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Leprosy Villages—Are They All Outdated? A Survey of two Leprosy Communities

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A medical and social survey is reported on 2 villages in India composed originally of rejected leprosy patients and developed over the past 30 years, near to a large leprosy hospital. The results are surprising. These communities pose no leprosy problem to the adjacent population, thanks to the concern of the hospital authorities. The general economic standard is low, with begging an important factor, but the level of child health and nutrition in these communities was found to be superior to that among the local population, while the residents have developed a sense of community responsibility which replaces that lost from their homes and has created a reasonable degree of stability.

Introduction

One of the major problems of leprosy hospitals has been that of patients who no longer need in-patient care but appear to have nowhere to go. Over the years, almost on the doorstep of the Victoria Hospital, Dichpalli, Central India, 2 villages have sprung up where a number of leprosy patients discharged from the hospital live. Most of them settled there because relationships with their families had broken down, some because of permanent deformities and disability which made them afraid to move away from a sympathetic community and medical facilities. The records show that the first house in Devanagar was built in 1948 by a patient discharged from the hospital. By 1954, with the population steadily increasing, the inhabitants decided to split the community, and some residents moved about half a mile away where they built the village of Devapalli.

Over the years both these villages continued to grow and many healthy children were born there. Various attempts were made to put these children on prophylactic dapsone and their parents on regular leprosy treatment, but it appeared that the weekly clinics in Devanagar and Devapalli were totally inadequate. In the first place relationships between these people and the hospital were not ideal. Patients from these communities were constantly coming to the hospital for treatment of complaints often of a trivial nature. Having been rejected by their own families, what they sought more than anything else was attention and affection. That the busy hospital outpatient department was not always in a

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position to meet this need resulted in misunderstandings and poor co-operation. Secondly, it appeared that many patients were not permanently resident in these villages, and this caused problems with registration and regular treatment. Finally, there appeared to be considerable general health problems which could not be dealt with during weekly visits. It was therefore decided in 1974 to hold daily clinics, to attend to general complaints as well as leprosy, and to establish an Under-Fives Clinic in each village.

Ten months later when relationships between the hospital and the leprosy villages had much improved, a survey was undertaken to assess the medical situation and the social problems which these patients are facing, using for comparison where nutrition was concerned, an Under-Fives Clinic at a neighbouring village of local people.

Materials and Methods

The registered population of Devapalli and Devanagar consisted of 432 and 494 respectively. Only a few of these were permanently resident, the majority leading an itinerant existence. A team of 2 doctors, 2 nurses and a paramedical worker visited every house and each member of the family was examined by a doctor. All patients were classified according to the Ridley and Jopling scale, deformities were noted, and records were made of other chronic diseases, especially tuberculosis. At the same time the nursing staff did a social survey amongst the adults to determine the size of each family, length of residence in the community, occupation and recent contacts with the home village.

On the side of the community there was much interest and co-operation in this survey. Three hundred and six adults and 112 children were examined out of a registered population of 926. The remainder were absent (see Discussion).

Results

LEPROSY SURVEY

Of the *adults* examined, almost half had lepromatous (LL) leprosy but most of it not very active. When skin smears were done only 6 patients (2%) had a positive Morphological Index. About 30% were within the BL, BB, BT range. Less than 10% had tuberculoid leprosy and the remainder, mainly healthy adults born in Devanagar or Devapalli, showed no signs of leprosy. Among the *children* only one case of leprosy (TT) was discovered, a boy who had never had any prophylactic

TABLE 1

Classification of leprosy amongst the surveyed population

Type of leprosy	Adults	%	Children	%
Lepromatous leprosy LL	150	49	—	—
Borderline lepromatous BL	31	10	—	—
Borderline BB	37	11	—	—
Borderline tuberculoid BT	32	10	—	—
Tuberculoid TT	28	10	1	1
Observation	—	—	5	4
No signs of leprosy	28	10	106	95

dapsone. Five children were placed on observation. The remaining 106 had no signs of the disease, though many were children both of whose parents had lepromatous leprosy. Twenty-eight patients (9%) were currently receiving treatment for tuberculosis.

DISABILITY SURVEY

Of the 306 adults examined 172 (56%) had noticeable thinning or complete loss of eyebrows and 114 (37%) had appreciable deformity of the nose. Those with contracted hands numbered 101 (33%), but many of these were very slight. Seventy-eight (25%) showed bone absorption of the hand and 71 (23%) bone absorption of the feet. Only 27 (9%) had trophic ulcers. There were 4 cases (1%) of Lagophathalmos and 4 (1%) of foot drop.

TABLE 2

Frequency of deformities amongst the adult population

Deformity		Number	Percentage %
Face	Eyebrows almost or completely lost	172	56
	Lagophthalmos	4	1
	Nose collapsed	114	37
Hands	Mobile contractures	69	22
	Absorption	78	25
	Stiff joints	33	11
Feet	Trophic ulcers	27	9
	Footdrop	4	1
	Absorption	71	23

NUTRITION SURVEY

In Table 3 the level of protein/calorie malnutrition among the 112 children in these leprosy villages is compared with that obtaining among a similar group among the local population attending an Under-Fives Clinic at the village of Mentrajpalli.

TABLE 3

Frequency of protein calorie malnutrition in Devanagar, Devapalli and in a nearby village, Mentrajpalli, estimated according to Morley's Road to Health Chart

Degree of nutrition	Devapalli and Devanagar		Mentrajpalli	
Normal "Road to Health"	29%	65%	16%	36%
1st degree protein calorie malnutrition	36%		20%	
2nd degree protein calorie malnutrition	29%	35%	39%	64%
3rd degree protein calorie malnutrition	6%		25%	

The general condition of the children in Devanagar and Devapalli compared favourably with that of the children in the neighbouring village who attend a similar Under-Five Clinic.

SOCIAL SURVEY

Almost half of the residents are totally or partially dependent on begging. The remainder work as coolies, farm their own land, follow village occupations or are involved in irregular practices, e.g. smuggling. Only 4 families claim to be receiving support from relatives.

Among the 166 women interviewed 71 (43%) have no children, 52 (31%) have one child, 22 (13%) have 2 children, whilst only 10 (6%) have more than 3 children.

Discussion

Experience over the past 10 months suggests that the 45% of the total population who were interviewed are representative of the number of people actually resident in Devanagar and Devapalli at any one time. We have described as "temporary residents" all those who were away at the time of the survey, plus 125 who stated that they spent more than 3 months of the year elsewhere. This leaves us with a permanent adult resident population of 181 (less than 20% of the total registered population).

Many of the *temporary* residents, who move between the cities of the north and Devanagar or Devapalli are involved in begging and appear to be quite content with their life. All they need from us is encouragement to continue regularly with their treatment. We make provision for them to take up to 6 months supply of DDS with them when they leave us. However, some expressed concern about the lack of regular education for their children.

The large number of patients with lepromatous leprosy (LL) and facial deformities, and the relatively small number of deformed hands incapable of work, suggest that social inacceptability rather than economic dependence is the reason for settling in a leprosy village. In this part of India the stigma attached to leprosy is very great and this has left many patients deeply resentful and suspicious. Fear of further rejection often suppresses all initiative to seek employment. This attitude even applies to projects for rehabilitation and the general attitude of the *permanent* residents is that of preferring to be left alone. Up to a point, they may be right: the majority have come to a compromise with their environment and have more or less rehabilitated themselves within the community of fellow patients. The number of rejected and disabled patients who really need what we usually call "rehabilitation" may well be much smaller than we are inclined to think. Among themselves the permanent residents form a happy community and appear to act as one family, forgetting or ignoring the barriers normally created by caste and religious differences. This is one of the most striking features of life in these leprosy villages.

The fact that of the 112 children examined, only one was diagnosed as having leprosy is most gratifying, as is the general level of nutrition among them. Nearly all children have had some prophylactic DDS in the past but this has certainly been very irregular. At the Under-Fives Clinic, started in 1974, there is 100% registration of the under-five population. These children are regularly examined and supplied with prophylactic dapsone. In addition, the following services are provided: immunization (BCG, Smallpox, DPT and polio), nutritional advice and the treatment of illnesses. This clinic has formed a valuable link with the adult population who are enthusiastic in bringing the children for examination and treatment.

The three main reasons for this rather surprising picture are:

The smaller families due to the high proportions of parents with lepromatous leprosy, which often causes sterility.

The fact that so many families are dependent on begging for their livelihood. Much of the "earnings" of a beggar are in the form of cooked food which is not resaleable but which will be eaten by the family.

The absence of the extended family where one or two wage earners may be required to feed and educate nephews and nieces. In Devapalli and Devanagar the normal family unit consists of the parents and their own children. However, the benefits of the extended family system (an abundance of affectionate and attentive relatives which gives such security to Indian children) are here provided by the whole village community.

Following the establishment of the Under-Five Clinic the most pressing need for the children is education. There is a well-established nursery school in Devapalli run by two devoted Christian patients. From there the children are able to attend the Government Primary School in a nearby village. In Devanagar a qualified teacher has been appointed by the Government. Following their education to junior level most of the children move away and go to live elsewhere with relatives who arrange for their marriage, while some remain behind to marry other children who were born in the community. These form the largest proportion of the adults examined who have no signs of the disease.

Conclusions

Living conditions in two communities of rejected or disabled leprosy patients appear to be much better than is usually presumed. Village hygiene and the health of the children compare favourably with those of the neighbourhood. Obviously there is no need to segregate the children from their parents. Another striking feature is the relative happiness of the community, possibly due to a "fellowship of suffering"—an experience shared by all of the residents.

Among the deformities caused by leprosy collapse of the nose appears to be one main reason for rejection. Regular nose care is therefore an essential part in the treatment of all lepromatous patients to prevent this disaster occurring.

The greatest needs of the two communities seem to be:

Regular leprosy treatment and general health care.
Educational facilities for the children.

Rehabilitation of the adult population is on the whole not a felt need, though there may be individual cases where this form of help is required. The community itself is the main factor in psychological rehabilitation and therefore such patient villages should not be regarded as undesirable.

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