The Explanatory Model Interview Catalogue (EMIC)
Contribution to Cross-cultural Research Methods
from a Study of Leprosy and Mental Health

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The Explanatory Model Interview Catalogue (EMIC) has been developed to elicit illness-related perceptions, beliefs, and practices in a cultural study of leprosy and mental health in Bombay. Leprosy is an especially appropriate disorder for studying the inter-relationship of culture, mental health and medical illness because of deeply rooted cultural meanings, the emotional burden, and underuse of effective therapy. Fifty per cent of 56 recently diagnosed leprosy out-patients, 37% of 19 controls with another stigmatised dermatological condition (vitiligo), but only 8% of 12 controls with a comparable non-stigmatised condition (tinea versicolor) met DSM-III-R criteria for an axis I depressive, anxiety or somatoform disorder. Belief in a humoral (traditional) cause of illness predicted better attendance at clinic.

The vigour of the so-called new cross-cultural psychiatry (Kleinman, 1977; Littlewood, 1990) reflects increasing clinical experience in diverse international settings, and with refugees and minorities (Westermeyer, 1985; Kleinman, 1988; Littlewood & Lipsedge, 1989). Impediments to a coherent methodology, however, have long bedevilled efforts to integrate clinical, epidemiological and social-science frameworks (Sartorius, 1973; Dohrenwend & Dohrenwend, 1974). The Explanatory Model Interview Catalogue (EMIC), developed in response to this challenge, was used to study cultural meanings of leprosy, its emotional impact, and compliance with treatment.

Tropical diseases pose special problems that are likely to benefit from improved links between psychiatry, medicine and anthropology in developing countries where such diseases are common. Leprosy, also known as Hansen's disease, is a prime example. As a major health problem with cultural, behavioural and emotional components, leprosy is the archetypal stigmatising medical illness (Jopling, 1991). It remains widespread in many parts of Asia, Africa, and Central and South America (World Health Organization, 1985). In India, with an average prevalence rate of 5–6 per 1000, approximately 300 000 new cases present annually for treatment (Park & Park, 1985, p. 353).

The advent of multidrug treatment for leprosy a decade ago (World Health Organization, 1982), using dapsone and rifampicin for paucibacillary disease and adding clofazimine for multibacillary cases, reduced the course of treatment for most patients to between six months and two years, and made leprosy not just treatable, but curable. Disentangling the fear of disfiguring outcomes, now preventable, from the popular meaning of the disease has become a major objective of leprosy programmes (Chen, 1988; Fassin, 1990), but persisting cultural meanings maintain its stigma.

Although research dating back to the last century identified higher rates of depression and other psychiatric conditions among in-patients with the disease, the effect of the diagnosis itself on the mental health of leprosy out-patients has not been studied. In the first study from the psychiatric clinic at the US Hansen's Disease Center in Carville, Louisiana, Cazanavette (1927) emphasised depression and anxiety, attributing them to "some irritating lesion of the nervous system brought on by . . . toxins" (p. 1496). Lowinger (1959, 1974), working at the same centre decades later, also favoured an organic explanation, suggesting that psychopathology resulted from bacterial invasion of the central nervous system, a hypothesis that is unsupported. A study at Carville found major depression to be the most frequent diagnosis (46%) among 84 patients seen in the psychiatric clinic (Olivier, 1987).

In India, mental health specialists have recognised a need for psychiatric services in leprosy treatment programmes (Vergheese et al, 1971; Behere, 1981; Chauhan et al, 1982). Behere reported suicidal ideation in 14 of 24 randomly selected leprosy in-patients in Banaras, India, two of whom had attempted suicide.

The EMIC
'vemic' and 'etic' frameworks for social analysis distinguish analytic frameworks that are rooted
in the culture of the group under study, the insiders' perspective (emic), or based on professional ideology, the outsiders' perspective (etic) (Headland et al, 1990). A study of local concepts of health and illness among patients for whom these concepts are meaningful is emic; an epidemiological study employing DSM-III-R or ICD-9 diagnoses is etic.

Explanatory models of illness refer to experience and the sense people make of it (Kleinman, 1980). To the extent that these explanatory models are rooted in local cultural concepts, reflecting the way people think about their world, themselves, health and health problems, explanatory models are emic; insofar as they reflect exogenous professional ideologies, they are etic. Although the EMIC (our semistructured interview) is concerned primarily with eliciting explanatory models of patients in their own terms, explanatory models are complex, reflecting influences from within and outside the culture. Our emphasis on the emic perspective is relative, not absolute.

The explanatory model and the emic/etic dichotomy guide research in cross-cultural psychiatry and medical anthropology, including studies of beliefs about leprosy in Thailand (Neylan et al, 1988) and Pakistan (Mull et al, 1989). The EMIC is a locally adapted semistructured interview based on concepts that collectively specify an explanatory model. Pre-testing to adapt the EMIC for research in any particular cultural and clinical context identifies locally meaningful categories with reference to the framework (see below) and elaborates the 'insiders' point of view. The technique studies the relationship between culturally defined experience and professionally defined outcomes.

The EMIC identifies normative cultural explanatory models as well as the diversity and implications of individual variation. In the current study of leprosy, relevant outcomes included psychiatrically significant emotional distress and attendance in the Hansen's clinic. Figure 1 illustrates the conceptual framework relating outcomes and explanatory models.

Efforts to develop the EMIC began by amplifying eight questions that Kleinman (1980, p. 106n) proposed for eliciting explanatory models. From open-ended pilot interviews with psychiatric and medical patients in Bombay, Bangalore, Ranchi and Banaras, India, an operational formulation of explanatory model emerged (Weiss et al, 1986). Qualitative analysis of clinical ethnographic data from these open-ended interviews enabled us to develop a coding strategy to represent explanatory models.

A research team translated and back-translated the EMIC to produce Hindi and Marathi versions. Established techniques of back-translation and 'centring', which values an accurate restatement of meaning in the translation over linguistic precision (Brislin, 1976), guided the process. A group of researchers familiar with the EMIC met with other clinicians in translation seminars and discussed the translation and back-translation item by item. Interviews scored by two raters to test inter-rater agreement in the pilot phase of the study identified ambiguous questions and category codes; these were eliminated or revised.

The EMIC elicits a structured explanatory model of illness (see Appendix) with qualitative prose elaboration of coded data and the interview process.

Inter-rater agreement for key items of the EMIC, measured by comparing two raters observing the same interview, yielded good or satisfactory results (Table 1), as indicated by Cohen's kappa statistic (Zwick, 1988). Weighting the significance of disagreements and clustering responses under appropriate summary categories yield higher kappa values, but the conservative estimates are all satisfactory or better.

Establishing validity poses a more challenging problem than testing reliability. The systematic validation of psychiatric disorders (or other categories of experience) questions how meaningful and useful they are (Robins & Barrett, 1989). Different meanings of illness across cultures both complicate questions about validity and provide another important

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**Fig. 1 Relationship of cultural explanatory model (emic) to outcomes of practical interest (etic). PD = patterns of distress, PC = perceived causes, HS/TX = help seeking and treatment preferences, SCID = Structured Clinical Interview for DSM-III-R, HDARS = Combined Hamilton Depression and Anxiety Rating Scale.**
The standard errors of point estimates for kappa ranged from 0.06 to 0.18. The number of categories on which assessment of agreement was based ranged from 3 to 13.

The coherence of explanatory models derived from the EMIC with respect to ethnographic data may be an appropriate indicator of construct validity. If emic categories predict outcomes of clinical significance (clinic attendance, diagnosis of depression, anxiety or somatoform disorder, and Hamilton scores – see below), this shows the criterion validity of anthropological explanatory models.

Kleinman's (1977) formulation of the category fallacy, which questions the power of clinical concepts defined in one culture as the basis for psychiatric evaluation in another, underscores the complexity of questions about cultural validity. Research that relates explanatory models to diagnoses, as in this study, helps to clarify the validity of professional diagnostic categories with respect to data from a culturally defined explanatory model. We used the Structured Clinical Interview for DSM–III–R and Hamilton scales to study depressive, anxiety and somatoform disorders, and to compare levels of emotional dysphoria among subjects within the sample. Clinical impressions in the study supported the use of these instruments as indicators of emotional distress, even though other indicators based on local patterns of distress may be worth developing (e.g. Manson et al., 1985). Psychiatrists in India routinely make DSM–III–R or ICD–9 diagnoses, and many use the Hamilton scales for research.

In addition to the EMIC, the Structured Clinical Interview for DSM–III–R (SCID; Spitzer et al., 1988) for diagnostic evaluation and the Combined Hamilton Depression and Anxiety Rating Scale (HDARS; Williams, 1988) to measure depression and anxiety were chosen because they are clinician-rated instruments: experience in the clinic showed a subject-rated questionnaire was inappropriate to screen these medical patients for depression, anxiety, and other psychiatric symptoms. The HDARS and the SCID were also translated and back-translated to Hindi and Marathi versions. Inter-rater reliability was good for the translated HDARS when tested on 34 subjects \( r = 0.89 \) (90% CI 0.81–0.97) for the depression scale; \( r = 0.90 \) (90% CI 0.83–0.97) for the anxiety scale). Psychiatrists using the SCID, which was added at a later stage of pilot testing, were familiar with DSM–III–R from their clinical training and practice.

The study site was in Bombay, India's largest and most prosperous city. It is a centre of urban migration where crowding and poverty sustain endemic leprosy. Prevalence rates average 11.9 per 1000, and in some slums they reach 22.8 per 1000 (Revankar & Ganapatil, 1988). The King Edward Memorial (KEM) Hospital is a teaching hospital on the campus of the Seth G. S. Medical College. It is run by the Bombay municipality, and enjoys a good reputation among the working-class and lower-class population it serves in a predominantly Hindu section of the city. Because of its reputation and inexpensive services, it also attracts patients from other parts of the city and surrounding rural areas. Most patients are working-class residents of the city who have lived there for many years or have recently immigrated from other parts of Maharashtra State (of which Bombay is the capital), from north India (mainly the states of Uttar Pradesh and Bihar) or from elsewhere in India.

The study sample consisted of 56 consenting patients beginning treatment in the Hansen's clinic of the KEM Hospital. New patients attending this clinic were referred to the study team, and interviews were arranged for those who agreed to participate. Two control groups were recruited in the dermatology out-patient clinic of the hospital: 19 patients with vitiligo and 12 patients with tinea versicolor. Vitiligo is a depigmenting condition that is biomedically unrelated to leprosy although some lay people and the traditional medical system (Ayurveda) consider them to be related (Jolly, 1977), and in many parts of India vitiligo is also stigmatised. Tinea versicolor is a fungal infection with lesions that may resemble the depigmented patches of early leprosy. Most people, however, consider tinea neither serious nor stigmatising.

Four psychiatrists were trained in the use of the EMIC, SCID and HDARS. Over seven months from July 1987 they completed 87 research interviews (median duration 2½ hours) in Marathi or Hindi; one psychiatrist interviewed the patient while a second recorded data.

Recognising that the clinic setting may impose expectations about how doctors might judge harshly what patients say, introductions to each section of the EMIC and the wording of queries emphasised our interest in subjects' ideas and experience. At the end of the interview, after

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Method

In addition to the EMIC, the Structured Clinical Interview for DSM–III–R (SCID; Spitzer et al., 1988) for diagnostic evaluation and the Combined Hamilton Depression and Anxiety Rating Scale (HDARS; Williams, 1988) to measure depression and anxiety were chosen because they are clinician-rated instruments: experience in the clinic showed a subject-rated questionnaire was inappropriate to screen these medical patients for depression, anxiety, and other psychiatric symptoms. The HDARS and the SCID were also translated and back-translated to Hindi and Marathi versions. Inter-rater reliability was good for the translated HDARS when tested on 34 subjects \( r = 0.89 \) (90% CI 0.81–0.97) for the depression scale; \( r = 0.90 \) (90% CI 0.83–0.97) for the anxiety scale). Psychiatrists using the SCID, which was added at a later stage of pilot testing, were familiar with DSM–III–R from their clinical training and practice.

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Recognising that the clinic setting may impose expectations about how doctors might judge harshly what patients say, introductions to each section of the EMIC and the wording of queries emphasised our interest in subjects' ideas and experience. At the end of the interview, after
administering the SCID and HDARS, the interviewer and rater discussed the data, made consensus ratings, and wrote process notes that became part of the clinical ethnographic database. The Hansen's patients were asked to return for a second scheduled interview approximately two months later, at which time the study team administered a follow-up version of the EMIC and re-administered the SCID and HDARS.

The Hansen's clinic keeps records for all patients, with demographic data, clinical findings, dates of clinic visits, and treatment, including the number of dapson tablets and other medications dispensed. Daily dapson was prescribed for virtually all Hansen's patients. The research team reviewed all records of patients who first came to the Hansen's clinic in 1987 and 1988 and computed an attendance index, which made it possible to relate clinic attendance and independent variables among the study group and the clinic population not participating in the study.

Variables with many categorical values were reduced to clusters under summary headings. Detailed response codes, summary groupings and clinical ethnographic notes constituted the database from interviews with the EMIC. Data reduction facilitated analysis of data from the ethnographic model and bivariate associations with SCID diagnoses, HDARS scores, return for follow-up in the study and attendance in the Hansen's clinic.

Results

The mean (s.d.) age of the Hansen's patients was 35.8 (11.2) years (range 18–68). Most (79%) were Hindus, and the rest Buddhists (11%), Muslims (9%) and Christians (2%). Buddhists in Maharashtra are first- or second-generation converts from Hinduism, usually Hindu attempting to escape low-caste status in mass conversions (Gokhale, 1986). While most residents of Bombay speak Hindi, those for whom Hindi or Bhojpuri is the mother tongue (22%) were predominantly immigrants from the north. Marathi, mother tongue of 64% of the Hansen's sample, is the regional language of Maharashtra, and Urdu (mother tongue of 5%), similar to spoken Hindi, is typically the language of the Muslim minority. Our sample was mostly male (89%), possibly reflecting a greater incidence of leprosy among men (Park & Park, 1985) and the greater reluctance of women to come to the clinic and participate in the study.

Most patients with leprosy complained of pain, swelling, heat, numbness or some other somatic symptoms (84%), and about half the patients (52%) told us these somatic complaints were the most troubling aspect of the illness. About half of the sample (49%) also told us they were worried about the implications of the disease, what it would mean or how others would respond, and for 21% this was the most troubling aspect of their problem. Most patients were able to keep others whom they did not want to know from finding out about their disease (71%), although nearly half (46%) chose to disclose it, usually to a close relative. The overwhelming majority (89%) said they thought their condition would worsen if not treated, many specifying deformities or death (61%) as likely results.

Culturally patterned stigma was the main concern in the early stages of leprosy, before deformities and disabilities ensued. It is the social meaning of the disease that results in clinically significant depression and anxiety. One woman told us:

"My disease is like a well. No one would like to jump into it by choice. . . . If people were to know, they might not talk to me anymore. I would have to leave if they treated me like that. I couldn't take it."

A young man, typical of many in the sample, recalled the effect of leprosy on others who were deformed and neglected:

"My uncle has leprosy. His fingers and toes are bent like this. . . . He can't eat or drink himself. I don't know why they haven't taken treatment for him. He stays in a separate hut in the village. I suppose his wife must be giving him food; I don't know exactly. People keep away from him."

Arranging a marriage remains a vital concern for many Indian families, involving parents, siblings, and frequently members of the extended family. Concern about its effect on marriage prospects is an indicator of stigma associated with any condition (Khandelwal & Workneh, 1986). Most Hansen's patients in the study (82%) said their disease would either make it more difficult to marry or that it would have if they were not already married. Fewer expected it to affect a relative's marriage (64%), and fewer still said it might cause problems in an existing marriage (43%). Marriage seems to create a strong bond that resists stigma, unlike the effort to marry, which is vulnerable to stigma.

None of the women with leprosy whom we interviewed thought their disease would affect their marriage adversely, compared with 48% of the men (P = 0.03, Fisher's exact test, two-tailed). Since fewer women participated in the study, the greater tendency of women in the sample to report a strong social network may indicate that without it, women are less likely to come for treatment. Dependent social status may make it difficult for some to reach the clinic. Arranged marriages may also render many women more vulnerable to stigma, since marriageability for them is linked more closely with self-esteem and community assessment of personal worth.

Table 2 summarises the perceived causes reported by patients with Hansen's disease. 'Artefacts' refer to responses that subjects made during the interview after our query, rather than ideas they said they had considered previously. Category groups that more than 20% of the sample identified included infection/germs and magico-religious causes.

Stereotypes of Indian religiosity have long focused on passivity, inferred from beliefs in fate and karma. While such ideas may be associated with failure to make use of available help, striking examples show clearly that a disposition to act is compatible with a belief in fate. One patient told us:

"With treatment mahârog [leprosy] may be cured, but only if it is written in your fate. We cannot tell what is written, so we must try to get treatment. Certainly without treatment a man will die."
For the Hindu and Buddhist patients who mentioned it, a reference to karma – the result of deeds in a previous life – also implied a cultural reference to fate; no one could elaborate what it was they might have done or give any more specific details when we inquired. Anthropological research on karma in popular Hinduism emphasises “moral responsibility and destiny” as well as the “unpredictability of human fortune in the short run” (Babb, 1983). Although karma specifies ideas of cause and effect in the context of a moral economy, the context in which leprosy patients mentioned it seemed to emphasise the unpredictability of events. They spoke of karma as though it were a cultural idiom meaning ‘I don’t have any idea, so it must be karma’. They appeared not to have a clear idea about a specific deed and its consequences. A closer look at these subjects compared with the rest of the sample, however, suggests they did in fact bear the weight of moral responsibility as well, akin perhaps to guilt (Weiss & Kleinman, 1988). A reference to karma as an explanation for the illness was associated with a diagnosis of depression ($P = 0.03$, Fisher’s
exact test, two-tailed) and significantly higher Hamilton depression scores (mean (s.d.) 18.3 (12.0) v. 7.2 (7.2), \( P=0.008, t\)-test) in the total sample (\( n=87 \)).

Islam rejects the concept of karma or rebirth, but nearly half the Muslim patients referred to fate (nastāb). Too much heat in the body, another popular response, specified a more definite explanation, referring implicitly to influential indigenous humoral medical traditions. All patients who referred to physical exertion, an injury or accident as the cause considered it the most important cause, and none of these responses were interview artefacts. While nearly the same number considered sorcery and evil eye, this was more typically an additional consideration than the most important cause. A Hansen's patient told us:

"I do not smoke or drink; nobody in my family drinks. I cannot give a scientific reason. . . . Black magic [kāla jādu] is the most important thing, even though science ridicules it. Some relatives may not like it when others go up the social ladder."

Such themes of jealousy, magic and guilt that were relatively common in accounts of both leprosy and vitiligo were absent in the explanatory models of patients with tinea versicolor. No patients with tinea versicolor considered punishment for a deed in the past life (karma) or present life among possible causes of their condition. Similarly, even for this small sample of tinea patients, the smaller percentage of them attributing their problem to magico-religious causes (i.e. deities and demons, sorcery or fate) (17\%) compared with the leprosy or vitiligo groups (48\% combined) approached significance (\( P=0.06, \) Fisher's exact test, two-tailed) (Table 3).

Failure to report magico-religious ideas among patients with tinea versicolor was not because they rejected them out of hand. One man explained:

"Brahmins turn into spirits [devās] after they die. Bad people may call upon them to hurt us. I know that many people don’t believe this, but still it occurs frequently. They may cause madness or serious illness."

The Will of God may cause leprosy or big diseases, but not my problem. This comes from dirty things and not washing."

Many with tinea versicolor typically mentioned wearing wet clothes or sweating from exercise in hot weather as causes. Vitiligo patients also referred to hygiene, dirty clothes, heat and local trauma (in several cases attributing it to irritation from popular, inexpensive plastic slippers), but ideas of karma, guilt, punishment and malevolent influences played a more important role than among the group with tinea versicolor especially among depressed and anxious patients, who were keenly aware of its negative social meanings. Ideas about its cause change over time. A 42-year-old man who had had vitiligo since he was 12 wore only shirts with long sleeves in all seasons to hide his spots. He explained how his thinking had changed:

"I used to believe that this came from karma. I sang bhajans with a group, and they spoke a lot about the influence of deeds in the past life; I thought that must have caused it. But I like to read. You know, doctor, even though I was educated only to the 3rd standard, I read a lot. I began reading books about science. Gradually I came to believe that it is wrong to explain diseases by black magic or by god. You know, my hair started turning grey. It became all white. But now I use dye. Can you tell? I ask others, and they cannot. If god were so powerful, why could he not do such a simple thing as to make my hair turn dark again? The hair dye can do that, and it comes from science. That is why I think so much of science."

Health education at the initial visit appeared to increase the percentage of leprosy patients who attributed their illness to germs, hygiene and related causes in the follow-up visit from 46\% to 60\% (Table 3). Eliminating artefactual responses in the first interview, that is, those who said they had not considered the idea until we asked, left only 31\% of the follow-up group who had considered these perceived causes on their own at the initial interview. None of
these responses in the follow-up interview were artefacts. This increase from 31% to 60% was significant (P = 0.01, McNemar's exact test, two-tailed). The increase from initial to follow-up interview in the percentage of the sample reporting germs irrespective of sanitation, hygiene and contamination, was also significant after eliminating artefacts (P = 0.02, McNemar's exact test, two-tailed), indicating retention of the health-education message: germs cause leprosy.

Cultural context of perceived causes
Carl Taylor's (1976) survey of beliefs about the cause of leprosy and other diseases in a community survey at four sites in India revealed striking regional diversity. One expects both the popularity of specific beliefs and their meanings to vary even more across cultures than subcultures. Neylan et al (1988) found that food was a relatively less frequent explanation for leprosy in northern Thailand (8%) than in Pakistan (34%) (Mull et al, 1989) or Bombay (25%) (Table 2). For the subjects in Karachi, foods affected the balance of heat and cold. 'Food taboo' for the Thai respondents, however, connotes a magico-religious quality. It is necessary to consider the context of beliefs to understand their practical significance. In an American psychotherapy clinic a belief among patients in the psychosocial underpinnings of presenting problems is consistent with the clinical model of professional psychotherapists. Foulks et al (1986) showed that such 'medical models' predicted a better outcome and smoother termination. Although one might expect a belief in germs and infection, the medical model of health professionals, to predict the best compliance for patients in a leprosy clinic, ideas of humoral imbalance, rather than of infection, contamination, sanitation or hygiene, were associated with the best attendance in the Hansen's clinic in the current study (P = 0.03, Fisher's exact test, two-tailed). Identification of the problem as 'medical' appears to be more important than the distinction between 'traditional' and 'Western' medical models. Because the traditional models are more deeply entrenched, they may exert a greater influence on behaviour. Patients' beliefs need not be congruent with healers' for the help they provide to be acceptable and effective. Beliefs arising from local traditions that doctors regard as competing ideologies may be complementary from the patient's point of view and motivate biomedically appropriate treatment (Weiss et al, 1988).

The same ideas about illness embedded in a different cultural context may affect compliance adversely. African-American women in New Orleans reporting "folk-illness beliefs for hypertension", including too much heat, were more likely to comply poorly with treatment than their counterparts whose explanation was consistent with biomedical hypertension (Morbidity and Mortality Weekly Report, 1990).

Our clinical ethnographic probe data indicate that it may be useful to consider alternative configurations of the groups of perceived causes that we analysed. For example, magico-religious influence, contamination, and humoral balance were three distinct themes associated with foods, and they constitute an alternative configuration for analysing food as a perceived cause. One patient told us, "Our God does not like that we should take goat's meat." Another, referring to contamination, said, "The food you get in Bombay - especially the wheat, rice and oil - has been sprayed with insecticide. They store it in the ration shops for 10 years, and there are so many cockroaches there."

Yet another emphasised humoral properties: "Hot foods, like eggs, cause heat. My wife and children went to the village in May, and I was eating too many eggs."

Help seeking and denial
Most subjects with leprosy first sought help outside the home from private doctors (59%), government doctors (14%) or the KEM Hospital clinic (21%). Although studies of help seeking in India and other traditional societies emphasise the diversity of help seeking and the importance of the indigenous medical system (Leslie, 1980; Bhattacharyya, 1983), only one patient went to an Ayurvedic doctor first. Few (5%) reported that the doctor they first saw told them they had leprosy. Disclosure of serious illness by physicians is a complex phenomenon (Good et al, 1990), and it is not immediately clear what this means. Some doctors had probably missed the diagnosis. One patient told us:

"I asked my doctor to be frank and to tell me whether it was leprosy. He said it was not and gave me vitamin tablets. Recently I asked another doctor, who is a personal friend. He said there was a 2% chance and referred me here."

Other doctors may have chosen not to worry their patients while referring them for appropriate treatment, as some clinicians and researchers recommend (Berreman, 1984). Other doctors probably had revealed the diagnosis, but as a result of denial some patients said they had not been told. This we infer from observing patients' reports about what they were told in the KEM Hospital's Hansen's clinic. The doctor there informs new patients referred to our study of their diagnosis, but only 75% said they had been told or knew they had leprosy. Among the 35 patients we saw in our follow-up interview, with whom we had previously discussed their illness in detail and who had been attending the Hansen's clinic, four (11%) did not mention leprosy when we asked them to name their problem.

Denial may be adaptive in coping with emotional consequences of myocardial infarction (Havik & Maeland, 1988) and other conditions. A meta-analytic review suggested that avoiding coping strategies are most likely to help with short-term emotional sequelae of medical illness (Suls & Fletcher, 1985). Among some regularly attending the out-patient department in the Hansen's clinic denial was sometimes significant and helpful, as long as it did not interfere with chemotherapy. Some patients who would neither speak the name of the disease nor endure our mention of it without considerable discomfort continued to come regularly.

Denial is a matter of professional concern, however, when it interferes with essential medical treatment. Strauss et al (1990) have proposed that a new diagnosis, 'maladaptive denial of physical illness', be included in DSM-IV. Mull et al (1989) reported that 54% of non-compliant out-patients in Karachi, but none of the compliant out-patients, denied...
Table 4
Depressive, anxiety and somatoform (D–A–S) diagnoses among out-patients with leprosy, vitiligo and tinea versicolor (%)

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<th>Leprosy (total at initial interview; n = 56)</th>
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<td>Major depression</td>
<td>17.9</td>
<td>16.8</td>
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<td>Major depression and dysthymia</td>
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<td>5.3</td>
</tr>
<tr>
<td>Dysthymia</td>
<td>3.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Generalised anxiety disorder</td>
<td>0.0</td>
<td>5.3</td>
</tr>
<tr>
<td>Anxiety disorder not otherwise specified</td>
<td>0.0</td>
<td>5.3</td>
</tr>
<tr>
<td>Undifferentiated somatoform disorder</td>
<td>3.6</td>
<td>5.3</td>
</tr>
<tr>
<td>Adjustment disorder (all types)</td>
<td>26.8</td>
<td>0.0</td>
</tr>
</tbody>
</table>

1. Because one patient was diagnosed undifferentiated somatoform disorder and major depression, the total number of diagnoses is greater by one than the number of patients with a D–A–S diagnosis.

having leprosy, which supports the cross-cultural validity of Strauss's proposed diagnosis. The inter-relationship of knowledge about the disease, non-disclosure to self (i.e. denial), disclosure to others, help seeking, treatment compliance, and the emotional burden of medical illness involve complex psychological, behavioural and cultural issues that require further study.

Psychiatric evaluation

Half of the leprosy patients fulfilled criteria for some depressive, anxiety or somatoform (D–A–S) disorder, as did a substantial percentage of the patients with vitiligo (37%), but only one (8%) of the patients with tinea versicolor (Table 4). This young man, upset after recently migrating to Bombay from a village in north India, had an adjustment disorder with anxious mood. Even though anxiety was sufficient to warrant a diagnosis only for this one patient with tinea versicolor, subclinical illness may have motivated others to seek help in the KEM dermatology clinic for a disease that many people do not usually bring to the attention of health professionals. Hamilton depression scores among tinea patients (mean (s.d.) 3.3 (3.3)) were lower than in the combined leprosy and vitiligo groups (n = 75, mean (s.d.) 9.6 (9.1), P = 0.0001, Student’s t-test). The mean Hamilton anxiety score for tinea patients, however, was 3.5 (3.8), and for the combined leprosy and vitiligo group it was 6.9 (5.8), a marginally significant difference (P = 0.06, t-test).

Significant differences in Hamilton depression scores indicate that education and higher job status may protect patients from depression. Mean (s.d.) Hamilton depression scores for Hansen's patients with diploma from secondary school (n = 13) and without it (n = 43) were 5.5 (4.4) and 11.2 (9.1), respectively (P = 0.004, t-test). Only one professional (a teacher) and two businessmen were in the leprosy sample, but among the six studied in the combined leprosy and vitiligo group the mean (s.d.) depression score (2.8 (2.7)) was lower than it was for the 69 others (10.2 (9.2)) (P = 0.0002, t-test).

Depressive disorders among leprosy patients at the initial interview, including adjustment disorder with depressed mood, constituted the bulk of the D–A–S diagnoses (71%), and anxiety disorders were next (43%). (They total more than 100% because a diagnosis of adjustment disorder with mixed emotional features was counted in both groups.) Concerns about self-esteem, stigma and the social impact of the disease were strongly associated with depression (Table 5). The four Hansen's patients who identified family conflicts or worry as a cause of their leprosy all met criteria for a depressive disorder, suggesting for some a relationship between the emotional impact of the illness and ideas about its origin (P = 0.01, Fisher’s exact test, two-tailed).

Among the 26% of vitiligo patients and 23% of Hansen’s patients who considered the role of punishment for deeds in a past life (karma) or present life, significantly more met DSM–III–R criteria for a depressive disorder (47%) than those who did not consider these causes (20%) (P = 0.03, Fisher’s exact test, two-tailed). The Hansens and vitiligo

<table>
<thead>
<tr>
<th>Questions in the EMIC</th>
<th>No. (n = 56)</th>
<th>Proportion with diagnosis (%)</th>
<th>P (Fisher’s exact, two-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diminished self-esteem yes</td>
<td>23 (41.1)</td>
<td>0.61</td>
<td>0.0001</td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>4 (7.1)</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>29 (51.8)</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Community stigma yes</td>
<td>31 (55.4)</td>
<td>0.55</td>
<td></td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>8 (14.3)</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>17 (30.4)</td>
<td>0.00</td>
<td>0.002</td>
</tr>
<tr>
<td>Self-stigmatising belief yes</td>
<td>16 (28.6)</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>3 (5.4)</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>37 (66.1)</td>
<td>0.24</td>
<td>0.003</td>
</tr>
<tr>
<td>Adversely affects marriage prospects yes</td>
<td>41 (73.2)</td>
<td>0.44</td>
<td></td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>5 (8.9)</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>10 (17.9)</td>
<td>0.20</td>
<td>0.09</td>
</tr>
<tr>
<td>Adversely affects marital life yes</td>
<td>15 (28.6)</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>9 (16.1)</td>
<td>0.33</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>32 (57.1)</td>
<td>0.22</td>
<td>0.01</td>
</tr>
<tr>
<td>Adversely affects relative’s marriage prospects yes</td>
<td>29 (51.8)</td>
<td>0.48</td>
<td></td>
</tr>
<tr>
<td>possibly/uncertain</td>
<td>7 (12.5)</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>20 (35.7)</td>
<td>0.15</td>
<td>0.06</td>
</tr>
</tbody>
</table>

1. SCID diagnosis of major depression, dysthymia or adjustment disorder with depressed mood or mixed emotional features.
patients whose explanatory models considered karma or punishment also had higher Hamilton depression (mean (s.d.) 15.3 (11.0) v. 7.7 (7.6), \( P = 0.01 \), t-test) and anxiety scores (mean (s.d.) 10.3 (7.7) v. 5.6 (4.6), \( P = 0.02 \), t-test). It is difficult to compare our findings with those from earlier studies (which were on in-patients) because of different standards for psychiatric diagnosis, the effect of institutionalisation, and the good prognosis currently for out-patient treatment with multidrug therapy. Olivier (1987) reported that 20% of Carville’s 330 in-patients had ‘a major psychiatric diagnosis’ based on evaluation only of those referred to the psychiatric clinic. Psychiatric studies of cancer patients, using methods comparable to ours, report similar rates and types of diagnoses: Evans et al (1986) found 23% of women in-patients with gynaecological cancers had DSM–III major depression; the survey of cancer patients reported by Derogatis et al (1983) from a multicentre study found 40% had a DSM–III psychiatric diagnosis in which depression or anxiety were the principal symptoms.

Patients who mentioned psychosocial stressors among the causes of other illnesses we asked about, usually ‘madness’, were more likely to return for our scheduled follow-up session than those who did not (\( P = 0.04 \), Fisher’s exact test, two-tailed). Perhaps because they recognised the power of social stressors and supports, these patients especially valued the support our research interview afforded, as it examined issues that are rarely considered in the routine clinic visit. An association between return for the follow-up research interview and attendance in the Hansen’s clinic was not significant (\( P = 0.18 \), Fisher’s exact test, two-tailed), probably because most subjects in the study sample attended the clinic more regularly than the rest of the clinic population.

Among the patients in the study, 79%, compared with 46% of those beginning treatment in the Hansen’s clinic in 1987 and 1988 who were not in the study (\( n = 704 \)), attended regularly enough to receive an adequate supply of dapsone for each day of the first six months of treatment (\( P<0.0001 \), Fisher’s exact test, two-tailed). Both willingness to participate and experience in the study probably contributed to the strength of this finding.

Discussion

Links between psychiatry and medicine are few and fragile in India and many other developing countries (Bhaskaran, 1990). Wise & Freyberger’s (1983) review of consultation-liaison psychiatry worldwide at the beginning of the last decade all but ignored Asia and Africa. In developing countries there are limited resources for mental health and a dearth of psychiatrists and other mental health professionals to meet demands. Research is also needed to document and clarify the emotional burden of tropical diseases both as a source of distress and as an adverse influence affecting the course of medical illness.

Treating leprosy presents one of the most gratifying clinical opportunities of medical practice. Rarely do patients seek help with lower expectations for a problem that clinicians can treat so effectively. Improving poor compliance is an important objective of leprosy eradication programmes. In our survey of all patients starting treatment in 1987 and 1988, 30% dropped out without completing treatment, and another 11% dropped out for at least two months before returning later to complete treatment. Prospective studies are showing the effectiveness of support groups for cancer patients in the US that improve both outcomes and compliance (Spiegel et al, 1989; Fawzy et al, 1990). Participation in the current study provided patients with a comparable, de facto intervention that improved clinic attendance.

Although more systematic intervention studies are required, our findings indicate that appropriate psychosocial supports may enhance the effectiveness of leprosy eradication and treatment programmes. A study at the Gandhi Memorial Leprosy Foundation in Wardha, India, is currently investigating the value of such psychological support in a health education programme for leprosy patients to improve compliance with medical treatment. Such supports may also benefit other tropical health programmes for diseases in which inter-relationships among stigma, culture and behaviour generate emotional distress and may determine outcome despite the availability of effective biomedical interventions (e.g. in tuberculosis – Murray et al, 1990). At the very least, medical personnel and paraprofessionals who treat leprosy should be trained to recognise and respond to depression and anxiety that may accompany stigmatising illness. Health professionals at every level should be trained to manage the emotional burden of leprosy or to make appropriate referrals, as resources permit.

Our findings highlight the emotional and sociocultural dimensions of stigmatising medical illness, as well as a method for studying them and their significance. Clinically significant depression or anxiety affected nearly half the patients studied with a recent diagnosis of leprosy. Belief in the humoral causation of illness and the support afforded by participation in this study motivated better attendance in the Hansen’s clinic. For this disease, in which cultural meanings and their emotional implications outweigh the burden of somatic symptoms and disability early in its course, findings show the importance of attending to psychosocial aspects of the illness. Health education should convey a positive message about what health professionals believe the disease to be, what causes it, and what to do about it, recognising that gratuitous efforts to ‘debunk’ indigenous humoral theories may be counterproductive.
Improved collaboration in developing countries among colleagues in psychiatry, medicine and the social sciences requires further research that is specific to both culture and tropical diseases. Development of the EMIC provides a needed method for studying cultural features of medical and psychiatric illnesses. It has begun to generate a database of explanatory models that specify cultural norms and intracultural diversity, to test hypotheses relating anthropological data to illness behaviour and clinical outcomes, and to facilitate comparisons in cross-cultural research. Additional experience with the method will further clarify the practical significance of cultural meanings. Findings will enable clinicians to work more effectively with patients' beliefs and to demonstrate the value of a sociocultural formulation for clinical practice in diverse settings.

Appendix

Outline of the Explanatory Model Interview Catalogue (EMIC) for study of leprosy and mental health

(a) Demographic background
(b) Patterns of distress identify subjects' illness-related concerns. The social meanings of the disease are clarified.
(c) Illness-related problems: open-ended and directed queries
   Name of illness, anticipated outcome, most troubling aspect
   Social and economic implications
   Stigma, disclosure and self-esteem
   Marriage prospects and marital relations
   Perceived causes from a patient's point of view, culturally defined properties of foods, morally conceived outcomes of behaviour, religious and magical forces, biomedical pathogens, psychosocial stressors, etc., may contribute to lay explanations of illness. Diverse ideas are not mutually exclusive. The rater records a prose response to the open-ended question about the cause and codes categories according to a list derived from pilot testing. A review of specific categories and details follows.
   Open-ended and directed queries about perceived causes, origins of beliefs and related ideas
   First perceived cause and changes over time
   Most important perceived cause
   (d) Help seeking and treatment elicits a history of help seeking from specific non-professional and professional providers, including various medical services, indigenous practitioners and magico-religious healers. A more detailed inquiry recognises the special significance of providers the subject consulted first, the help considered most important, and the clinic from which the patient was referred into the study.
   Family supports
   Past help seeking according to culturally recognised types
   First help seeking and most important help-seeking details
   Current preferences for help seeking
   Current treatment clinic experience
   (e) General illness beliefs (about other illnesses) clarifies the context of beliefs and practices by examining health problems widely associated with particular cultural explanations. For example, in many parts of India joint pains are popularly attributed to a humoral excess of wind (vāt) or cold (Matthews, 1979), smallpox to a goddess (Mather & John, 1973; Nichols, 1981), and boils and other skin ailments to other magico-religious causes (Skultans, 1987; Stanley, 1988). These associations constitute hypotheses about normative cultural beliefs with both ethnographic and popular support that the EMIC tests in our sample.
   Smallpox, asthma, joint pains, fits and madness; perceived causes, help-seeking preferences, stigma and disclosure
   Relationship between mind and body
   (f) Leprosy-specific queries conclude the interview with questions about leprosy-related perceptions, beliefs, and practices in general, contrasting these with the previous focus on the patient's particular problem.

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THE EMIC AS A CROSS-CULTURAL RESEARCH METHOD


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