

A Developing Country, Leprosy Control, and the Severely Disabled*

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Patients who are severely disabled by reason of past leprosy are frequently neglected by government planners and communities, when emphasis is increasingly laid on medical care and preventive measures. Even in the presence of economic stringency, efforts should be made to help these patients.

Introduction

Although leprosy policy planners in Tanzania emphasize the medical aspects of the disease, they are also interested in helping the patient to deal with his disease-linked, non-medical problems. On the basis of this concern, the writer undertook a study of severely deformed patients in the four major leprosy settlements† of a central region of the country to see if their difficulties warranted special external assistance. The following is a synopsis of the findings, and various suggestions emerging from this investigation.

The Four Settlements in an Historical Setting

Large-scale care of leprosy patients in Singida region probably began in the early 1900's near the government posts of Kilimatinde and Mkalama to which patients often came seeking medical help. Some officials did what they could for the patients, but worsening conditions in the settlements soon caused the government to turn to nearby missions. Around 1930, the Church Missionary Society (CMS) agreed to supervise the leprosy work in the Nunge settlement near Kilimatinde, and in 1947 the Augustana Lutherans at Mkalama and the Lutheran dispensary at Tintigulu were giving the only available treatment for leprosy. In time, the Nunge and Mkalama settlements developed into leprosaria, each treating around 1000 patients. At both places the growing of food presented problems, since the land at Mkalama was rocky, and that at Nunge was too dry. Only at Tintigulu was the land good for agriculture. The situations at Nunge and Mkalama finally deteriorated to such a degree that their sponsors began to look for more fertile areas in which to relocate. In 1959 both leprosaria did move, the Lutherans to Iambi in the Singida region, and the CMS to a neighbouring region. Former patients at Nunge, Mkalama, and Tintigulu who no longer required medical attention, remained. The severely deformed patients left in these 3 settlements,

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† "Leprosy settlements" will be used here to signify locales with very high densities of patients with active or "burnt out" leprosy who are largely dependent on their own resources.

together with those in a 4th that has since developed outside Iambi leprosarium itself, form the subject of the present paper.

Methodology

The writer studied especially the severely deformed patients in the 4 settlements on the assumption that these would also be the most severely disabled, and therefore the most in need of external assistance. A sample was attempted of those who "looked" severely deformed or disabled. Such a subjective criterion for selection must be explained. A survey of patients attending re-opened leprosy clinics in the settlements revealed that at least 22% of the 300 to 400 patients in each of the settlements were "severely disabled" (World Health Organization, 1970: *Field Classification of Leprosy Disabilities*). It was, however, apparent that most of them were not in reality so disabled that they could not pursue their usual work. Therefore only those who seemed to be obviously and severely disabled (the blind, and patients with several paralysed or absorbed fingers or toes) were interviewed; about 130 such patients were eventually located through clinic surveys, local clinic chiefs, community leaders, and fellow patients.

The patient's disabilities were assessed according to the "Tanzanian Workman's Compensation Chart" and 80 questions (dealing with the interviewee's background) were put to each patient. The interviews were conducted in Swahili or in a local dialect.

Results

GENERAL CHARACTERISTICS

Of the 129 patients interviewed, 59% were male: men were more likely to have lepromatous leprosy, to be better educated, to speak some language other than their tribal dialect, and to have been employed at some time. The deformed patients were generally older than the average leprosy patient in the settlements. Only 4% were aged under 30 while 29% were over 60 years of age. About one-fourth of Singida's population (458,000) are reported to be Christian; 67% of the patients studied gave this as their religion.

Medical Information

Of the 129 patients 31% had lepromatous leprosy; 95% learned that they had leprosy from someone other than a doctor or clinic worker; 52% had close relatives suffering from leprosy, and 57% had tried "native" treatment before seeking medical advice. After beginning treatment with chaulmoogra oil or sulphones, 84% had been admitted, at least once, to a leprosy institution. Of these, 16% had spent less than 2 years as in-patients, and 15% more than 15 years, while 53% had been discharged from in-patient care more than 10 years previously.

Only 46% of the patients wore footwear or gloves to protect themselves, although 80% admitted having been instructed to do so; two-thirds of them had persistent ulceration of the feet or hands. The same proportion were taking sulphone treatment, and 15% had absconded.

ECONOMIC AND SOCIAL PROBLEMS

The severely deformed patients faced many economic and social problems related to their disease and resulting deformities; 44% were 100% disabled, and only 3% had under 24% disability. Significant differences (at the 5% level) existed between the groups in their ability to contribute to the support of their households; with increasing disability the patient's contribution decreased. About the same proportion of patients in each category had resorted to begging.

Most of the patients could not count upon the help of their families. They had either lost contact with them, or had married another leprosy patient with problems similar to their own; 70% had remained in the settlements near the institution after discharge. The fear of rejection was advanced by one-third (32%) as a reason for not returning. Of those who did go home 27% soon returned to the settlement because they had been repudiated by their families or communities, while of those who had been married at the time of diagnosis 71% were later divorced; 80% of these divorced patients afterwards married other leprosy patients.

Severe disabilities, lack of support from able family members, and poor land were important factors in the economic stress of patients. 66% had *no* money, poultry, or livestock, and not enough food to eat. The poorest area was Nunge, where 86% were in this category.

PATIENT'S ATTITUDE TOWARDS CONDITIONS

Most (80%) of the patients were basically unhappy, and 50% attributed their unhappiness to "leprosy". 25% thought that their leprosy had been caused by "witchcraft" and 87% imagined, on learning the diagnosis, that their lives would be ruined. Nearly all (91%) thought that if they had never contracted the disease they would be more respected, and 79% thought that they would be wealthier. Yet only 11% felt that they were now abused by their neighbours because of their leprosy.

ABILITIES OF THE SEVERELY DEFORMED

Despite their severe deformities most of the patients wanted to, and did in fact, contribute to the support of their households. Only 27% said that they could do nothing but beg. 62% of the severely disabled farmed occasionally, 40% cut wood, 39% cooked, and 15% reported that they carried heavy loads. While 94% desired government assistance, only 8% thought that their lot would be improved if the government took complete care of them.

The patients had, in general, low levels of skill. Only 8% had ever been employed in jobs other than farming; 86% had received no formal education, and 70% spoke only their tribal language.

Comments and Suggestions

Although most of the severely deformed patients in the settlement areas need help from outside, the government assistance is limited by lack of resources. The government has proposed two plans for assisting the settlement populations: (1) to remove all destitute and friendless patients to centres for the destitute, where they would receive food, clothes and shelter; (2) to encourage other settlement patients and their families to form *ujamaa* villages (collective farms);

for those who do so the government promised assistance in the form of dispensaries, schools, water supply, agricultural aid and marketing facilities.

The question may, however, be asked: do these proposals meet the felt-needs of the patients? The centre for the destitute would draw the patient away from his community—a genuine fear. Moreover, most patients did not consider that they needed such complete care. 53% had already joined *ujamaas* in the early stages, and 23% indicated that they would join if they could. The remainder did not want to join because they feared the consequent ostracism.

The government was therefore advised to create *ujamaas* rather than centres for the severely disabled. While *ujamaas* should be organized in other settlements, it was suggested that these should not be exclusively for leprosy patients and their families. Nor should they all be concentrated on agriculture, which may be economically insecure. Severely disabled patients should be encouraged to join the communities, and there be assigned useful but less physically demanding jobs, provided with special tools, or subsidized directly by the government through the *ujamaa* administration so that their presence would not jeopardize the success of the *ujamaa*. Helping the patient in his own community is not only more in accord with the wishes of the patients themselves and also more within the goals of leprosy-control philosophy, but it should prove less expensive than providing for the patient in a centre for the destitute. Nevertheless, such latter centres may be necessary in some instances; but patients should be sent to them only after all efforts have failed to help them in their own communities. Since only 30% of the patients knew any other than their own tribal language, removal to a distant centre would entail an added linguistic hardship.