

## Letter to the Editor

### **DISCRIMINATION AGAINST LEPROSY PATIENTS AND THEIR FAMILIES: THE SITUATION (EARLY 2005) IN WEST DARFUR, SUDAN**

Sudan (population 33.5 million) has suffered civil war and disruption for the past 21 years. Conflict in the Darfur region in the West of Sudan, bordering Chad, has displaced 1.5 million and resulted in the deaths of tens of thousands of people.<sup>1,2</sup> Many have been forced out of their traditional areas into make-shift situations with limited supplies of water and food, together with difficulties in accessing help from government and non-government agencies.

Following a preliminary baseline report for The Leprosy Mission Sudan on a leprosy village called Ashara Biyuut (literally Ten Houses), near Geneina, West Darfur,<sup>3</sup> we recently interviewed a random sample of 51 'heads of household' in the same village, 16 of whom had been rejected (refused admission) to the Internally Displaced Person (IDP) camps set up in their area by various agencies. They were thus systematically excluded from any humanitarian intervention or help which might have been available at the time, on the basis of their being affected by leprosy. The following are typical statements from six different patients interviewed:

1. *"I was living in Mastra. I was diagnosed and treated for leprosy at the age of 12 years old. Though I was rejected by my relatives I continued there until the war started. I left the village to the IDP camp but unfortunately I wasn't allowed into the camp because I was a leprosy affected person and was advised to go to the leprosy village."*
2. *"I was living in Koranga, but I left my village to go to Koranga IDP camp because of the war, but unfortunately I have been rejected by the camp's authority; because I'm a leper, that is why I have come to the leprosy village where I feel accepted among my brothers and sisters."*
3. *"I came here because of the war from Sarva to Abu Isar IDP camp. But I was not allowed into the camp; for they said I'm a leper, therefore I decided to come to brothers and sisters in the leprosy village."*
4. *"The national Camps authority told me to go away from here to the leprosy village for it is your place not here; that is why I have come to the leprosy village."*
5. *"The health worker has chased me away from the camp."*
6. *"I'm begging to support my family because I don't have any alternative."*

In talking to other leprosy patients and our colleagues in relief work in this area, we have heard of many further examples of outright discrimination against patients or ex-patients on the grounds of their disease, thus leading to additional psychological and physical suffering in an already disadvantaged section of the community.

The number of patients in this preliminary study is obviously small, and we acknowledge that their health problems have to be assessed in the context of many others, including tuberculosis, malaria, HIV/AIDS and chronic malnutrition. Their experiences, however, seem to amount to a violation of the Geneva Convention on the Protection of Civilian Persons in Time of War and many recent statements and publications on the need for egalitarian and humanitarian treatment for all patients with this disease.<sup>4–6</sup>

Stigma against leprosy in Darfur (and other parts of Sudan) was known to be high before the current crisis. A Knowledge, Attitude and Practice (KAP) study conducted by The Leprosy Mission Sudan in 2002 in Darfur confirmed some indicators: 63% of those interviewed considered that people affected by leprosy should not live in the community; 94% would not share food with them and 91% would not shake hands.<sup>7</sup> The exclusion and rejection described above has forced leprosy patients to regroup in 'settlements' and rebuild some of the leprosy villages. This has destroyed the progress previously made by the National Leprosy Control Programme to promote social integration and acceptance of people affected by this disease, and may force some patients back into begging and debilitation.<sup>8</sup>

We work under difficult conditions in which there are no easy solutions, but in an effort to address the current situation, our Mission has responded by organizing a 'livelihood programme', aiming at a kind of 'reverse' integration, by improving living conditions and clean water supplies in the leprosy villages. Apart from improving the quality of life for the inmates, it is envisaged that this may well attract the local community into the villages, thus helping to reduce stigma.

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## References

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- <sup>3</sup> Rui Nako. Ashara Biyuut: a leprosy village near Geneina, West Darfur. Baseline study for The Leprosy Mission Sudan, February 2005. Unpublished document.
- <sup>4</sup> International Covenant on Economic and Cultural Rights. Resolution 2200A (XXI), 16 December 1966.
- <sup>5</sup> Frist T. 'Don't treat me like I have leprosy'. *A guide to overcoming prejudice and segregation*. Talmilep, 234 Blythe Road, London W14 0HJ, United Kingdom.
- <sup>6</sup> Sasakawa Y. *You are the main actors*. WHO Goodwill Ambassador's Newsletter: for the Elimination of Leprosy, December 2004, Number 11, page 1.
- <sup>7</sup> Buddingh H *et al.* *Knowledge, attitude and practices concerning persons with disabilities in Darfur, Sudan, 2002*. Unpublished document.
- <sup>8</sup> Kaur H, van Brakel W. Dehabilitation of leprosy-affected people – a study on leprosy-affected beggars. *Lepr Rev*, 2002; **73**: 346–355.