

Letters to the Editor

UNMET NEEDS OF REHABILITATION IN LEPROSY SERVICES

Editor

Leprosy, a disease caused by *Mycobacterium leprae*, if untreated results in various degrees of disability, deformity, debilitation, destitution and death.¹ The current leprosy services place great emphasis on MDT coverage but generally ignore preventative and timely management of disability, both physical and social.² Leprosy is a socio-medical disease, but the social aspect is often neglected. Usually a sick person is cared for by family members to become independent,³ which is not so with leprosy patients, who either hide the disease from their families or are disowned by them.^{3,4} Each person has a status and a role in society;⁵ inability to perform this role makes it difficult to meet the needs in life, especially as a main breadwinner of the family.

The Scheiffelin Leprosy Research and Training Centre, Karigiri, has been responsible for carrying out the national leprosy control programme since 1962 in Gudiyatham Taluk (population 360,000 in 1961) of Vellore District in Tamil Nadu State. All patients detected are registered for treatment and followed up. Relevant data at registration and during follow-up to release from treatment (RFT) and are stored on a computer system. All persons registered during 1955–1985 were visited to assess their disease/deformity status and well-being. In 1989, it was decided to survey all persons registered for leprosy treatment to assess their medical and socio-economic needs.

There were 16,601 cured leprosy patients during 1955–1985, of whom 9245 could be interviewed; the remaining 7356 had died or migrated. A special proforma was developed to identify various medical and rehabilitation needs, and a multi-disciplinary team collected the data.⁶

More females (79%) had no source of independent living as compared to males (65%). Nearly 75% of the persons affected by leprosy had no land of their own, which is a reflection of their economic status in the community. Nearly 10% of the persons did not have their own shelter. Out of 9245 interviewed, 2040 (22%) were identified as having various rehabilitation needs. Six hundred and sixty (7.13%) needed socio-economic assistance and the remaining 1380 (49.2%) required some medical assistance. In all, 1275 persons (14%) had grade 2 deformity or more.

For the vast majority of persons treated in the pre-MDT era, rehabilitation help came rather late. Most had adapted themselves to a life of dependency or destitution. Many were suffering from a variety of general debilitating conditions. Among the persons requiring social assistance, more than half were in need of self-employment. The second highest category of persons were those in need of a pension/subsistence allowance. An overwhelming majority in this category were over 60 years of age and incapable of productive employment. The rest were in need of job placement and training.

The need for timely, effective and acceptable methods for socio-economic integration of leprosy cured persons is great. Assistance offered so far had ranged from simple welfare measures to enabling independence.^{2,7} Unless economic support is under-girded by strengthening social networks within the family and outside, they are likely to fail.⁸ Public health measures and rehabilitation programmes have not addressed this issue adequately.⁹ In a country such as India with over-population, illiteracy and poverty, the need for identifying effective and appropriate strategies is evident.^{3,10}

Several articles have referred to the needs of rehabilitation among leprosy patients, but no systematic

follow-up seems to have been done in the rural areas.^{11,12} A study done by Kushwah *et al.* in 1981 shows that even in a well-run leprosy control project, 9% had rehabilitation needs.¹³

Persons cured from leprosy have a wide variety of needs and should be offered a wide variety of vocations, compared to the traditional type of rehabilitation based on sheltered workshop in order to prevent them from debilitation. True community-based rehabilitation is essentially participatory, supplemented by counselling and assistance for those who find it difficult to take independent decisions. For those severely disabled who cannot be vocationally rehabilitated, the assistance should be extended to a family member, provided community support is attached to it.

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