

## **Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil**

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*Summary* There appear to be regional differences in gender ratios of leprosy patients being diagnosed and treated. In Asian countries, more men than women are registered whilst in Africa female patients outnumber males. The Netherlands Leprosy Relief (NLR) therefore initiated research into factors underlying these regional gender differences. Between 1997 and 1999, leprosy control teams in Indonesia, Nigeria, Nepal and Brazil supported by social/public health scientists, conducted comparative exploratory research. They looked at three groups of potential explanatory factors: biological, socio-cultural/economic and service-related. The studies were partially quantitative (analysis of the records of patients who according to prescription could have completed treatment) and partially qualitative (interviews/focus group discussions with patients, their relatives, community members and health staff on perceptions of leprosy, its socio-economic consequences, treatment and cure). Biological factors appeared similar in the four countries: irrespective of the M/F ratio, more men than women were registered with multibacillary (MB) leprosy. Strong traditions, the low status of women, their limited mobility, illiteracy and poor knowledge of leprosy appeared to be important socio-cultural factors explaining why women were under reporting. Yet, accessible, well reputed services augmented female participation and helped to diminish stigma, which in three out of the four societies seemed greater for women than for men. These positive effects could still be higher if the services would enhance community and patient education with active participation of patients and ex-patients themselves.

## Introduction

During the 1990s leprosy services were intensified in a WHO stimulated effort to decrease the prevalence of leprosy. They paid a lot of attention to hidden groups in remote areas which had hitherto been underserved. As the reporting of women for leprosy treatment lags behind that of men in many parts of the world, the Netherlands Leprosy Relief (NLR), supported by the Health Department of the Royal Tropical Institute (KIT), Amsterdam, researched factors influencing female patient engagement with leprosy services. The researchers distinguished biological, socio-cultural/economic and service factors.

The research focussed on two areas in Asia where female attendance had hitherto been low: Indonesia and Nepal. Comparative research was conducted in countries where females used the services equally well or better than males: Nigeria, and parts of Brazil. In all four countries the prevalence of leprosy was above 1/10 000 at the onset of the study.

In Indonesia we concentrated on clinics in Aceh Province, in Nigeria on Plateau State, in Brazil on Rio de Janeiro (RJ) State, and in Nepal on the Eastern and Far Western Development Regions (EDR and FWDR). The clinics in Rio de Janeiro State were mainly urban, the others rural. In each research area a public health physician responsible for leprosy control carried out the study, if possible together with a local social scientist or a public health person experienced in research. An anthropologist and a physician (both MPH) from the Royal Tropical Institute in Amsterdam supported the studies.

The fieldwork was conducted between 1997 and 1999 and resulted in four booklets published between 2002 and 2004.<sup>1-4</sup> The key findings are presented here.

## Material and Methods

We used a comparative exploratory study design with a similar methodology and comparable tools in each country. We started with a literature search, including obtaining national leprosy statistics and relevant reports. The field study comprised a quantitative and a qualitative part. The quantitative part consisted of an analysis of at least 500 records of patients who could have removed from the register in 1997. Thus the cohort of patients registering in 1994 was the starting point. In Aceh and Nigeria the research team included all patients registered between January 1993 and December 1997. The Brazil and Nepal teams, which only started their study in 1998, limited themselves to the 500 patient cards, systematically sampled from the 1994 cohort (for numbers, see Annex 1). For Rio de Janeiro, State case finding statistics segregated per sex were available over the period 1981–1999, enabling us to compile the M/F ratio over the years 1993–1997 and compare it with the M/F ratios of Nigeria and Indonesia.<sup>1</sup> In Nepal the national statistics were available per region as well, but we could not use them since after 1993/94 sex was no longer segregated.

Data was retrieved from the cards on age, type of leprosy, grade of deformity and reporting for, and complying with treatment. We defined ‘reporting for treatment’ as going for the first time to a health facility where the diagnosis of leprosy can be made and leprosy treatment is provided. For the definition of compliance we followed the WHO guidelines as

<sup>1</sup>If the figures are adjusted for sex differences in the general population, the figures in Indonesia and Nepal remain broadly the same, whereas the Plateau State figure becomes 0.92. For Nepal and Brazil we used in the table below the national statistics for the number of new male and female leprosy patients registered in the research areas in order to have a total sample like in Aceh and Nigeria.

reflected in the different national leprosy programmes: prescribed doses of treatment taken within  $1\frac{1}{2}$  times the prescribed time.

The exploratory qualitative part of the study comprised 443 loosely structured interviews and 81 focus group discussions (FGDs) with patients, ex-patients, their relatives and neighbours, women's groups and community leaders as well as with leprosy and general health staff (for numbers per country see Annex 1). Qualitative data covered the perceptions of all informants on leprosy and its socio-economic consequences for male and female patients; on gender differences in case finding and case holding, and on perceptions of cure. The data was collected per village, with registered patients as a point of departure. The different data sets per village therefore complemented and strengthened each other.

Gender differences were explored through analysis of age, marital status, socio-economic status of male and female patients, in particular with respect to differences in access to material and immaterial resources and in relative freedom to make choices (e.g. for treatment). We also analysed gender differences in stigma experienced. Following Goffman<sup>5</sup> we defined stigma as an undesirable 'differentness' that disqualifies an individual from full social acceptance. We distinguished stigma at three social levels: that of blood relatives, that of spouses and in-laws, and that of the community. Five point scales were developed for each level in an attempt to measure stigma.

## Discussion

Before we started the study, it was acknowledged that a prevalence survey would be the best study design, but this would be far too costly and time-consuming. The comparative exploratory design chosen limited itself to registered patients. In Nepal the spreading of the research over two regions resulted in a limited number (240 + 390) of patient cards analysed per region. These cards mainly originated from the two referral centres in the regions, which covered over 80% of the registered patients. Patient cards in health- and sub-health posts were, until 2000, of doubtful quality or missing, in particular in the Far West. Unfortunately in Plateau State, Nigeria the computer was struck by lightning before analysis of the 1367 patient cards was complete.

## Results

### MALE:FEMALE RATIOS

The M/F ratios of registered patients were compared for the four study areas (Table 1).

In Indonesia and Nepal the M/F ratios were higher than in Nigeria and Brazil. In the FWDR in Nepal even twice as many men reported for treatment as women.

### *Aceh, Indonesia*

At diagnosis the 2741 males registered over 1993–1997 were more seriously affected than the 1756 females, with higher rates of MB leprosy (M 65.8% against F 59.9%,  $P \leq 0.001$ ) and grade 2 deformities (M 20% against F 17%,  $P = 0.003$ ).

Several socio-cultural and economic factors influenced case-finding, according to the 66 individual interviews and 8 FGDs conducted (Annex 1). Women were quicker to notice

**Table 1.** Comparison of M/F ratios of registered leprosy patients in the four study areas

Study areas	M/F ratio 1994	M/F ratio 1993–97
Indonesia (Aceh Province)	1.45	1.56
Nigeria (Plateau State)	–	0.87
Brazil (Rio de Janeiro State)	1.14	0.99
Nepal (Far Western Dev. Region)	2	–
Eastern Dev. Region	1.8	

bodily problems than men. They could independently decide where to go for treatment. Such freedom might well have been influenced by the high social status of women in Aceh where traditional matrilineal traits persist within a now Islamic society. Yet, these favourable factors were nullified by strong beliefs in traditional causes of leprosy. The wrath of God for committed sins, the curse of an angered father, disturbed *djinn*, the breaking of food and other taboos, all of these could trigger leprosy, according to community members and patients. Living and dead relatives were also thought to cause the disease (heredity), or a person could be infected through body fluids (such as blood, urine, genital fluids and pus). Fear of deformities, which according to the community were inevitable, incurable and extremely infectious, could lead to public avoidance of sufferers from leprosy and ultimately their expulsion from the community. If married, the healthy partner (whether male or female) was allowed a divorce, certainly when deformities appeared, but the divorce was far from always executed (two of the 10 female and four of the 15 male patients interviewed lived separated or divorced). Among first line blood relatives expulsion of someone with leprosy was rare and only occurred when the headman, as guardian of the village's health, announced its necessity. Nowadays expulsion means forced admission to a leprosy village. Only when villages had been touched by a so-called 'chase survey' (a follow-up of new patients in their village, hand in hand with health education services and a voluntary skin examination of villagers) or when a headman was otherwise enlightened about the curability of leprosy with MDT did he forward suspected leprosy cases to the nearest health centre (HC) for treatment.

The ambulant leprosy services provided by a *juru kusta* (leprosy worker) at the HC were still hardly known to the community despite having been provided since 1993. People attended Health Centres mainly for MCH preventive services. Over half of the informants (FGD included) had never gone to a HC. For health complaints including leprosy patients went to the highly respected *dukun* (traditional healer), often several sequentially, or to the *mantri*, a private practitioner (nurse or other health worker) who can be found in almost every village. If lucky a leprosy patient contacted a *dukun* who admitted that the disease was 'too much' for him or met with a *mantri* who had been trained in leprosy, or who knew the *juru kusta*'s work and referred the patient to the HC. Patient delay was on average 4.5 years. Once diagnosed and cared for by the *juru kusta*, 90% of the patients took treatment regularly. (Aceh booklet:48).

#### Plateau State, Nigeria

Here men were more seriously affected by leprosy than females too. Of the 613 male patients, 85% had MB leprosy against 78.5% of the 684 females ( $P = 0.002$ ), and 23% of the male patients had grade 2 deformities against 15.9% of the female patients ( $P < 0.001$ ).

With regard to socio-cultural and economic factors, the 37 female patients and discharged females interviewed as in Aceh had been aware more quickly than the 20 men of persistent, abnormal symptoms and were more inclined to ask for advice and take action. Over 40 years of ambulant services had made leprosy and its treatment widely known. Patient delay was only 1.5 years, slightly more for men than women. Men often travelled further than women for treatment in search of high quality and to ensure secrecy (e.g. they went without referral to the Mangu (former leprosy) hospital as a first visit, or to private doctors). Of the 236 patients from Plateau State registered in Mangu between 1994 and 1998 50.4% were men. Those not needing special care were referred to peripheral clinics. Nevertheless, two thirds of the patients registered in the peripheral clinics of Plateau State were women. (Plateau State booklet: 64–65).

People considered the disease curable until deformities appeared. Deformities and ulcers were considered highly infectious. In addition to infection, patients and community members mentioned heredity, witchcraft and breaking of taboos as possible causes of leprosy. Surprisingly few patients had visited traditional healers, though for other diseases they often sought traditional treatment first.

Stigma was mainly concentrated on destitute patients with visible deformities. For most patients fear of the stigma attached to leprosy served as an encouragement to seek treatment quickly before deformities could develop. Most discharged deformed cases tried hard, sometimes with success, to re-register to diminish community fear. Expulsion from the community is rare nowadays; only three older patients reported gradual isolation when deformities had developed. Spouses usually remained loyal to new patients, though tradition allows divorce for male as well as female healthy partners. However, men often discontinued sexual intercourse with their sick partners for the first few months after diagnosis till symptoms started to subside; women enjoyed less freedom to do so. Blood relatives tolerated leprosy even more than spouses. One third of the 57 interviewed patients and RFTs had experienced leprosy in their family, which may have contributed to the tolerance. In 1990, leprosy services were integrated into the general health system. Yet in 1999 only one out of four PHC clinics staff could treat leprosy, and these integrated leprosy clinics had two or three patients. The scarcity of clinics, roads and transport were major problems for staff and patients. Often the leprosy supervisor, who should visit leprosy clinics once a month, not only diagnosed and counselled new patients, but also treated them instead of the PHC worker. Incomplete integration hampers both case finding and case holding which oscillated between 35–70%. Counselling of patients also suffered from the diffuse patient-healer relationship. Most patients were unsure about biomedical causes and transmission of the disease.

#### *Rio de Janeiro State, Brazil*

Male leprosy patients were more seriously affected than females. Of the 497 leprosy patients registered in 1994, 69.3% of the (264) men had MB leprosy against 57.9% of the (253) women ( $P \leq 0.01$ ); 14% of the males had visible grade 2 deformities, whereas only 7.9% of the female patients were visibly deformed ( $P = 0.04$ ).

As in Aceh and in Plateau State, women in RJ (18 patients and 10 RFTs) were more alert than men (17 patients and 9 RFTs) in noticing bodily problems. Women sought professional help within a year (11.8 months). Private and government doctors who had had no training in leprosy, including dermatologists, often failed to recognise leprosy so that it took women another 5.4 months (average) to be diagnosed with leprosy. Men took longer than women to

seek professional help (14 months) but then had a shorter doctor's delay (2.1 months) perhaps because their symptoms were more explicit. Most patients, without deformities and living in urban surroundings, believed they went unnoticed. Relatively few had experienced stigma, though stigma had been prevalent in the past and was still feared at present. Only 16% of the 54 patients and ex-patients interviewed, most with visible signs, had experienced avoidance of some sort, women more often and more severely than men. About one quarter of the married women reported abandonment or divorce compared with 10% of men. The same women found that some close relatives also avoided them, in contrast to only 4% of the men who experienced such behaviour. Twenty percent of the women and 12% of the men had experienced gossip and avoidance from their workplace or living environment. Obligatory replacement of the term *lepra* (still widely used by the population) by the less familiar term *Hansenias* has probably had less effect on stigma than the abolition of the leprosaria and a decrease in the number of patients with deformities.

From 1963, ambulatory vertical leprosy services replaced in-patient treatment in Rio de Janeiro State, with one treatment point per municipality. In the '90s these services were gradually integrated into the general health system, which increased their accessibility. In the four municipalities included in our research (comprising 80% of the State's population) the number of leprosy clinics increased from 9 in 1997 to 22 in 1999. Female case registration in RJ State also increased. Only 59.3% of the males and 49.6% of the females of the 1994 cohort had taken treatment regularly in 1998. These low figures may be attributed to the then long duration of treatment, to the large home to clinic distance that patients had to travel before 1996 and to defective health education. The obligatory use of the term *Hanseniasis* in the leprosy services also appears to confuse patients.

### Nepal

In the Eastern Development Region, the 243 male leprosy patients had higher levels of MB leprosy than the 145 women (48.6 against 35.2%,  $P < 0.05$ ) and had more grade 2 deformities (13.6 against 6.2%,  $P < 0.01$ ). However, in the Far Western Development Region of Nepal, males (148) and females (88) had comparable rates of MB leprosy (59.5 and 56.8%, respectively) and over 10% of both men and women had grade 2 deformities, rising to 13% for both sexes. Delays in reporting for treatment were very high in the inaccessible hill and mountain areas on which we focussed our qualitative research: on average 10.5 years for men and 12.3 years for women. In the Far Western Development Region the overall delay was 5.3 years for males and 6.7 years for females; in the Eastern Development Region 2.5 and 4.4 years.

An important socio-cultural factor helping to explain women's relative inertia appears to be their low social status. Low literacy or none at all, a young marriage age, a heavy workload, poor knowledge and awareness of clinical signs of leprosy and its treatment, dependence on the permission of the mother-in-law or husband to leave the homestead, the need for escort and money for transport and sometimes treatment, all these factors impeded women from reporting early for treatment. Moreover the hills and mountains of the Far West lack roads suitable for motor vehicles so that in large areas there is no public transport. A strong tradition fosters traditional beliefs in supernatural causes of leprosy (wrath of one god or another, witchcraft) which initially made women in particular visit a *shaman* or priest (see also Maskarinec).<sup>6</sup> These authorities were much more accessible, culturally as well as physically, than the still scarce public health services. Perceptions of leprosy as an inherited

or contacted disease were widespread as well. People perceived leprosy as an incurable, deforming and deathly condition and therefore avoided patients. Women suffered most from stigma, but also deformed men had, in the recent past, been chased to the outskirts of the village where they were neglected till they died.

In the Eastern Development Region leprosy was concentrated in the much flatter Terai (valley) zone; public awareness of leprosy was greater with a longer history of leprosy services, greater literacy and the fading of traditional beliefs. Stigma decreased accordingly. Fear of stigma was greater than the stigma actually experienced. Of 16 women who married into families with no history of leprosy only one was abandoned by her husband and four had troubles with in-laws, husband or co-wife. Eleven young husbands preferred to keep the disease and the treatment of their wife (all without visible deformities) hidden from their parents in order to save their marriage.

Leprosy treatment has been provided to out-patients in Nepal since the 1950s. Only in the '80s (Eastern Development Region) and late '90s (hills and mountain zones of the Far Western Development Region) did the services decentralise to health post and sub-health post level, which greatly improves their accessibility. In the rough landscape of the Far West, women, homebound by their many domestic duties, benefit most from the increase in case finding and case holding that were facilitated by massive training of the general staff. Nevertheless, the rudimentary condition of most health facilities, the dominance of male staff (if at all available) and the scarcity of health education by local staff formed major bottlenecks for women to attend the leprosy services. However inspecting the treatment cards revealed that 69.6% of the 103 males and 68.2% of the 60 females in the FWDR completed treatment, against 58.4% of the 142 males and 56.6% of the 82 registered females in the EDR.

## Discussion

The higher M/F ratios of registered patients found in Indonesia and Nepal compared to those in Nigeria and Brazil do not seem to be explained by biological factors. In all four settings male registered patients had higher rates of MB leprosy and grade 2 deformities than females. This has been found previously by Fine<sup>7</sup>; Noordeen<sup>8</sup>; Pönnighaus *et al.*<sup>9</sup>; Schroeder<sup>10</sup> and Richardus *et al.*<sup>11</sup> Only in the FWDR of Nepal were these gender-related differences absent. Apparently we had identified in the Far West a group of seriously deformed women who in 1998/99 had hardly been touched by leprosy control services.

The M/F ratios of registered patients do not remain constant over time. In RJ State where we analysed the annual leprosy control reports from 1981 to 1999, changes were seen around 1996. Before 1996, slightly more men than women reported for leprosy treatment (M/F ratio 1981–1996: 1.06), whereas in the period from 1996–1999 significantly more women than men reported: M/F ratio 0.95 ( $P < 0.001$ ,  $X^2 = 28.11$ ). Then the leprosy services were integrated into the general health services and decentralised. This implies increased accessibility, which seems to benefit women most (see also Morrison).<sup>12</sup> In Nepal, a similar trend could be observed in the Western Development Region as the leprosy services expanded. Pearson<sup>13</sup> in 1982 found a M/F ratio of 3 whereas Theuvenet<sup>14</sup> in 1994 found a ratio of 1.6. In the FWDR of Nepal the M/F ratio of all reported leprosy cases decreased from 2.6 to 2 between 1985–1986 and 1993–1994.

The low social status of some patients seems an important factor in the late reporting of women for leprosy treatment in Nepal (Compare what Zodpey *et al.*<sup>15</sup>; Vlasoff *et al.*<sup>16</sup> and

Rao *et al.*<sup>17</sup> stated for India). However, Aceh and Nepal were very different with respect to the social status of women, though in both study areas two thirds or more of the registered cases were males and the average delays about 5 years (in E Nepal slightly less, in the Far West more). In Aceh, the adult literacy rate was high for both sexes (90%–80% respectively).<sup>18</sup> Both patients and community members stated that females could take the decision to go for treatment independently, as did males. In Nepal this was unthinkable, especially for newly wed women. At marriage a young woman (15–18) would join her husband and be dependent on her in-laws or husband for any decision. The educational level between men and women differed greatly, particularly in the Far Western Region (7% of the women having at most 4 years of education against 60% of the men).<sup>18</sup> In the Far West, women's awareness and knowledge of symptoms of leprosy were the lowest of all the patients interviewed. Yet in Nepal the low position of women seemed for only a few (4/27 or 15% in our sample) to be a real hindrance to go for treatment. (Compare Heynders).<sup>19</sup>

Patients in Nepal and Aceh shared a strong belief in traditional causes of leprosy which compelled them to visit traditional healers, often a number in succession, before going for biomedical care. In the isolated mountainous Achham (Far West Nepal), all patients we interviewed, particularly the women, had visited a *dhami* first. Men were more knowledgeable and mobile and able to shift to biomedical care. In RJ State and Plateau State where average delays of only 1.5 years were found, patients who had leprosy in the family even reported for leprosy treatment within 1 year from noticing the first symptoms.

Such promptness cannot be attributed to weakness of the traditional health system. In Plateau State, traditional medicine men are frequently visited by men and women for herbs and supernatural treatment for afflictions other than leprosy. Yet, over 40 years of ambulant leprosy services had convinced most people that biomedical treatment for leprosy was superior and could cure the disease, at least when deformities had not yet appeared. Patients in Rio de Janeiro State were also convinced of the superiority of biomedical drugs over natural remedies as were the younger and more educated patients, even in Nepal.

Men are more mobile than women, especially in rural areas. Women have their child care, domestic and economic duties that tie them to their homes. In all four research areas men were both more mobile and financially better off than women. This did not necessarily mean that men got better care. Indeed, in Plateau State we found that some men had made considerable detours, visiting famous traditional healers and leprosy referral centres or private doctors on their own initiative. Such treatment either delayed them or was unnecessary costly.

In Nepal we occasionally observed similar male behaviour. Not only were men in search for what they conceived as high quality care but also for secrecy, which seemed better guaranteed if they sought care far from their community.<sup>20</sup>

In all four countries within patients' basic social groups (the family of origin; the family of procreation, and the community, school or working environment) varying degrees of stigma existed, which is in leprosy literature generally regarded as a delaying factor in seeking treatment. Stigma seems to depend on three pillars: the belief in strong infectiousness of the disease,<sup>21</sup> the belief that leprosy is incurable; and the repulsiveness of disabling deformities and reactions. All the social groups had the power to isolate and expulse patients, but did so in different degrees. The community seemed the most threatening because in all research areas village authorities could, when unmistakable and irreversible signs of leprosy appeared, request patients to move to the edge or altogether leave the village.

Men were most afraid of losing their economic and social status in the community. Deformed beggars in public places served as horrifying examples of where the disease could ultimately lead. For women the biggest fear concerned the domestic group: their spouse and in-laws. In Nepali FGDs, men and women alike often called mothers-in-law the worst enemies of female patients. At marriage, girls had entered a foreign and sometimes inimical environment where they were judged on their ability to work and produce healthy children. Men in Nepal, who remained in their own family, called woman's virilocality the principal reason why stigma was applied to female patients more severely than males. Still, among young people the stigma seems to diminish in Nepal but also in the other study areas. Participants in FGDs revealed that nowadays, with modern treatment available, most people would (and even should according to their Christian or Muslim religion) wait until deformities appeared before they left their spouse. Even despite deformities we found many spouses would remain loyal, though women more often than men. Divorce occurred in all four countries, the exception being as long as sick spouses could still perform economic/domestic duties, their health improved and the relationship between the spouses was good. Interruption of sexual contact was more common, initiated more frequently if the healthy spouse was a man than a woman.

Without exception, first line blood relatives were the most loyal even when deformities appeared. In particular the bond between parents and children was strong.

Did the fear of stigma then result in delay? At the onset of the disease, when symptoms were not yet clear, suppression of awareness occurred in men more often than in women. Yet Helman<sup>22</sup> observed such gender difference in awareness of disease in many cultures and diseases. The younger generation of leprosy patients who were familiar with the services thought fear of stigma would rather make patients hurry for treatment than delay. Such swiftness presupposes the existence of accessible leprosy services of good quality. Service factors appeared to override all others in explaining patients' health seeking behaviour.

Leprosy services have undergone major changes in the past 20 years with the introduction of Multi Drug Therapy (MDT), which has changed leprosy into a disease that is curable within a limited period. By integration of leprosy services into the general health system the accessibility of these services increased, much to the benefit of rather immobile female, but also of male patients. This process was occurring in all four research areas, though in the FWDR, Nepal integration only started around the year 2000. In Plateau State, general health staff had only been trained to recognise and treat leprosy in a quarter of the clinics. This reveals a dilemma of cost efficiency: due to the shorter duration of treatment and cleaning of the registers, the average number of patients has been heavily reduced. Training of general staff is indeed an expensive but crucial factor in leprosy control. In none of the four research areas had staff received training in leprosy and leprosy control during their general training. In RJ State our study most clearly illustrated the need for such training: the 35 patients interviewed had in total seen 12 health practitioners at different public health facilities (including dermatologists) before they were finally diagnosed as having leprosy. For women, the doctor's delay almost equalled their personal delay!

Staff-patient relationships of the opposite sex are another potential problem in the diagnosis of leprosy patients. In Aceh, Nigeria and Nepal male staff were in the majority; females were overrepresented in RJ State. Both encountered difficulties in approaching and thoroughly investigating patients of the opposite sex. They often transferred these suspected cases to referral centres. Privacy during diagnosis was another issue. The present integration of leprosy services into general health structures facilitated privacy, except in Far Western

Nepal, where health facilities were so small that several activities had to take place in one room. This made female patients reluctant to undress.

Patients defined good quality services as having a quick and noticeable effect: symptoms should disappear, or at least dwindle. Kindness and politeness of staff were also desired. Patients were satisfied with their treatment overall but many resented their discharge: they did not consider themselves cured while signs such as deformities were still visible. Notwithstanding the declaration of the doctor, or a certificate of cure, half of the patients in Nigeria, Indonesia or Brazil and three quarters of the Nepali patients resented their discharge fearing the return of the disease.

Another aspect of the services that patients in all research areas judged insufficient was the quality of patient counselling and education of the community. They got some information on treatment and curability, but too little or nothing about symptoms, causes and infectiousness. Their spouses and relatives, who in most cases were still more afraid of the disease than the patients themselves, were seldom informed. But most important of all, the community – the patients' biggest enemy – remained unenlightened! To combat stigma, services should attack the three pillars on which stigma is based: fear of infectiousness, incurability and deformity and explain *in the community's terms* how treatment helps to overcome them. Staff rarely explained that most patients on treatment were non-infectious. Curability needs to be explained in more detail. Prevention of deformities by early treatment already seems to be well understood.

In Aceh and Plateau State we used non-deformed, young and eloquent ex-patients to explain to the community that leprosy can be cured. In all research areas the majority of patients were willing to assist new patients and some brave ones volunteered to enlighten the community, if supported by health staff. To quote Jopling: 'Can we really afford to neglect such a reservoir of potential allies in the fight against leprosy?'

#### MAJOR RECOMMENDATIONS

*To Medical Faculties:* Include essentials of leprosy and its treatment in the module on Communicable Diseases in countries where leprosy still is, or recently was, a public health problem.

*To policy makers and managers of leprosy control services:* Keep or reintroduce the entry 'sex' on the patient cards and in the national statistics, in order to be able to assess the consequences of changes in policy on male and female patients.

Start or continue with integration of leprosy services in the public health system, accompanied by training in leprosy and clear job descriptions of staff and supervisors, to ensure adequate coverage of the leprosy services.

Pay more attention to the social aspects of leprosy and use participatory teaching methods, e.g. role plays and focus group discussions during in-service staff training

- to enhance staff skills in the diagnosis of leprosy in sensitive staff-patient relationships (opposite gender; differences in status).
- to enhance staff's skills to remove unnecessary community/patient fears involved in the belief in traditional causes, and to explain clearly the working of MDT on infectiousness, reactions and cure.
- to enhance staff's alertness to questions and problems of patients, in particular of (silent) women and strengthen staff's skills for taking adequate action in case of stigma.

Make full use of patients and ex-patients of both sexes who are willing to participate in case finding and case holding activities, in particular in health education (see Nepal booklet:118 for further suggestions).

When and wherever possible, inform community leaders, teachers, women's groups about leprosy and leprosy control.

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### Annex 1. Data sources from Aceh, Plateau State, Rio de Janeiro State and Nepal

Quantitative data	Aceh Indonesia	Plateau State	RJ State Brazil	Far West Nepal	East Nepal
	4-501 (1993–97)	Nigeria 1-367 (1994–98)			
Interviews					
Patients	35	26	35	28	30
RFT	8	31	19	25	26
Relatives	5	30	–	–	2
Neighbours	–	25	–	–	–
Community Leaders	9	19	7	10	1
Health staff	9	25	19	10	9
Total	66	156	80	73	68
FGDs					
RFTs	2	4	–	–	–
Community members	6	10	–	Women 8 Vill.lead 7 Teachers 6 Trad.heal.4	6 5 5 2
Health staff	7	8	–	1	–
Total	15	22	–	26	18
Case-studies (pts) for IEC experiment	4	4			
Staff-pt observations		15			