

## Culture

# We are "Negative" But We are Not Healed: The Cultural Construction of Leprosy and Gender in Bangladesh

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### Article abstract

In this paper I discuss the ways in which leprosy is culturally constructed in Bangladesh and the ways in which that construction impacts patient experiences of leprosy. Concepts of pollution and purity are strong and leprosy patients are routinely ostracized by their families and communities. As a result patients are reluctant to label themselves and often postpone diagnosis for fear of the social repercussions. Nevertheless, male patients tend to seek treatment earlier in the course of the disease than females do. Women regularly wait until they are severely disabled before seeking treatment. Women in Bangladesh are routinely viewed as unproductive, non-contributing members of the community. Expected to live virtuous, submissive, secluded lives, their behaviour a symbol for family honour and prestige, women with leprosy are often considered as having failed to meet these criteria and, accordingly, are abandoned by their families without recourse and without support. The seclusion of women provides the opportunity and fear the motive for women to hide their disease for the longest possible time. Understanding these behaviours as logical outcomes of the culturally constructed experience of leprosy provides a focus for developing more inclusive treatment and rehabilitation programming and for addressing not only the physical but the social problems associated with leprosy as well.

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# We are "Negative," But We are Not Healed: The Cultural Construction of Leprosy and Gender in Bangladesh

Margot E. Wilson-Moore \*

Dans cet article, j'examine la construction culturelle de la lèpre, et l'effet de cette construction dans la vie des malades atteints de la lèpre. Les notions de pollution et de pureté prennent de l'importance dans ce contexte, et les malades sont, de façon générale, bannis par leurs familles et leurs communautés. En conséquence, les personnes atteintes de la lèpre hésitent à porter l'étiquette et donc retardent le diagnostic à cause des retombées sociales. Cependant, les patients masculins sont portés à se faire traiter plus tôt que les femmes. En règle générale, les femmes attendent d'être sévèrement handicapées avant de se faire traiter. Les femmes du Bangladesh sont généralement perçues comme des êtres non-productifs, qui ne contribuent aucunement à la communauté. On attend d'elles qu'elles soient vertueuses, soumises, et qu'elles restent cloîtrées, leur comportement étant un symbole de l'honneur et du statut de la famille. Les femmes atteintes de la lèpre sont perçues comme ayant échouées vis-à-vis ces attentes et sont souvent abandonnées par leur familles, sans recours et sans soutien financier. La séclusion fournit à ces femmes l'opportunité – et la peur, la motivation – de cacher leur maladie le plus longtemps possible. En voyant dans ces comportements le résultat logique de l'expérience de la construction culturelle de la lèpre, nous trouvons un cadre pour le développement des programmes de traitement et de réadaptation, et pour traiter autant les problèmes physiques que ceux d'ordre social.

*In this paper I discuss the ways in which leprosy is culturally constructed in Bangladesh and the ways in which that construction impacts patient experiences of leprosy. Concepts of pollution and purity are strong and leprosy patients are routinely ostracized by their families and communities. As a result patients are reluctant to label themselves and often post-*

*pone diagnosis for fear of the social repercussions. Nevertheless, male patients tend to seek treatment earlier in the course of the disease than females do. Women regularly wait until they are severely disabled before seeking treatment. Women in Bangladesh are routinely viewed as unproductive, non-contributing members of the community. Expected to live virtuous, submissive, secluded lives, their behaviour a symbol for family honour and prestige, women with leprosy are often considered as having failed to meet these criteria and, accordingly, are abandoned by their families without recourse and without support. The seclusion of women provides the opportunity and fear the motive for women to hide their disease for the longest possible time. Understanding these behaviours as logical outcomes of the culturally constructed experience of leprosy provides a focus for developing more inclusive treatment and rehabilitation programming and for addressing not only the physical but the social problems associated with leprosy as well.*

## IN SHANTIGRAM

"We are negative," the woman said, "but we are not healed. Our lives have no value." We were sitting in a cool spot under the trees in the courtyard formed by the inward facing bamboo huts in Shantigram when Bala said this to me. I first heard about Shantigram from the administrator of the Danish-Bangladesh Leprosy Mission (DBLM). Named "the village of peace," Shantigram is home to some of DBLM's oldest patients, those who received treatment and were released from the programme many years ago. Most residents are disabled and many are severely disfigured. These patients have formed a loose community, making

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their living primarily by begging. They had been squatting in an old building adjacent to the DBLM compound until one night when the police evicted them and partially demolished the building. For a while the people were living under trees, in the fields and on the road sides. When a hail storm injured a number of them, they sought refuge at the DBLM hospital. Subsequently, DBLM donated a plot of land inside the compound and the residents built Shantigram with materials supplied by DBLM.

“Negative” is a technical term used in leprosy treatment to designate a patient whose chemotherapy has successfully killed the leprosy bacillus (*Mycobacterium leprae*). Listed as released from treatment (RFT) in the mission records, these patients are considered to be cured. Used by Bala, however, the term clearly articulated a vague notion which had persistently evaded my conscious grasp. “Take your medicine and *ek dom bhalo hobe* — everything will be OK.” I had heard leprosy caregivers use this phrase during rounds in the hospital wards, in the physiotherapy room, in the rehabilitation training center, in the ulcer clinic, in the shoe shop, and in the village outreach sessions and yet I knew that for many patients everything was not “OK”; in fact, it would never be “OK” again.

Many listed as RFT are unable to return to their families and communities once their treatment is completed. They are barred from public areas, they are denied access to water sources and are prevented from walking on public roads. They cannot attend religious functions or holiday celebrations. They cannot find housing. Shopkeepers will not wait on them and will not take their money. Their children cannot attend local schools. Their siblings and children have trouble finding marriage partners. They are isolated, deserted and ostracized. Thus Bala’s lament cut to the heart of the dilemma which faces leprosy patients and caregivers alike: treating the patient with drugs, physiotherapy and surgery is not sufficient and curing the biomedical aspects of the disease does not ensure that the patient will be able to pick up the threads of his or her life. Healing goes beyond killing the bacillus and repairing the bodies of leprosy patients. It requires a broader focus, one which recognizes the ways in which the leprosy illness experience is culturally constructed and one which accounts for the social impact of that construction on the lives of leprosy patients.

Comprehending the broader task of healing may prove difficult for Western and Western-trained biomedical professionals steeped in the Cartesian mind-body separation; an approach which views the diseased human body as a broken machine. Rothman has discussed the “body-as-machine” metaphor with reference to childbirth, but the metaphor applies equally to leprosy.

The Cartesian model of the body-as-machine operates to make the physician a technician, or mechanic. The body breaks down and needs repair; it can be repaired in the hospital as a car is in the shop; once fixed, a person can be returned to the community. The earliest models in medicine were largely mechanical; later models worked more with chemistry, and newer, more sophisticated medical writing describes computer-like programming, but the basic point remains the same. Problems in the body are technical problems requiring technical solution, whether it is a mechanical repair, a chemical rebalancing, or a “debugging” of the system (Rothman 1982: 34).

The complex pathogenesis of leprosy has long focused the efforts of leprosy researchers on the biomedical aspects of the disease. Today, however, a remedy is available through multidrug therapy although disability is preventable only through early diagnosis and adherence to a lengthy treatment programme (patients require approximately two years of chemotherapy). In addition, physiotherapy and surgery are often required to repair or reverse common physical symptoms of leprosy such as anaesthetic limbs, claw hand, foot drop and lagophthalmia<sup>1</sup>.

In addition to biomedical intervention, successful leprosy programming requires innovative approaches to the culturally constructed problems associated with leprosy. The ways in which families and communities view leprosy patients and the ways patients view themselves have an enormous impact on early diagnosis, treatment-seeking, compliance and patient rehabilitation. Understanding the ways in which patients experience leprosy at first hand and the ways in which families and communities respond to patients diagnosed with leprosy comprise an imperative first step in developing efficacious, and holistic, treatment.

To promote such holistic programmes, I describe the experiences of leprosy patients and offer four case studies which document these experiences in the lives of individuals. Presented as examples of the impact of leprosy on the lives of both male and female patients, these cases speak not only to the issue of how families and communities respond to leprosy patients based on their perceptions of the disease but also how the patients themselves define their illness roles using the same kinds of perceptions. As common perceptions of leprosy dictate the treatment of patients, so too the cultural construction of leprosy informs patient responses to having the disease. I provide evidence of the culturally defined problems which leprosy patients face. I can offer no simple solutions for these problems, for there are none. The problems facing leprosy patients go far beyond the obvious physical symptoms. Successful rehabilitation requires that patients remain integral members of their families and communities. Eradicating the physical disease alone does not ensure rehabilitation, only eradicating culturally constructed prejudices will.

## **SOCIAL DIMENSIONS OF LEPROSY**

Defining disease as a purely biological manifestation sets up a dynamic in which curing delineates control over biological processes often to the complete disregard of the social and personal problems created by and associated with that disease. Today, the curing of disease lays claim to scientific truth, while in reality it represents only the biases and shortcomings of the biomedical paradigm. This is not to deny the efficacy of biomedicine, but rather to suggest that disregarding the social dimensions of disease may preclude an effective cure. In the context of leprosy treatment, an emphasis on understanding and treating the biomedical aspects of the disease has translated into differential emphases in research and treatment. The complexities of finding an efficacious cure for leprosy along with appropriate physiotherapy and surgery has occupied significant proportions of researchers' and caregivers' energies for many years to the detriment (or at least disregard) of the many social and cultural aspects of the disease. Multi-drug therapy now provides a cure for leprosy, however, early intervention and treatment compliance are imperative to effecting that cure. Since such factors as patient decisions about treatment-seeking and adherence to treatment

regimes are largely informed by society's view of the disease, considering leprosy as a culturally constructed illness experience provides an important alternative approach to biomedically focused leprosy programming, an alternative which has been largely neglected to date.

A substantial literature exists on the biomedical aspects of leprosy, much of which contains references to the disfigurement, societal rejection, and stigmatized status of those afflicted with leprosy. Although the stigma of leprosy is often mentioned as though it were a widely known and well understood phenomenon, a review of the literature indicates that it is not. The association between leprosy and social stigma is discussed by Gussow (1971, 1989) and Gussow and Tracy (1970). Kellersberger (1951) and Valencia (1983) have demonstrated the impact of social attitudes on early diagnosis and effective treatment. Nevertheless, in a state-of-the-art lecture presented at the XIII International Leprosy Congress in 1989, Valencia remarked upon the dearth of research which brings a social science perspective to bear on what she calls the "social dimensions of leprosy" (1989: 862).

Notable exceptions to Valencia's observations include the work of Neylan *et al.* (1988) and Waxler (1981). Neylan *et al.* highlight discrepancies in patient and care-giver perceptions of leprosy. They conclude that improved patient compliance in completing chemotherapy programmes and more general success for leprosy control programmes may be largely dependent on improved communication and an appreciation of alternative patient and caregiver explanatory models. Waxler discusses the continuing stigmatization of leprosy and leprosy patients in a cross-cultural context. Her conclusions emphasize the minor role of the leprosy bacillus, the relatively greater importance of the social transformations which accompany the disease, the impact of those transformations on the social career of leprosy patients, and the cross-cultural differences in the ways leprosy is meaningfully constructed. Aside from these studies, however, little has been published regarding the ways in which leprosy is culturally constructed (see Justice 1991 for similar conclusions) and virtually nothing has been published on the impact of leprosy on the lives of patients in Bangladesh. Furthermore, there appear to be few studies which specifically consider gender differences in the social experience of men and women with leprosy although sex differentials in morbidity and treat-

ment have been suggested. Accordingly, this paper considers the ways in which the leprosy illness experience is culturally constructed in Bangladesh and more specifically the differential impact of that experience on male and female patients. I suggest that differences in women's experiences of leprosy (compared to men) are grounded in a more general disregard for women in Bangladesh.

Patients generally postpone seeking treatment until their symptoms can no longer be disguised — many report seeking treatment only after family or community members begin remarking upon their symptoms. Many women, however, seek treatment only after they can no longer fulfil their productive roles in the household. The ostracism of patients is not always a one-sided process, however. Very often patients actively engineer their own withdrawal from society (as in the case of Mohammed Ali below) in a form of self-ostracism following diagnosis. The greatest impact of biomedical advances in the treatment of leprosy will be felt only when early diagnosis and intervention become widespread. Thus, if the ways in which leprosy is culturally constructed discourages patients (especially women) from disclosing their disease until it has reached an advanced stage, then this represents a major obstacle to the success of any treatment.

## RESEARCH METHODS

There are an estimated 136,000 untreated leprosy patients in Bangladesh today. Following WHO policy recommendations, a country-wide programme has been implemented to eradicate leprosy by the year 2000 (personal communication, J. H. Richardus, Country Director, The Leprosy Mission, Bangladesh). DBLM has been treating leprosy patients in northwest Bangladesh since 1976 and has registered some 20,000 patients in their catchment area. The research presented here is part of an ongoing study which considers the social and cultural context of leprosy. It complements other research at DBLM which includes an epidemiological study of disability and its treatment in field situations.

My association with DBLM dates from 1988 when I was conducting other research in a village near to Thakurgaon and began visiting in the mission hospital there. A formal research project was established in 1991<sup>2</sup>. Participant observation has

been ongoing in the mission hospitals in Nilphamari and Thakurgaon since that time but was concentrated primarily in the summers of 1992 and 1993 (four to six weeks each year). I directed a series of four workshops intended to reinforce the collaborative aspect of the research: the first was a planning workshop at which the issues of greatest interest to DBLM were determined; the second was a training workshop at which I trained DBLM leprosy workers in ethnographic interviewing techniques and field tested the questionnaire; the third was a debriefing workshop at which the DBLM interviewers discussed the interviewing process once the data collection was complete; and the fourth was a results workshop at which I presented preliminary results and discussed possible interpretations with the DBLM interviewers. Over a three month period, two hundred interviews were conducted by DBLM interviewers and the figures presented here are based on a preliminary analysis of seventy-nine of these interviews<sup>3</sup>. The questions were open-ended and not all questions applied to all patients. As a result, the patient responses are given here as a proportion of the total responses of all patients answering that particular question. The interviews took from forty-five to ninety minutes to administer and addressed such issues as: the patients' knowledge of leprosy and treatment seeking history; the patients' attitude toward the disease, at first diagnosis and at present; the nature of problems experienced in his or her personal, family, work, religious, or community life; the attitudes and behaviours of his or her family following diagnosis; and the attitudes and behaviours of his or her community. I also conducted informal interviews with the field director, training officer, administrator, doctors, head nurse, physiotherapists, rehabilitation officers as well as field workers, staff nurses, and patients during five separate field trips to DBLM between 1992 and 1994 (a total of twelve weeks).

In response to the final interview question, "Are there any other things that I need to know but have not asked?" a number of patients spontaneously gave short life histories. The spontaneity of the telling of these life histories and the willingness of patients to discuss the details suggest that patients need to express themselves and discuss their experiences openly in a "safe" context. DBLM found these outpourings difficult to hear, especially in the face of such sorrow, despair and frequent tears. Usually cast in the role of care provider or "doctor," DBLM personnel are more familiar (and

comfortable) with a top down communication style. This presented a challenge in the training workshop where DBLM interviewers had to learn to receive, rather than give, information. In the interview situation, it was equally difficult for the interviewers to relinquish control of the conversation and allow the patients to speak. Nevertheless, in the debriefing workshop (and informally since), those interviewers who successfully created a rapport with the patients report that patient-staff communications are much freer and patients continue to spontaneously offer information about their treatment and their personal experiences with leprosy. This somewhat unexpected side-effect of the interviewing process deserves additional research attention.

Although the four case studies presented below are taken from my own interviews with patients at the DBLM hospital, they resemble the life histories in that they were told to me in Bangla by the patients in the same spontaneous way. They reveal common patient experiences with leprosy and demonstrate many more general themes emerging from the interview data. I refer to them as case studies because I originally wrote them in my field notes in the third person and, thus, they cannot be presented as patient narratives. Nevertheless, I have tried to translate them and reproduce the details as closely as possible to the way in which they were told to me by the patients<sup>4</sup>. I have tried to retain the distinctive "character" of the conversations and to distinguish my own perspectives from those of the patients wherever possible. I chose these four as they provide individual faces for leprosy patients and a context in which to view the leprosy experience as it is culturally constructed in Bangladesh. The need to hide the widely-recognized signs of leprosy or to beg for a living, the isolation, social "hatred," fear of deformity, shame, self-stigmatization, thoughts of suicide, concerns for the future and marital problems are all common themes found in the patient interviews and highlighted in the cases which follow. The ostracism of patients from their families and communities and the reciprocal problems of reintegrating them into the greater community following treatment are confounded by the ways in which leprosy is perceived by members of the wider community and by the leprosy patients themselves. Thus, the data discussed here are intended to bring an anthropological perspective to bear on the way leprosy is culturally constructed in Bangladesh. My conclusions call for a broad-

er approach to treatment which incorporates the important, and until recently largely ignored, social dimensions of leprosy.

## CASE STUDIES

### Bala

Bala is thirty years old and she lives in Shantigram. She is "negative" now, but her experience with leprosy has been a difficult one. When it was first discovered that she had leprosy, her husband divorced her and sent her away. He refused to let her see their two children again. She came to the DBLM hospital when people in her father's community began complaining that they were having problems arranging marriages for their children because she was living in her parent's home. She had completed her course of treatment and since she could not return home to her family, the hospital staff arranged a second marriage for her with another patient. Her new husband is also "negative," but badly deformed. He makes his living by begging in the nearby town and she takes care of the house and their two children. Bala says that she is "settled" now but that sometimes people "hate" them and tell them to "stay away." Sometimes in the market, vendors refuse to sell things to her and her husband cannot go to the mosque. She is sorry that her husband has to beg in the street but people will not give them work. They are managing their own lives, they pray on their own, send their children to the DBLM school and arrange marriages for their children among themselves. Bala feels that the problems of leprosy patients will be solved when the "old" people die because the deformities will die with them.

### Nani

No one knows what her real name is. Everyone just calls her Nani (grandmother). She is an elderly woman who has had leprosy for many years but is "negative" now. Nani was pregnant with her second child when she was diagnosed as having leprosy. It was cold and she was sitting near the fire to keep warm. It seems likely that her arms and legs were already largely anaesthetic, for when she fell asleep, she fell into the fire and burned large portions of her body quite badly. Her family took her to the hospital and after her burns had healed, they sent her to DBLM. She claims that this happened about twelve years ago and

although she claims that her son was only a child at the time, he is now a grown man in his late twenties or early thirties. She has no legs: one leg was amputated twice, first below and then above the knee; her "good" leg was subsequently amputated when she fell in the shower and fractured it. She has no fingers and virtually no teeth either. Nevertheless, whenever I see Nani in the hospital, she is standing in a crowd (on her two artificial limbs) making jokes and laughing. Until recently, Nani understood that she would remain at the hospital until she died. About a year ago, however, the hospital staff decided to rehabilitate her and sent her to live with her son in the village. Apparently her son was happy to have her but Nani tells about a big fight between her son and his brother-in-law about Nani living there. Now the two families are living separately. Nani returned to the hospital because she developed some ulcers under one of her artificial limbs. Now she says that she will stay at DBLM until after the rainy season and then go to live in a small house which DBLM should build for her on the land left to her by her father. Apparently, her husband is dead, as are her parents. I wonder how she will manage on her own.

### **Mohammed Ali**

Mohammed Ali is a young man approximately thirty years of age who comes from the southern part of the country. He is different from many of the other patients in that he is well-educated and interested in learning as much as possible about leprosy. In fact, he has asked the physiotherapist to provide him with books so that he can read more about leprosy. His physical symptoms are minimal and he has no visible disabilities at the present time. He first went to the doctor because of a white patch on his face. The doctor did not know what he had — perhaps a fungus infection, he suggested. Then Mohammed Ali went to another doctor who told him that he had leprosy. He came to DBLM with a doctor's referral letter and has been responding well to both chemo- and physiotherapy. The staff are hopeful that he will regain the feeling in his foot which is anaesthetic at the present time. His family do not know that he has leprosy. He has told them that he is being treated for a skin infection. Mohammed Ali says that when he was first diagnosed, he felt that "if this is leprosy and if it is not curable, then I will commit suicide." His attitude has changed immensely since then and he is expressing an interest in working for the leprosy hospital when his treatment is finished.

### **Shakim Uddin**

Shakim Uddin is a twenty-five year old man who lived in a village close to the DBLM hospital. He developed leprosy as a child when three white patches developed on his back. By pinching them, his father discovered that the patches were anaesthetic and brought him to DBLM for treatment. Although he completed his course of treatment, the villagers treated him badly and requested that he leave the village. He was not allowed to pray at the mosque. He had nowhere to go and was sleeping secretly on the veranda of the local primary school. One morning, it was raining heavily and he was wondering where he could take shelter. Some people saw him at the school and came with sticks and beat him severely. He feels that his future is very uncertain and that his life has no value.

## **THE CULTURAL CONSTRUCTION OF LEPROSY**

These case studies provide insights into individual illness experiences of leprosy. Their value lies not only in the detailing of similarities and differences of individual stories, but also in their ability to illustrate the ways in which the leprosy experience is culturally shaped. All four stories demonstrate the isolation of patients and their segregation within or ostracism from family and community. Of the patients interviewed, 89% reported that isolation and social segregation was a problem for them. Social isolation includes physical segregation, being told not to come near to others, inability to attend social and/or religious programmes and being prevented from playing with the neighbours' children<sup>5</sup>. It also includes abandonment or desertion by husband and family, divorce, being told to leave the family, being denied access to the patient's own children and food problems such as refusing to eat with the patient or to eat food cooked by the patient and being denied access to the water supply.

Mohammed Ali instigated his own separation explaining that by withdrawing he was "protecting the honour and safety of his family," ensuring their ability to remain in the community. This is a common response; 23% of the patients interviewed reported that they had voluntarily withdrawn from their families and communities and were now living in self-imposed isolation.

Shakim Uddin, on the other hand, was driven out of the community and expresses grave concern for his future and the welfare of all leprosy patients if societal attitudes don't change. Bala was divorced by her first husband and separated from her children immediately following diagnosis. Of twenty-five female patients interviewed, 64% reported that they were separated, divorced or still unmarried as a direct result of having leprosy. As a result of her divorce and extreme social prejudice, Bala, her second husband and eleven other families have established their own community (Shantigram) which insulates them from the "hatred" of the larger society. Social prejudice is expressed in many ways; by refusing to allow the patient into shops, refusing to take the patient's money, being afraid to touch or be near the patient, saying "bad" words to the patient, and the inability of patients to find housing or to marry except among themselves. When asked to propose solutions to their problems, 29% of the patients interviewed answered that they believed public education, especially of their family members, would help reduce social prejudice. Nani, in contrast to Bala, may have fared better. She retains ties with her children although there appears to be considerable tension in the family<sup>6</sup>.

Mohammed Ali's contemplated suicide clearly expresses the desperation felt by many patients faced with a diagnosis of leprosy. When asked what they thought when they first learned that they had leprosy, 22% of the patients interviewed reported that they contemplated suicide. Bala has similarly suggested that the social problems of leprosy will die out only when the badly deformed patients die and when early diagnosis and intervention prevent disfigurement. Even after receiving treatment from DBLM, 6% of the patients interviewed still report that death is the only solution which they can envision. The case studies of Bala, Nani, Mohammed Ali and Shakim Uddin are but small pieces of the larger fabric of leprosy experience in Bangladesh and worldwide. Nevertheless, the insights they allow into the illness experiences of leprosy patients provide a focus for considering the impact of culturally constructed perceptions, understandings and appraisals of the disease.

## A GENDERED ANALYSIS OF LEPROSY

Clear differentials exist between male and female patients with reference to their possible susceptibility to leprosy, their treatment seeking behaviour, and the degree to which the disease has incapacitated them prior to seeking treatment. For example, male patients are represented in a 2:1 ratio over female patients in DBLM patient registrations, hospital admissions and outreach clinics. A similar ratio of male to female patients (44:17) has been demonstrated in a study in Thailand where Neylan *et al.* (1988) attribute it to differential male morbidity in leprosy, a factor further exacerbated in Bangladesh by an already existing imbalance in the overall sex ratio (125 males to 100 females)(Statistical Yearbook of Bangladesh, 1991). Imbalanced sex ratios are common throughout South Asia and have been discussed by Miller (1981, 1983) as indicative of pervasive negative attitudes toward women, who often suffer neglect at the hands of their families as children because they are less valued than their male siblings. In the case of female leprosy patients, these negative attitudes licence husbands and families to abandon women once the leprosy diagnosis is confirmed.

Miller has explained imbalanced sex ratios as they relate to women's economic importance, their productive activities in the subsistence sphere, and marital patterns especially the custom of dowry. As women's economic contributions increase, so to will their status in the family. Dowry payments will be lower and the sex ratio more equal. Miller (1983) has suggested that women's economic roles were always more valued in Bangladesh than in either Pakistan or northern India. Certainly women are more active in post-harvest processing of field crops in eastern India and Bangladesh where wet rice agriculture and jute production are the primary subsistence activities. Recently, argues Miller, changes in the valuation of women's productive roles and in the size of dowry payments in Bangladesh indicate a trend toward the patterns of northeast India where women are more secluded, dependent, and far less active in the subsistence sphere. My own research in a rural Bangladeshi village (Wilson-Moore 1989, 1990) indicates that women's productive roles are restricted to the household and devalued as a result. Dowry costs are prohibitively high, and the sex ratio remains disproportionate.



Neylan et al. further suggest that the 2:1 male to female ratio among leprosy patients in Thailand reflects a "tendency for males to be more likely to enter medical institutions for leprosy treatment" (1988:232). Admission records from general health care facilities in Bangladesh substantiate this claim and D'Souza and Chen (1980) have shown that "higher mortality rates are registered for females than males at each age category" (1980: 261). Akhter (1985) and Islam (1985) confirm these findings and suggest that early age of pregnancy and multiple births combined with reduced caloric intake account primarily for differential mortality and morbidity rates between men and women in Bangladesh. Other contemporary issues, such as the use of amniocenteses for prenatal sex identification and the procuring of sex specific abortions for female fetuses indicate a general devaluing of women in South Asia, as do the continuing (although illegal) acceptance of dowries and the escalating incidence of dowry deaths (Bumiller 1990). A number of studies addressing gender issues in Bangladesh exist (cf. Aziz and Maloney, 198; Chaudhury and Ahmed, 1980; Kafi, 1992; Khan, 1991; White, 1992, among others), however none provide a gendered analysis of leprosy. Similarly, aside from Neylan *et al*, few other studies of leprosy address gender differentials in treatment seeking or morbidity.

In the case of leprosy, males tend to seek treatment much earlier in the course of the disease (often at the first onset of symptoms) while females regularly wait until they are severely disabled before they present themselves for treatment. A disability score was calculated for interviewed leprosy patients based on self-reported disabilities. A significantly greater proportion of female patients reported having two or more disabilities ( $p=.0206$ ) and a significantly lower proportion reported hav-

ing no disability ( $p=.0892$ ) compared to males in the sample.

Similarly familial responses to the diagnosis of leprosy differs for male and female patients. Table 1 presents a comparison of these responses as reported by the patients.

Of fifty-four male patients, forty-two (78%) reported having no problem with their family members following diagnosis. It is difficult to interpret this response as patients of both sexes with no or few visible symptoms successfully hide their disease (60% report hiding in the past and 16% continue to hide at the present time). In cases where other family members are also leprosy patients there are few behavioural problems reported. This is an area of research which would benefit from additional consideration. Nevertheless, that 78% of all male patients compared to only 36% of female patients report having no problems suggests differential familial behaviours associated with the gender of the patient. Since 80% of female patients in the sample are married, patrilocality residence patterns undoubtedly play an important role in familial problems. An additional eight males (15%) are still living as an integral part of their family despite some tension within the family. None report being separated from their family. Only one man had divorced but this, he reported, was of his own volition — another example of self-imposed isolation. Three elderly male patients report having no family. That no women make this claim suggests that women may be more closely embedded in their families. Alternatively, women may be unable or unwilling to live completely independently regardless of how uncomfortable the situation in the family may be. In this sense, men without families (6%) may be the reciprocal of women remaining with their families but living

Table 1  
*Comparison of responses of families*

	Male patients		Female patients	
No problem	42	78%	9	36%
Problems but still with family	8	15%	2	8%
Problems and separated from family	0		6	24%
No family	3	6%	0	
Divorced	1	2%	4	16%
Other marital problems			4	16%
TOTAL	54		25	

separately (24%). These proportions reinforce the argument that women are more susceptible to ostracism than are men.

Only nine of twenty-five female patients (36%) report experiencing no problems in the family and two others (8%) report that although there is considerable tension, they are continuing to live with their families. One woman reports that her husband beats her regularly and tells her to go away, but she does not because she cannot bear to leave her young child. Another woman, presently an in-patient in the hospital, reports that her family has threatened that they "cannot keep her" and she fears what will happen when she is discharged. Twenty-four percent of all female respondents report that although they remain physically in the family compound, they are living separately from their spouses and families. In the case of one patient, a young girl under the age of 10, she has been isolated in a hut by herself and is restricted from joining in any family activities. She receives only that food which is sent to her. In another case, the husband has given the patient an ultimatum of a cure in three months or a divorce. Sixteen percent of the female respondents have been divorced by their husbands due to leprosy and an additional 16% are having other marital problems. In two cases, young unmarried women have been unable to find marriage partners despite the offer of substantial dowries. In another, a young girl and her mother were abandoned by her father once he learned she had leprosy.

## GENERAL PERSPECTIVES ON WOMEN AND LEPROSY

In Bangladesh, women are generally viewed as unproductive, non-contributing members of the community — in essence, depleters of family resources. Through dowries, arranged marriages, and seclusion, men take charge of women first in their relations to them as fathers and brothers and later as husbands and fathers-in-law<sup>7</sup>. Thus, I argue that the differential treatment-seeking behaviour of men and women is based not only in cultural beliefs about leprosy, but also in more general cultural attitudes toward and perceptions of women and men.

Bangladesh is a predominantly Muslim country (85% of the population) where men are permitted to have up to four wives and to remarry when widowed. Women, by contrast, are expected to be

virtuous, submissive and monogamous, even when widowed. These expectations have become institutionalized in the custom of "purdah." A Persian word, "purdah" translates as "curtain," "veil," or "barrier" and is ostensibly intended to protect women. In essence, however, "purdah" dictates a circumscribed existence for women, secludes them within the household, negates their productive roles and emphasizes their reproductive capacities. Chastity and a virtuous demeanor become primary components of a woman's worth and her proper conduct within the constraints of "purdah" symbolize the honour and prestige of the family. Women who fail to meet these criteria may be routinely and unceremoniously abandoned by their husbands and/or families, without recourse and without support. That married women live in the households of their husband's family further complicates the issue as they are perceived as perpetual strangers and their only avenue to acceptance lies in producing male heirs early and often. Although the term "purdah" is most appropriately applied to Muslim women, these same expectations apply no less rigidly to Hindu or Christian women in Bangladesh.

Concepts of pollution and purity are strong in Bangladesh, as they are throughout South Asia. Pollution is contagious, radiating out from the source to anyone in close physical or kinship proximity. Leprosy is viewed as not only biologically contagious but as ritually polluting as well. Leprosy patients pose a grave threat to the symbolic purity (and honour) of their families and members of their households. Thus the expulsion of leprosy patients from family and community becomes an imperative for protecting family (and community) honour. The difficulties faced by the families of known leprosy patients underscore the force of this mandate. Often the whole family will be ostracized by the community. Patients speak openly of problems finding spouses for themselves, their siblings, and their children; of being denied access to their usual place of worship; of their children being expelled from school; of people refusing to speak to them or come near them; of difficulties in finding work, food and shelter; and of the "hatred" expressed by other members of the community.

These circumstances speak directly to the issue of leprosy and women's treatment-seeking behaviours. Women are provided not only with the opportunity (through "purdah" and seclusion) but also with a strong motive for hiding their dis-

ease. Women with leprosy will "cover up" both literally and figuratively until they can no longer perform any of their household duties for fear that when they are discovered to have leprosy, they will be driven out. Banished when they can no longer hide their disease, they become disposable and are relegated to the roadside to beg or, perhaps, to the leprosy clinic. The present analysis indicates no significant differences in the experience of leprosy for Muslim, Christian or Hindu women.

Traditionally all leprosy sufferers were ostracized regardless of gender. For women, however, leprosy elicits paired fears; first, the horror of the disease itself and the ostracism it precipitates, and secondly the dread of being expelled into the hostile outside world of which they possess little or no knowledge and even fewer coping skills. Using "purdah" and seclusion to their advantage, then, women hide their disease for as long as possible, despite the negative impact this behaviour may have on their prognosis.

For men, on the other hand, leprosy interferes with their ability to fulfil their roles in society much earlier in the course of the disease. Men must walk to their fields and to the market; they are more centrally placed in the public sphere. Thus, men may be prevented from hiding their illness for a longer period (as women do). They may also experience less impetus to hide their disease. Men with leprosy routinely remain married to their healthy (i.e. non-leprosy) wives, contract marriages after they develop the disease, and remarry after the death of their spouse often with healthy women. Women, on the other hand, are routinely separated from or divorced by their husbands following diagnosis and rarely remarry and then only to another leprosy patient. The inequality of divorce legislation in Bangladesh, and the ease with which a man can divorce his wife under normal circumstances is exacerbated by the presence of leprosy. Women are extremely dependent upon their husbands and cannot simply leave — there is nowhere to go and few alternatives for supporting themselves independently. Only women with the backing of a powerful natal family can negotiate a divorce through the courts (see Sobhan, 1978 for a discussion of women's legal rights in Bangladesh). Few of this type of woman are present among DBLM patients since women with substantial financial resources and family support are more likely and more able to seek treatment privately.

This is not to say men are not stigmatized by having leprosy — for they are — only that leprosy appears to have a less severe social impact on men than on women. Furthermore, increased mobility of men in the public sphere may provide an opportunity for men to seek treatment in a location distant from their home where, like Mohammed Ali, they can remain anonymous and protect the honour and reputation of themselves, their families and their communities. This option is not open to women. Caught on the horns of a dilemma, women fear diagnosis and disclosure of their illness and thus precipitate severe disabilities on themselves. These in turn contribute substantially to, if not guarantee, their ostracism and abandonment.

## DISCUSSION AND CONCLUSION

The illness experience of leprosy reinforces and is reinforced by existing cultural attitudes and perceptions of the disease process. The tenacity of culturally constructed responses to leprosy, despite constitutional guarantees of equal treatment of all people under the law, challenges the efficacy of biomedical treatment in Bangladesh today. This is especially true in the case of female leprosy patients. For if healthy women are devalued, women with leprosy become valueless and if women are the property of men, women with leprosy become disposable property. Patrilocality, residence patterns and traditionally antagonistic relationships between daughters-in-law and mothers-in-law and among sisters-in-law also thwart female solidarity and amplify the isolation of female leprosy patients. Under these circumstances, it is not difficult to understand why women routinely choose to conceal their disease despite the risk of severe deformity and disability inherent in postponing diagnosis and treatment.

Understanding the motivations which lie behind differential treatment-seeking behaviours represents an important first step in planning and implementing effective diagnostic and treatment programmes. Research is ongoing at the DBLM. Documentation of the ways in which leprosy is culturally constructed in Bangladesh will address such issues as patient's understanding of and attitudes toward leprosy, patient's perceptions of diagnosis and medical treatment and patient experiences within their families and communities following diagnosis and treatment. The involvement of DBLM medical care-givers, leprosy control offi-

cers, and rehabilitation workers in the interviewing, data analysis and interpretation has sensitized them to the ways in which leprosy is culturally constructed and how those constructions affect patient behaviours, decision-making, and adherence to treatment regimes. Of immediate relevance to DBLM, these findings will be used to redirect and/or strengthen existing components of the programme and to innovate new ways of addressing the culturally constructed problems facing leprosy patients. Similarly, rehabilitation takes on a broader connotation in the context of these findings and planning for a community based rehabilitation programme based on the results from this study and from an epidemiological study of disability will begin in the next year. The results also have broader relevance for other leprosy treatment programmes in Bangladesh and provide a format for leprosy missions in other countries interested in understanding the cultural construction of leprosy and the impact of those constructions on treatment and patient behaviours.

## NOTES

1. Loss of sensation in the extremities along with anaesthetic patches on various parts of the body are common first signs of leprosy; claw hand is a deformity resulting from atrophy of the interosseous muscles with hyperextension at the metacarpophalangeal joints and flexion at the interphalangeal joints; foot drop is paralysis of the dorsiflexor muscles of the foot and ankle as a consequence of which the foot falls, the toes dragging on the ground in walking; lagophthalmia is the failure of the upper eye lid to move down when the patient is asked to close his [her] eyes.
2. Preliminary funding for this research comes from the University of Victoria's Centre for Asia-Pacific Initiatives.
3. Data input of the 200 interviews is nearing completion and analysis of the full sample is expected to begin in August 1995.
4. The names of the patients and all identifying details have been changed or omitted to provide anonymity.
5. It is important to remember that leprosy is also a disease of children. Seven percent of the DBLM patient population are under the age of fourteen years.
6. It is an unusual household in Bangladesh which contains two brothers-in-law. The traditional pattern is for women to move to the household of their husband following marriage. Extended fami-

lies normally consist of brothers living together with their wives and children. That Nani's son is sharing a household with his wife's elder brother (*bar giri*) indicates that their household does not follow the traditional pattern. The relationship between a husband and his wife's brother is one of respect, thus Nani's son occupies the tenuous position of sister's husband (*dula bhai*) in his brother-in-law's household. This places him in a rather awkward position for bringing his mother to stay with them (especially given her diagnosis) and may explain the separation of their households.

7. Research from elsewhere in South Asia suggests that while some women accept the dominant culture (cf. Bumiller, 1990; Jeffrey, 1979), others contest it (cf. Bennett, 1983; Liddel and Joshi, 1985; Raheja and Gold, 1994; *Manushi: A Journal about Women and Society 1979-1995*). This is true to some extent in Bangladesh where *Nari Pokho*, Women for Women and other feminist groups are active; nevertheless, members of these groups tend to be wealthy middle and upper class urban women. Poor rural women, on the other hand, tend to remain embedded in more traditional expectations for their behaviour.

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