Introduction

Leprosy is a disease that has been characterized for centuries by immense social stigma. Given the fact that stigmatization occurs for both males and females affected by leprosy, a number of interesting questions arise. Does stigmatization tend to equalize status differentials between men and women, as both may become outcasts from “normal” society? Or does the lower social status of females, typical of many cultures, result in greater suffering for women? And to what extent do status differences between men and women contribute to differentials in the detection and treatment of the disease?

This article presents evidence from two states of India, Bihar and Maharashtra, on the process of “dehabilitation” (leaving or being sent away from home because of leprosy) among male and female leprosy patients, and suggests gender-sensitive interventions to address existing problems in leprosy control. While the study investigated a wide range of gender differences in the impact of leprosy, this article focuses on only two – marriage and family reactions.

Gender differences in the impact of leprosy: evidence from previous research

Leprosy is often reported to be more prevalent among men than women, at least in its clinical forms, at a ratio of about 2:1 (1, 2). However, similar prevalence rates have been found in some areas of Africa (2, 3), and in a survey of two slum areas in Bangalore, India (4), Marshall et al. found similar numbers of males and females with leprosy. Women appear to develop stronger immunological responses to M. leprae which are observed during puberty, in association with increasing estrogen and other hormone levels (1). During pregnancy, however, these responses may be weakened, with severe consequences for the progression of the disease (5). While the incidence of leprosy in infants is rare, congenital transmission of the infection to the fetus appears to be possible (1).

It has been observed that leprosy services fail to take account of the special needs of women, perhaps because such services are often vertically orientated. For example, leprosy personnel may not counsel pregnant women or those of child-bearing ages about their risks. As Duncan (5) points out:

...physicians, who – being leprocentric and not obstetrically orientated – do not notice the bump in the abdomen, the neonate in a shawl on its mother’s back, or that a young child is carrying the baby that cannot be held by the mother because of her “rheumatism” and (silent) neuritis; nor do they think to ask the date of the last menstrual period, or last delivery as a matter of course, let alone to take an obstetric history. It is worth pointing out that it is for lack of these very observations that retrospective reviews of patients’ records regarding the effect of pregnancy on leprosy are so totally misleading...

Similarly, women are frequently not told about the side effects of the drugs they are given for leprosy treatment. In Karachi, Pakistan, for example, Mull et al. (6) noted that women were not forewarned that one of the drugs in a multi-drug therapy regimen (MDT), clofazimine, causes noticeable dark stains, especially in the area of leprosy lesions.

Empirical evidence of gender differences in the social and personal impact of leprosy is scarce and inconclusive. Naik et al. (7), in a study of female leprosy patients at leprosy centres in Goa and Bombay, found that around one-fifth acknowledged that they had experienced domestic problems when the disease was first diagnosed. However, they said that these “initial disturbances” had been resolved and that they were satisfactorily settled in their families. It is not clear, however, whether these patients were resettled in their original families or had formed new unions.

Mull et al. (6) highlighted several gender differences with respect to treatment among leprosy patients in Karachi. They noted a much higher proportion of men (62%) than women (38%) among patients at the leprosy centre at which the survey was based. They observed that this imbalance may have been due partly to the practice of purdah in the area and the lack of female health workers,
which may have prevented some women from visiting the centre. Also, a significantly higher proportion of females were suffering from tuberculoid leprosy, the milder form of the disease resulting from a powerful cell-mediated immune response to the infection, whereas more males suffered from the more severe, lepromatous type. Once diagnosed, females were more compliant with treatment than males, possibly because women were socialized to conform to prescribed behaviour.

Although the Karachi study does not examine differences in stigma by sex, the cases of severe suffering cited are mainly female, indicating, perhaps, that leprosy has more dramatic personal consequences for women. For example, several women who were abandoned by their husbands said that their children were taken away from them; another had been sent to live in a cave; and others had problems marrying because a male relative was known to have leprosy. Interestingly, leprosy was widely considered to be caused by having intercourse with a "bad" woman or with a menstruating woman.

**Data and methods**

A questionnaire survey of 2,495 respondents from Bihar (46% of the sample) and Maharashtra (54% of the sample) was conducted. The sample consisted of 934 non-dehabilitated patients, i.e., those who were taking treatment, staying in their own families and continuing to live relatively normal lives; 1,071 dehabilitated patients, i.e., those who had to leave their family, community or job (or, in most instances, all of these) due to leprosy; 100 rehabilitated patients, i.e., those who were once dehabilitated but had been integrated into their previous social milieu; 300 members of the families of non-dehabilitated patients; and 90 health workers who were treating these patients. Of the non-dehabilitated sample, 59% were male and 41% female; while in the dehabilitated sample, 63% were male and 37% female. Among the rehabilitated sample, 55% were male and 45% female. The structured questionnaires were supplemented by in-depth interviews and 25 case studies (13 males and 12 females).

**Findings**

In Maharashtra and Bihar, the male:female ratio was similar to those reported elsewhere: 1.7:1. These samples were taken from registered leprosy cases rather than from a population survey. It is likely that some cases remained undetected due to the absence of regular and close surveillance, on the one hand, and the tendency to hide the disease on the other. This was also evident from the fact that as many as 10% of women in leprosy colonies were not taking any treatment although they were aware that they were suffering from leprosy. These women were not reflected in any register. One possible explanation for the lower number of women on leprosy registers is that women may be more compliant and finish treatment more quickly than men, hence being removed from registers earlier (V. Pannikar, personal communication, 1993).

**Gender differences in family reaction**

In the non-dehabilitated group, the majority of patients, upon learning their diagnosis, had discussed it with their families. However, the proportion of those who shared this information was higher among females (85%) than males (76%). Status within the household was an important determinant of whether or not a person was dehabilitated. The large majority (72%) of non-dehabilitated males were heads of household, compared to only 39% of the dehabilitated; among females the proportions were 15% and 11%, respectively. Male household heads thus wielded sufficient power to maintain their position in the family despite their affliction. Women, few of whom were heads of the family, suffered an additional disadvantage by virtue of their inferior status.

**Table 1**

Reaction of spouse and sex of dehabilitated and non-dehabilitated leprosy patients: percentage distributions

<table>
<thead>
<tr>
<th>Reaction of spouse – Réaction du conjoint</th>
<th>Dehabilitated – Exclu de chez soi</th>
<th>Non-dehabilitated – Non-exclu de chez soi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive – Positif</td>
<td>M 19 F 7</td>
<td>M 32 F 18</td>
</tr>
<tr>
<td>Negative – Négatif</td>
<td>M 81 F 93</td>
<td>M 68 F 82</td>
</tr>
<tr>
<td>Total – Total</td>
<td>M 677 F 394</td>
<td>M 552 F 382</td>
</tr>
<tr>
<td>( \chi^2 )</td>
<td>29.30, p&lt;.00001</td>
<td>22.29, p&lt;.00001</td>
</tr>
</tbody>
</table>

*Wild hth statist. quart., 49 (1996)*
Table 2
Isolation of patient in selected activities and sex of dehabilitated leprosy patients: percentage distributions

<table>
<thead>
<tr>
<th>Activities – Activités</th>
<th>Dehabilitated - Exclus</th>
<th>M</th>
<th>F</th>
<th>x²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sitting – S’asseoir</td>
<td>22</td>
<td>37</td>
<td>27.98</td>
<td>p&lt;.00001</td>
<td></td>
</tr>
<tr>
<td>Eating – Manger</td>
<td>18</td>
<td>39</td>
<td>57.47</td>
<td>p&lt;.00001</td>
<td></td>
</tr>
<tr>
<td>Shares sleeping quarters – Partager les dortoirs</td>
<td>20</td>
<td>30</td>
<td>13.83</td>
<td>p&lt;.01</td>
<td></td>
</tr>
<tr>
<td>Fetching water – Aller chercher de l’eau</td>
<td>15</td>
<td>38</td>
<td>18.94</td>
<td>p&lt;.00001</td>
<td></td>
</tr>
<tr>
<td>Physical contact (Touch) – Contact physique (toucher)</td>
<td>15</td>
<td>25</td>
<td>16.83</td>
<td>p&lt;.00001</td>
<td></td>
</tr>
<tr>
<td>Physical contact (Sex) – Contact physique (rapports sexuels)</td>
<td>9</td>
<td>24</td>
<td>31.83</td>
<td>p&lt;.00001</td>
<td></td>
</tr>
</tbody>
</table>

The degree to which leprosy patients in the dehabilitated sample were isolated from family activities is shown in Table 2. While isolation was not widely admitted by either males or females, women were isolated more often from all activities. Women said that when they were restrained from their roles of cooking and caring for children they felt redundant in the family and decided to leave.

For women, the most difficult adjustment was refraining from touching others, especially their children. Women are accustomed to receiving reinforcement for their caring role by the freedom to touch and be touched. When afflicted by leprosy, patients were frequently forbidden, or themselves declined, from touching others, for fear of contaminating them. It was touch, more than anything, that women longed for, and the loss of this intimate female right symbolized isolation and rejection.

For leprosy patients, one of the most telling signs of rejection was indifference of others towards them. Patients who remained in their families frequently complained of this failure to acknowledge their presence, symbolizing their loss of significance to others. One woman said she had been served food in a dog’s dish. Another said that she would have preferred her husband to beat her because such a strong reaction would have proved that he had some feelings towards her. Indifference, by contrast, was “worse than anything”. Several women said that their husbands entered into extramarital relationships after learning of their wives’ illness, but said nothing about it, their indifference sufficing to keep their partners silent and subdued. When they finally announced that they wanted a divorce, the wives had neither energy nor power to protest. In the non-dehabilitated sample, exclusion from family and community events was uncommon (less than 20% of the time for most activities) but again, women were more often excluded than men.

Table 3 gives a summary of the critical factors that influenced the decision of dehabilitated patients to leave home. Women admitted to having experienced pressure to leave more frequently than males: 68% of the males said that they themselves had made the decision to go, compared to only 49% of females. Also, 15% of the men said that they had been advised not to leave their homes, compared to only 10% of the women.

Understandably, respondents were unwilling to discuss their innermost feelings, particularly those relating to hurtful events such as leaving home, with interviewers. In the in-depth interviews, however, bittersweet memories revealed the depth of the hurt experienced. For example, one woman recalled the joy that everyone in the family once shared in the celebration of the festival of lights, Divali. But on this very day she was asked to leave the family. Thus she looked back on Divali with mixed feelings. Despite the rejection, she remembered how pleasant it had been before this happened and commented, “How nicely we used to celebrate it!”

Surprisingly few patients had developed severe deformities at the time of leaving home; many more (49% of males and 63% of females) said that it was the fear of deformity that compelled them to leave. Women’s work tends to involve the hands, and if they lose sensation, things slip from their
Table 3
Factors influencing decision to leave home among dehabilitated leprosy patients: percentage distributions

Tableau 3
Facteurs influençant la décision de quitter le foyer parmi les malades de la lèpre exclus de chez eux: distributions des pourcentages

<table>
<thead>
<tr>
<th>Factors</th>
<th>M</th>
<th>F</th>
<th>χ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who took decision? – Qui a pris la décision?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self – La personne elle-même</td>
<td>68</td>
<td>49</td>
<td>37.82</td>
</tr>
<tr>
<td>Family – La famille</td>
<td>20</td>
<td>31</td>
<td>p&lt;.0001</td>
</tr>
<tr>
<td>Other – Autres</td>
<td>12</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Fear of deformity – Crainte de la difformité</td>
<td>49</td>
<td>63</td>
<td>27.70</td>
</tr>
<tr>
<td>Patches – Taches</td>
<td>41</td>
<td>46</td>
<td>7.47</td>
</tr>
<tr>
<td>Correcetable – Diffomité pouvant être corrigée</td>
<td>36</td>
<td>27</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Boils/knots – Pustules/nœuds</td>
<td>12</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Loss of digits – Perte des doigts</td>
<td>11</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Experienced family pressure to leave –</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A subi la pression de la famille pour qu'il/elle parte</td>
<td>49</td>
<td>63</td>
<td>27.70</td>
</tr>
<tr>
<td>p&lt;.00001</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Impact on marriage
Marriage can be affected in many ways by stigmatizing diseases such as leprosy. These include chances of marrying, problems during marriage and ability to stay married, and possibilities of remarriage if the first marriage fails. The qualitative data from the study indicate that girls with leprosy found it more difficult to marry than boys, and that they made more compromises in the choice of partners. Children of leprosy patients also had difficulty marrying and again, girls seemed to suffer more. In fact, 35% of patients said that one of the reasons they left home was worry about the marriage prospects of their daughters.

The interviews with children of leprosy patients provided insights into an often overlooked dimension of the disease, the impact on children in families affected by leprosy, and on their marriage prospects. One young boy explained:

We don’t mind that our parents are deformed and disfigured: we have accepted that fact. But do you have an answer to why I should suffer from a disfigured future? We have a literally hopeless future. It is branded not by our potential, skills and dreams but by stigma that our parents own, and that is all that we inherit. Nobody wants to give us jobs when they take our address, but if we do not give our address we get no job. We will marry one day to one of the girls in this community itself. So there is no curiosity, no excitement. We know who are the probable matches, and they are few. But the situation of girls in our colony is worse. At least we boys go out and spend time on the main road, listening to songs and watching televisions that are displayed in the shops in the market. But these girls do not go out. You know we brew and sell liquor and all sorts of people come here. If any of these girls is found to be loose and outside the colony, the men won’t leave them alone. Their world remains very small within the bounds of this colony. And then we boys find them very boring as partners.

While most respondents (68% of males and 62% of females) reported that they were married, the term “married”, in the context of this population, is misleading. Those who reported that they were married were not necessarily with their original spouses. On rechecking, many rehabilitated respondents admitted that they were previously married and had left first spouses when they became noticeably disfigured. In fact, most of the leprosy-affected couples living in colonies were in common-law unions.

More women than men reported that they were married. In-depth interviews revealed that many female patients continued to say they were “married” even though they were not living with their husbands, and sometimes had not seen their spouses for many years. They did so as a security mechanism, both because it was psychologically comforting and because it protected them from the possible advances of male patients in leprosy.
homes (treatment centres) or colonies. For example, a 70 year-old woman who had claimed that she was married later disclosed that she had not even seen her husband for 50 years. She explained that she was married, "but presently he is not living with me".

Generally, women were less likely to mention marital problems than men, but three factors stood out as distinguishing women who stayed with their families from those who left. These were, firstly, a strong marriage, in which the husband supported his wife in seeking early treatment. Secondly, prompt detection of the disease was important in preventing dehabilitation, as it could be arrested early with less possibility of disfiguration. In the non-dehabilitated group, 89% of married males and 95% of females had sought treatment at the early stages of the disease, whereas in the dehabilitated sample, nearly one-third of males and females had severe damage before seeking care. Finally, whether a woman had children appeared to play a role in whether or not she was able to stay with her husband. In the dehabilitated group, of the women who said they had borne children, those currently married had an average of 2.6 children as opposed to only one child for divorced females. More interesting, however, was the number who claimed that they had never had children - 119 of the 227 women - of whom only 24 were unmarried. This indicates considerable childlessness and sub-fertility for leprosy-affected women, and their dehabilitation status also implies a probable link between childlessness and departure from their original marital union. Non-dehabilitated married women had 2.5 children on average, and only 6% of them were childless; their higher status due to motherhood may have helped them to remain in their families.

Almost all women who left their homes before the 1970s were sent to, or dropped at, leprosy homes (treatment centres) by their families. At the time of leaving, half of them were unmarried and the rest said that they did not have children or that their husbands were living with other women. In the leprosy colonies which have grown up around leprosy homes, and which are growing in number as a result of the increasing cure rate and released, cured inmates, leprosy patients were making new alliances with other ex-patients. All the women who had joined a new union had settled down with severely handicapped men suffering from deformities that were more advanced than their own. One remarried woman, wife of a leprosy colony leader explained, "Why would they take us if our hands were wasted? They have married our hands which cook and clean and sweep!"

Among the 72 married couples in the four leprosy colonies, 45 households had both male and female leprosy patients. In the remaining households 16 leprosy-affected men were married to non-leprosy-affected, able-bodied women, four of whom were brought from an orphanage adjacent to the leprosy home. Only one female leprosy patient was married to a non-leprosy-affected man who was physically handicapped due to a road accident. Male leprosy patients in the colonies thus made fewer compromises than women in the choice of spouse or companion.

Patients' understanding of treatment
The study revealed insights concerning the way leprosy patients experienced and interpreted the disease. For example, women were very concerned about the fact that their urine turned dark orange-yellow as a result of rifampicin, one of the drugs used in MDT. Women associated the change in urine colour with jaundice, which was considered as one of the deadliest diseases.

Women and health workers alike were also unaware of the possible side-effects of other drugs, such as prednisolone. Prednisolone is contraindicated for pregnant and lactating women because it can make their bones brittle and can cause severe bone pain. In an area where women already are deficient in calcium, iron and vital nutrients, the effects of the drug could be especially problematic. Yet when prednisolone or steroids are used, women report instant improvement and demand the same tablets repeatedly.

Women's interpretation of the medicines received, in terms of perceived attributes such as colour, size and smell, was also enlightening. Dapsone, for example, is very small in size and women tended to see it as less effective than the glossy, brightly coloured and attractively packaged multivitamin tablets. Further, the small tablets must be taken in a rather rigid regimen that was difficult for women to follow: before going to bed every night and preferably not on an empty stomach. A "blister pack" had been introduced to simplify the process, but this gave rise to the suspicion among women, especially mothers-in-law, that they were contraceptive pills being distributed surreptitiously by the family planning programme.

Conclusions
Several conclusions relating to improved leprosy control can be derived from these results:

1. One of the greatest obstacles to leprosy treatment is late reporting of signs of the disease. Because of social stigma, women may be afraid to disclose early patches when visited by leprosy workers. As women were very concerned about the condition of their skin, a possible entry point for detection of leprosy is that of skin disease. Asking women about the condition of their skin, rather than about "patches" as such, is more likely to be acceptable, and seeking treatment for skin ailments is much less subject to social stigma. Train-
ing in skin disorders for health workers could also help them distinguish signs of leprosy from other, similar or overlapping problems.

2. Our study has pointed out the importance of people’s perceptions of medicines. Smaller pills may be viewed as less effective, or be confused with contraceptive pills. It is important for leprosy workers to be aware of these concerns and alleviate them, as much as possible, with female patients. Family members should also be informed about the role of the medicines for curing the disease, and the importance of carefully following prescribed regimes.

3. Women should be informed about the risks of pregnancy when they have leprosy and of the need to carefully protect themselves by MDT during this period. Both women and health workers should be fully informed about possible negative side effects of drugs that should not be administered to pregnant women. More attention also needs to be given to the special problems of leprosy patients giving birth, when sensation in certain parts of the body may be lacking.

4. Following the MDT regimen is complicated, and the amount of drugs to be administered depends on type of disease, body weight and state of health of the patient. Simple calendars should be developed to help leprosy patients follow their regimes, particularly for women who are illiterate, non-numeric and hence at considerable disadvantage in treating their condition. The role of illiterate family members can be especially important in these situations.

5. Gender sensitization of leprosy workers may be an important step to more effective disease control. For example, leprosy workers should be informed about the need for different approaches to women and men in their work. In India, most leprosy workers are male, and being touched or examined by men may be unacceptable to women. The involvement of local women can help to allay such fears or concerns. In some areas, especially women who are in purdah, female specialists may be required to perform these examinations.

6. The distinctive problems and needs of children of leprosy patients have received very little attention. Even though most of these children are not infected, they suffer severe deprivation in their daily experience and few chances for a better life. Special attention should be given to this group, in terms of assuring equal access to education, jobs and health care.

Summary

This article presents evidence from two states of India, Bihar and Maharashtra, on the process of "dehabilitation" among male and female leprosy patients, and suggests gender-sensitive interventions to address existing problems in leprosy control. While the study investigated a wide range of gender differences in the impact of leprosy, this article focuses on only two – marriage and family reactions. Important gender differences were apparent in the impact of the disease. While both men and women were negatively affected in terms of their family and marital lives, women suffered more isolation and rejection. Psychologically, women appeared more vulnerable because they were deprived of personal contact with others in the domestic environment where they were accustomed to receiving their greatest emotional rewards. Women reported that indifference to them by other family members, or seeming negation of their presence, caused them the greatest suffering. This underscores the importance of providing information to both leprosy patients and their families about the disease and its treatment, including the possibility of cure with MDT (multi-drug therapy) and of counseling family members about their crucial role in helping patients cope and recover. This support is even more critical for women, who often lack access to the variety of outside advice and assistance available to men. The evidence presented in the article demonstrates the importance of analyzing leprosy from a gender perspective, not only because this approach helps to inform our understanding of the determinants and consequences of the disease, but also because it provides new insights for improved disease control.

Résumé

Double péril: les femmes et la lèpre en Inde

Cet article présente des témoignages en provenance de deux États de l’Inde, le Bihar et le Maharashtra, sur le processus de «dégénération» survenu chez les malades de la lèpre, hommes et femmes, et suggère des interventions tenant compte du rôle spécifique des deux sexes pour aborder les problèmes de la lutte contre la lèpre. Si l’étude a porté sur une vaste gamme de différences entre les sexes concernant l’impact de la lèpre, le présent document n’est axé que sur deux aspects: le mariage et les réactions de la famille. D’importantes différences entre les sexes sont apparentes pour ce qui est de l’impact de la maladie. Tant les hommes que les femmes sont touchés de manière négative dans leur vie familiale et leur vie maritale, mais les femmes souffrent davantage d’isolement et de rejet. Psychologiquement, les femmes semblent être plus vulnérables car elles sont privées de contact personnel dans le milieu domestique où elles avaient l’habitude de recevoir les plus grands stimulants affectifs. Les femmes ont fait état de l’indifférence qui leur est manifestée par les autres membres de la famille, qui pouvaient aussi faire semblant d’ignorer leur présence, et cela leur causait les plus grandes souffrances. Cela montre l’importance qu’il y a à fournir des informations tant aux lépreux qu’à leur famille sur la maladie et son traitement (y compris la possibilité d’une guérison grâce à la polychimiothérapie) et à conseiller les membres de la famille sur le rôle spécial qu’ils peuvent jouer pour aider les malades à faire face à la maladie et à guérir. Cet appui est encore plus essentiel pour les femmes, qui, souvent n’ont pas accès à la gamme de conseils extérieurs et d’assistance dont disposent les hommes. Les
témoignages présentés dans ce document montrent qu'il est important d'analyser la lepra du point de vue de chaque sexe, non seulement parce que cette approche nous aide à comprendre les déterminants et les conséquences de la maladie, mais également parce qu'elle offre de nouvelles perspectives permettant de mieux lutter contre la maladie.

References – Références


