	560
030	San Julian	656
031	Sinabaan	326
032	Taguipuro	530
033	Taleb	1,870
034	Tay-ac	1,865
2		

## APPENDIX II

		: Population :	Active Cases	PR/1000 pop.
		683	1	1.46
	Aggay	753	3	3.99
	An-Annam	1976	9	4.55
	Balaeng	269	1	3.72
	Banaoang	382	2	5.24
	Boquig	1817	13	7.15
	Bulag		5	15.38
	Cabalanggan	325	1	2.66
	Cabaroan	376		2.00
	Cabusligan	440	0	-
	Capangdana	440	3	6.83
	Guimod	744	32	43.01
	Lingsat	682	12	17.60
	Malingueb	862	6	6.96
	Mira	192	2	10.42
	Naguidaya	291	0	0
16.	Ora	1161	1	0.86
	Paing	1253	11	8.78
18.	Poblacion (Zone I-VI)	3720	24	6.45
19.	Puspus	368	0	0
20.	Quimarayan	378	3	7.94
	Sagpat	350	1	2.86
	Sagneb	180	2	11.11
	Sallacong	171	0	0
	San Isidro	468	1	2.14
	San Julian	565	10	17.70
	Sinabaan	306	0	0
10000 C.	Taleb	1077	5	4.64
Deservation 1800	Taguiporo	462	2	4.33
	Tay-ac	1683	24	14.26
Tot		22372	1	74 7.78

# Prevalence Rate as of 1980 of the Different Barangays of Bantay, Ilocos Sur



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