

## Illness Beliefs of Leprosy Patients: Use of Medical Anthropology in Clinical Practice<sup>1</sup>

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The success of leprosy control depends on the quality of communication between patient and practitioner, particularly with regard to negotiating mutually agreeable therapeutic practices and goals. Adequate treatment requires long-term compliance with a drug regimen which brings about few immediate results. Significant improvements may take years to develop and patients must guard against relapse by taking medications continuously for years after their symptoms disappear or no further improvements are gained. Many patients take the medications infrequently or discontinue them altogether, resulting in poor control and the emergence of drug-resistant bacilli.

As is true in most areas endemic for leprosy, patients and practitioners employ different cognitive systems for understanding sickness which may reflect differences in educational and cultural backgrounds. The McKean Rehabilitation Institute in Chiang Mai, Thailand, is similar to many leprosy hospitals in that communication problems arising from these differences are particularly important. Northern Thailand is an area of rich cultural diversity which has a wide variety of indigenous health practitioners employing different explanatory systems for understanding and treating sick-

ness (<sup>2, 11, 12</sup>). McKean is a Christian missionary leprosy rehabilitation center with a hospital which serves as a major referral center for leprosy patients in northern Thailand. The patient population reflects the cultural diversity of the area and includes members of Thai, Chinese, and minority hill tribe groups.

One approach toward better communication between the practitioner and patient which is particularly relevant to leprosy concerns the distinction found in the medical anthropology literature between "illness" and "disease." Kleinman defines "illness" as "the culturally constituted, socially learned response to symptoms that includes the way we perceive, think about, express and cope with sickness." He defines "disease" as the technical reconstruction of sickness into the terms of the particular theoretical system used by health practitioners (<sup>9</sup>). He cites evidence that modern health practitioners tend to treat disease but not illness, and that part of the success that indigenous healers have in treating patients is attributable to their willingness and ability to treat illness problems (<sup>10</sup>).

Yet, health practitioners traditionally have been well aware that leprosy has social implications. Leprosy is imbued with a rich and complex mythology, and in Western cultures is perhaps unsurpassed in its ability to evoke adverse social responses (<sup>4</sup>). However, leprosy is not stigmatized in all cultures and there are no universally held conceptions of the disease (<sup>6, 14, 15</sup>). Nancy Waxler studied leprosy in India, Sri Lanka, Nigeria, and the United States and found marked differences in the "career" of leprosy patients, depending on the historical and cultural factors governing social expectations for the disease.

Kleinman points out that "it is so difficult to see clinical reality the way others see it." (<sup>8</sup>) He suggests that there is a "need for

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translating or interpreting different languages of medicine," and that what is needed is a "framework which allows the investigator to place various cognitive systems side by side." To this end he has developed the concept of the explanatory model, which he defines as "the notions about an episode of sickness and its treatment that are employed by all those employed in the clinical process."<sup>(8)</sup> He suggests that common questions about sickness that are shared by both patient and practitioner include concerns about: "(1) etiology; (2) time and mode of onset of symptoms; (3) pathophysiology; (4) course of sickness (including both severity and type of sick role—acute, chronic, impaired, etc.); and (5) treatment." The explanatory model framework provides the clinician and public health worker with a means of access to patient belief systems. It can give valuable information about the cultural context of experiencing sickness, and can illuminate potential conflicts between divergent patient and professional perspectives.

The elicitation of patient explanatory models has been developed into a simple format that has been applied to assessing individual belief systems in such disorders as hypertension <sup>(1)</sup> and black lung disease <sup>(3)</sup>. This study reports the findings from a survey of explanatory models from leprosy patients receiving care at McKean.

### METHODS

In this study 61 leprosy patients who were admitted to the inpatient wards at the McKean Institute over a period of 9 months were interviewed following an open-ended questionnaire adapted from Kleinman's Explanatory Model Format. Patients excluded from the sample were those who were admitted on days when interviewers were not available and those few who did not wish to be interviewed or who were acutely ill.

Our sample included 46 Thai, 5 Chinese, 2 Thai-Chinese, 6 Karen and 2 Thai yay. The male-female ratio was 44:17 which reflects both the greater prevalence of the disease in males and the tendency for males to be more likely to enter medical institutions for leprosy treatment. The patients' ages ranged between 16 and 74 with a mean of 42. With regard to religion, 37 patients were

Buddhist, 23 were Christian, and I was animist. The educational level was divided into three groups: 17 of the patients had no education, 36 had between 1 and 4 years of education in primary school and only 8 patients had more than 4 years of education. The patients in our sample were similar to other Thai leprosy patients in that most came from lower income groups from rural areas.

All interviews were conducted in either Northern Thai (52 patients: 85%) or Central Thai (9 patients: 15%). Central Thai is the standard written form of the language. Northern Thai is an oral informal dialect which shares many words with Central Thai. The interviews were administered by one of two trilingual (English, Central Thai and Northern Thai) Thai nurses who were both from Chiang Mai province. Both nurses were trained in public health and were not directly associated with the institute. The interviews lasted between 45 and 90 minutes and were held in a private setting with one interviewer. The patients were assured of anonymity and that the information would not be related to the hospital staff.

The questionnaire was composed of 31 questions which included the general headings of etiology, onset of symptoms, labeling, health seeking practices, pathophysiology, course of illness, illness problems, treatment modalities, evaluation of treatment effectiveness to date, expectations concerning the future course of the illness, and expectations for future therapeutic outcome. The focus of the interview was open-ended, that is, the patients were asked questions about "their problem." The wording and sequence of questions were adjusted to meet the needs of the circumstance and patient. At appropriate moments during the interview, the interviewers elicited demographic data, family history, and data about migration.

All terms used to describe illness concepts, practitioners and treatments were defined by the patients during the course of the interview. Because of limited resources, the interviews were not tape recorded and the interviewers, therefore, were required to write down responses during the course of the interview. On the same day, the interviewers discussed the course of the inter-

view with one of the investigators (TN) using the questionnaire as a guideline, and each of the health related terms used by our patients was translated into English. All of the data presented and discussed are derived from the written information obtained during the course of the interviews and the subsequent data collection interviews.

### RESULTS

The explanatory models used by patients in our sample reflect an eclectic approach to health care. Patients interchangeably used different theories of sickness, consulted different practitioners, and used both modern medicines and a variety of different indigenous treatments. Many patients embraced differing explanatory concepts concurrently. Some patients used biomedical concepts in the context of traditional categories, e.g., bacteria causes a humoral imbalance. Despite the growing influence of biomedical theory, there was no trend in the younger patients to use biomedical concepts more frequently than older patients.

In general, treatments were started and discontinued in accordance with perceived gains and losses. The patients frequently changed practitioners and treatments throughout the course of their illness. At the time of the interviews, many patients stated that they used both herbal and modern drugs. The various therapies were generally evaluated by short-term criteria, and often were seen as equal in efficacy. For example, a patient who develops a foot ulcer may see his wound as constituting "the problem." Herbal treatments are often more accessible and in general employ the same principles, i.e., cleaning, soaking, etc. Modern chemotherapy is slow in producing results and in this regard, alternate therapies impart the same degree of reinforcement.

Among the 61 patients there were 13 major categories explaining the etiology of leprosy (Table 1). Of the 97 responses to questions concerning etiology, 35 patients gave single answers; the remaining 26 used multiple ideas. Very few of the patients, 8 of 61 (13%), believed their illness was caused by a bacterial infection; 6 of this group were in the small minority who had greater than 4 years of education. Of these 8 patients, only

TABLE 1. Patient categories of explanation of the etiology of leprosy.

	Total no.	Sole explanation <sup>a</sup>
Infection		
Bacteria	8	2
"Skin parasite"	1	0
Unknown agent	7	1
Veneral illness	5	2
Karma ( <i>ween kam</i> )	16	3
Sin/Demerit ( <i>baáp</i> )	4	4
Spontaneous ( <i>pen ?eeng</i> )	12	6
Important circumstantial events	6	2
Heredity	4	1
Spirits ( <i>phī'i</i> )	1	1
Curse	1	0
Humoral disorders—"wind illness"	9	4
Dangerous food ( <i>aaha'an sala'eng</i> )	5	4
Resistance ( <i>khwaan tn thaan</i> )		
"Resistance"	7	4
"Weak skin"	2	0
"Weak blood"	3	0
Hygiene	6	1
Total	97	35

<sup>a</sup> Number of patients using this category alone to explain etiology.

2 used "bacteria" as a single concept to explain causation; the remaining 6 patients also incorporated the terms for resistance (4 patients), karma (2 patients), humoral disorders (1 patient), and circumstantial events (1 patient).

The patients rarely described in mechanistic terms the cause and pathophysiology of their sickness. One of the most frequent responses to questions concerning leprosy was "it came by itself" (*pen ?eeng*). (The phonetic system of transliteration used throughout the text is derived from the "Thai-English Student's Dictionary" (?). The vowel sounds designated as "or" and "ae," and the consonant "ng" are modifications made in order to use Roman letters exclusively.) Several patients considered important circumstantial events as sufficient cause for leprosy. For example, one man believed his illness began after a gun had backfired in his hand. Other categories included heredity and in the case of several hill tribe patients, curse and spirits. Two concepts used frequently by both Christian and

Buddhist patients were karma (*ween Kam*) and sin or demerit (*baàp*).

A category which deserves special attention includes the variety of humoral imbalances and "wind disorders" which were used to explain both the etiology and resulting manifestations of leprosy. A few examples include, "wind illness" (*rōog lom*), "major wind" (*lom lưang*), and "bad blood wind" (*lưad lom mây dii*). These disorders are indigenous diagnostic categories which are commonly used to describe a tremendous variety of symptoms<sup>(1)</sup>. Humoral theory relates to the general state of health of the person and holds that life requires a certain orderliness to maintain normal function. Certain "dangerous foods" (*?aa-ha'an sala'eng*) and practices have to be avoided during times of humoral instability, such as after parturition (*lom phid dyan*), or after certain illnesses. An excess of any form of activity can make one susceptible to sickness.

We found that the term "resistance" (*Khwaan tãan thaan*) was commonly used and understood. The idea of resistance to explain why only certain people get leprosy is a part of patient education at McKean. Resistance in the biomedical sense refers to immune competence. For some patients, "resistance" was a concept that was related to categories such as "weak blood," "weak skin," and hygiene. "Dirtiness" could cause leprosy, independent of a transfer of a causative agent simply by affecting resistance. For some, resistance was both a necessary and a sufficient cause. Resistance is an idea that fits well into several different theories of disease and represents a fortuitous compatibility between differing systems of explanation.

Altogether, the 61 patients applied 16 different labels to their illness (Table 2). We found that questions concerning usage and meaning of the various labels for leprosy yielded valuable information. An aspect of these different labels was that several of them have associations with particular symptoms. For example, *khii thuud* refers to the condition which causes severe shortening of the hands and feet, *Lom lưang* (major wind) is associated with thickening of skin, *thay kor* is associated with a clawed-hand de-

formity, *padong lưad* is associated with red nodules, and *lom maha'eng khud* causes numbness and blindness. However, these labels do not directly translate to the symptoms of leprosy. It is not possible to construe a folk definition of leprosy by mapping out the progression of the illness with these various labels. For example, not all of these names will be recognized by all patients as referring to leprosy. As previously discussed, the various labels referring to humoral disorders are used to describe a wide variety of problems. The words *burud* and *padong lưad* can both also mean venereal disease. Other labels have additional meanings related to problems such as irregular menstruation (*lưad lom mây dii*), allergies (*padong lom*), and nervous disorders (*rōog lom*). The various labels used by our patients functioned as associations to both physical symptoms and a variety of psychosocial concerns.

## DISCUSSION

Several comments must be made about the applicability of the results obtained from this sample to the general population of leprosy patients. This sample has several biases in that: a) all patients have decided they have a problem that requires treatment; b) all were capable and willing to enter an institute of biomedicine; c) all have entered an institute associated with Christian missionaries; and d) this study represents a single cross-sectional assessment of illness beliefs. Nevertheless, the data are helpful in elucidating general issues about clinical communication. Since this study was designed to examine problems of communication within a defined clinical setting, this sample serves that purpose.

The associations between labels and symptomatology did illustrate the fact that there is no unifying label "leprosy" to which all terms refer. It is possible for a person to develop *thay kor* (claw-hand deformity) and later *khii thuud* (shortening of hands and feet) without believing that it represents the same disorder. Leprosy is rarely understood as a single chronic disorder with progressive symptomatology. More commonly, it is perceived and experienced as a series of acute



disorders not necessarily related to one another. This observation was supported by the fact that many of our patients neither understood how long they would have their illness nor the need for prolonged therapy. Many came from families in which two or more members had leprosy. There were several cases in which a new family member developed leprosy that was unrecognized by a patient receiving regular therapy, even if the initial symptoms were identical.

The fact that the idea of bacterial etiology was believed by so few of our patients, despite efforts at teaching this concept, illustrates a point of conflict in communication between patients and staff. The germ theory of disease and the accompanying metaphor of the killing of the organism as a means of obtaining a cure originated in Western cultures and is not universally used. In strict terms, it has the potential of leaving many unanswered questions, e.g., why is it that some people get the disease and others do not? Such questions entail larger, more complex and more fundamental issues which in biomedicine are approached in such disciplines as genetics and immunology. For the patient, these unanswered questions amount to the essential inquiry: Why me?

There is an inevitable degree of ambiguity in the explanation that any medical system offers. People employ those symbols and explanations which provide the most meaning. In Western societies, the germ theory holds a position of prominence within the semantic networks of the popular health sector. In other cultures, these core symbols can vary greatly, depending on the theoretical vantage of the indigenous health systems. In our patients, the most cogent illness explanations were represented by concepts such as karma and resistance.

Despite the growing influence of biomedicine on the cognitive domain of various illnesses, traditional categories of illness still predominate for leprosy. Muecke has suggested that the function of traditional illness categories which have vague and broad meanings may be used to provide a "euphemistic gloss for otherwise incurable or demeaning health problems".<sup>(13)</sup> Gussow and Tracy did a survey in the United States of public knowledge about leprosy and found

TABLE 2. *Labeling of leprosy.*

Name	No.	Comments
<i>rōog ryàn</i>	50	Most common written form
<i>khūi thūud</i>	58	Most common spoken form
<i>lom lưang</i>	11	"Major wind"
<i>rōog lom</i>	2	"Wind illness"
<i>lom maha'eng khúd</i>	1	"Wind cancer" (Northern Thai)
<i>lưad lom máy dii</i>	4	"Blood wind illness"
<i>padong lưad</i>	2	"Blood disorder"
<i>padong lom</i>	2	"Wind disorder"
<i>thay kor</i>	6	Chinese—commonly used by both Thai and Chinese
<i>burút</i>	2	"Man's illness"
<i>phayāad myy chaa</i>	2	"Parasite numb hand"
<i>phayāad phīwnāng</i>	1	"Skin parasite"
<i>yáy</i>	2	Literary form
	1	Used in east Thailand—translates literally as "big"
<i>pong</i>	1	Translates literally "to bulge"
<i>tacha'eu</i>	1	Karen

that people knew very little about the disease<sup>(6)</sup>. In another study, they suggested that the popular view of leprosy represents "a fantasy of total maximal illness."<sup>(5)</sup>

Muecke has also suggested that traditional categories may persist for disorders in which biomedicine has been inadequate in providing explanations. Old categories can place a bewildering array of problems into a socially defined explanation which is meaningful to the patient. Old categories remain in use because they are better able to provide meaning to the sufferer. The biomedical explanation when used alone is less capable of encapsulating a wide variety of physical and psychosocial concerns.

The Explanatory Model Format can be used with each patient to provide interpretive strategies for the clinician, particularly in defining what constitutes "the problem." Despite the associations between a leprosarium and "leprosy" which seem obvious, patients coming in at different intervals during the course of their sickness may consider

themselves to have new and unrelated problems. Therefore, patient education at follow-up visits should stress the relationship between symptoms and should repeatedly emphasize the need for prolonged therapy.

Negotiation over therapeutic strategies does not necessarily require a full integration of patient and practitioner explanatory models. In this setting, such attempts may be neither possible nor desirable. Kunstatter points out that a patient need not subscribe to modern medical theory in order to desire modern treatments<sup>(11)</sup>. However, an inquiry into indigenous illness beliefs, such as can be approached with the Explanatory Model Format, may reveal potent illness concepts such as "karma" and "resistance" which have the facility to provide culturally meaningful explanations. These indigenous terms can be employed together with the notion of bacterial infection to help introduce and reinforce the important idea of chronicity and, hence, the need for prolonged therapy. Modern chemotherapy for leprosy, although effective, will not win over most patients by its own merit.

### SUMMARY

Illness beliefs of 61 patients identified as having leprosy were assessed by Kleinman's Explanatory Model Format. Our patients used a wide variety of etiologic theories which were grouped in categories such as venereal disease, heredity, dangerous food, sin, karma, and humoral disorders. Despite efforts at patient education, very few patients adopted the concept of bacterial infection to explain their illness. The patients identified their illness with a variety of different labels, some of which had associations with particular symptoms. Leprosy was perceived and experienced more as a series of acute disorders not necessarily related to one another. The various theories of illness were instrumental in directing treatment choices which included a number of indigenous healing practices. Such information may be useful in improving patient care and compliance by providing practitioners with interpretive strategies for communicating with their patients.

### RESUMEN

Se aplicó el formato de Kleinman para establecer la idea que sobre su enfermedad tenían 61 pacientes con

lepra. Los pacientes usaron una amplia variedad de teorías etiológicas las cuales fueron agrupadas en categorías tales como enfermedades venéreas, herencia, alimentos peligrosos, pecados, el destino, y desórdenes humorales. No obstante los esfuerzos de educación de los pacientes, muy pocos de ellos adoptaron el concepto de infección bacteriana para explicar su enfermedad. Los pacientes identificaron su padecimiento con una gran variedad de circunstancias, algunas de las cuales tuvieron asociaciones con síntomas peculiares. La lepra se percibió más como una serie de desórdenes agudos no relacionados necesariamente unos con otros. Las diferentes teorías sobre la enfermedad fueron decisivas en cuanto a la selección del tratamiento, el cual incluyó un buen número de prácticas indígenas de curación. La información obtenida puede ser útil si se pretende mejorar el cuidado y la constancia de los enfermos, al proporcionar a los médicos las estrategias más adecuadas de comunicación con sus pacientes.

### RÉSUMÉ

Au moyen du modèle explicatif de Kleinman, on a évalué les croyances se rapportant à la lèpre chez 61 malades atteints de cette maladie. Les malades interrogés ont eu recours à une large variété de théories étiologiques, qui ont été groupées en catégories telles que maladies vénériennes, hérédité, aliments dangereux, péché, destin, et désordres humoraux. Malgré les efforts déployés pour l'éducation des malades, très peu d'entre eux ont admis le concept d'une infection bactérienne qui expliquerait leur maladie. Les malades ont identifié leur maladie avec une variété d'étiquettes différentes, dont certaines présentaient des associations avec des symptômes particuliers. La lèpre était perçue et vécue davantage comme une série de désordres actifs, qui n'étaient pas nécessairement liés les uns aux autres. Les diverses théories se rapportant à la maladie se sont révélées fort importantes pour le choix des traitements, y compris de nombreuses pratiques indigènes de soins. Ce type d'information peut être utile pour améliorer les soins au malade, de même que l'assiduité de ceux-ci, en fournissant aux praticiens des interprétations rationnelles pour communiquer avec leurs patients.

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