Lepr Rev (1990) **61,** 366–374

Disabilities in leprosy patients ascertained in a total population survey in Karonga District, Northern Malawi

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Accepted for publication 18 May 1990

Summary This paper describes the pattern of disability among 1654 leprosy patients ascertained between 1973 and 1987 in Karonga District, Northern Malawi. Approximately 20% of patients identified prior to 1980 had some disability at registration, but this percentage fell to approximately 10% with the introduction of total population surveys in the Lepra Evaluation Project. The proportion of patients with disabilities at registration increased with age, was higher among males than females, was higher among borderline and lepromatous than tuberculoid patients, and was higher for passively than for actively detected patients. The risk of developing disabilities among patients without any disabilities at registration was approximately 5 per 1000 person years, and appeared to be slightly higher after the completion of treatment than during treatment.

Introduction

If leprosy is a public health problem, it is because of the disabilities it causes. Given this fact, it is surprising how little is known of the extent of leprosy-attributable disabilities in endemic populations. Published estimates vary widely, and are difficult to interpret. These estimates are typically expressed as percentages of leprosy 'cases', but the leprosy case definitions, and their representativeness of all leprosy cases in the population, are more often than not unclear. Twenty years ago, Bechelli *et al.* gave estimates of percentages disabled ranging from 7·6% in Cameroon and 23·4% in Nigeria to 48·7% in Burma and 80% in Taiwan.[1,2] Noordeen & Srinivasan reported an overall 'deformity' rate of 19·4% among leprosy patients in South India, and noted increasing deformity associated with increasing age and duration of disease.[3] They also found deformity rates higher in lepromatous than in tuberculoid patients, and higher rates among males than females.

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 0305-7518/90/061366+09 $01.00

Several other authors have discussed disability or deformity in specific groups of patients—often in institutionalized patients or urban leprosy clinics.[4–13] Except for the WHO surveys carried out in Nigeria and Cameroon[14] and a small study carried out in Kenya,[15] there is little published information on the pattern of leprosy-attributable disabilities in African populations.

Very few studies have attempted to relate disability figures to population denominators, let alone to relate leprosy to other causes of disability in the populations concerned. Another fundamental problem is the definition of disability appropriate for leprosy studies. The so called 'WHO-scales' were first proposed almost thirty years ago for this purpose[16,18] but they have been revised repeatedly and there are still very few examples of their use in an epidemiological context. Though the WHO scales have been incorporated into OMSLEP reporting forms, they have never been validated rigorously; and thus many workers have derived alternative schemes for use in various studies around the world.[19–22] We are aware of no attempts to describe leprosy disabilities in the context of the international classification system for impairments, disabilities and handicaps.[23]

We present here a study of disabilities associated with leprosy in Karonga District, Northern Malawi, based on detailed records of patients ascertained over the years 1973–87. The work was carried out in the context of the Lepra Evaluation Project (LEP).

Background

Karonga District is a rural area with a population of approximately 120,000 people in 1980. It has long been known to have a relatively high prevalence of leprosy. The first targeted leprosy control programme was started in 1973 as the Lepra Control Project (LCP). Except for school surveys, the LCP relied entirely upon passive case detection. Large scale active detection of cases began only in 1980 with the onset of the LEP. All households except those in the southern tip of the district were included in the project during the years 1980–84, and more than 112,000 persons were examined for leprosy. The methods of the LEP have been described in detail elsewhere.[24]

The history of leprosy control policies in Malawi and trends in incidence and prevalence of the disease have been described in previous publications.[25,26] Routine treatment policies changed over time, and are described in detail in Table 4 of reference 25. Type I reactions were treated routinely with a 12 week course of prednisolone.

Materials and methods

Several types of records were available for the purposes of this study:

(a) *LCP records made out at registration of patients.* These records include a pictorial representation of lesions, enlarged nerves and disabilities at the time each patient was registered.
(b) *LCP treatment records.* These include a record of all treatment received, of reactions, and of clinical changes during the course of treatment.
(c) *LCP discharge records.* These include a description of lesions and disabilities at time of discharge.

(d) *LEP general and detailed examination forms.* These include independent detailed clinical descriptions prepared each time an individual was met by the LEP survey teams.
(e) *MDT surveillance records* prepared for patients included in a study of WHO-recommended multiple drug therapy regimens in paucibacillary leprosy.[27]
(f) *Repeat examinations* carried out by the principal investigator of this study (IP).

Only individuals who were seen by the LEP at least once, and whose leprosy diagnosis was confirmed by published criteria ('narrow' or 'middle' group—see reference 28) were included in this study. This criterion was chosen as the diagnosis of leprosy prior to the

Table 1. Classification of disabilities into mild, moderate and severe categories, as used in this study

	Comparable WHO classifications		
Malawi disability study definitions	1960 grade	1970 grade	1988 grade
Minor			
Any of the following:			
Face—paresis of eyelids, corneal anaesthesia paresis of mouth, partial collapse of nose	—	—	0 or 1
Hands—median, ulnar or radial paresis, indefinite (doubtful) median, ulnar or glove anaesthesia	—	—	—
Feet—paresis of toes or foot indefinite anaesthesia, dorsum, or plantar anhydrosis with cracking of skin	—	—	—
Moderate			
Any of the following			
Face—lagophthalmos (without loss of vision) collapsed nose mouth drop	2 or 3	1 or 2	1
Hands—definite median, ulnar or glove anaesthesia definite median, ulnar or radial paralysis (but not fixed)	1 or 2	1 or 2	1 or 2
Feet—definite anaesthesia, dorsum or plantar definite paralysis toes or foot	1 or 3	1 or 2	1 or 2
Severe			
Any of the following			
Face—definite lagophthalmos plus loss of vision in various combinations	4 or 5	2 or 3	1 or 2
Hands—definite anaesthesia and/or paralysis on both hands plus ulcer or partial loss of any finger loss of an entire finger	3 to 5	2 or 3	2
Feet—bilateral anaesthesia plus any ulcer or paralysis loss of an entire toe	2 to 5	2 or 3	2
Combination of disabilities in any two extremities			

Table 2. Correspondence between classification employed in this study and the 1960, 1970 and 1988 WHO scales

	WHO scale		
Malawi study	1960	1970	1988
Not included	Grade 1 (on face)	Not included	Not included
'Minor'	Not graded	Not graded	Grade 1 (corneal anaesthesia)
'Moderate'	Grades 1 to 3	Grades 1 and 2	Grades 1 and 2
'Severe'	Grades 2 to 5	Grades 2 and 3	Grades 1 and 2

LEP was not routinely subject to the same rigour as it was thereafter.[28] In addition, this study excludes all individuals with a history of initial antileprosy treatment given either outside Karonga District, or prior to 1973. This criterion was established as there are no good records of the disability status of these individuals at the time of their initial diagnosis and treatment. The exclusion of these groups may have important implications, as will be noted in the discussion.

All records were coded on specially designed forms and entered onto a microcomputer for analysis. Information coded included descriptions of all enlarged peripheral nerves, of doubtful (indefinite) or definite anaesthesia in extremities, of paresis, of paralysis, of diminished vision, and of present or past ulcers and loss or absorption of digits as well as information on the history and treatment of reactions in the past.

For the purposes of this study, disabilities were classified as being either 'minor', 'moderate' or 'severe', according to the schedule presented in Table 1. It will be noted that the disabilities here classified as 'minor' are less than those included on the 1960, 1970 or 1988 WHO scales. Grade 1 disabilities of the face as defined by the 1960 WHO scale (i.e. 'permanent stigma, loss of eyebrows, or deformity of ear') were not included in our study as we do not believe that they represent real disabilities or cause stigma in this Malawian population. On the other hand, the WHO 1988 Grade 1 only includes disabilities of the eyes. Other facial disabilities are not included at all within this scale. Our 'moderate' group comprises items classified as grade 1 or 2 on the WHO 1970 and 1988 scales, or as grades 1 to 3 on the WHO 1960 scale. The correspondence between the classification employed in this study, and the 1960, 1970, and 1988 WHO scales, is summarized in Table 2.

Results

1654 confirmed leprosy patients satisfied the criteria for inclusion in this study. These include 968 females and 686 males. Figure 1A shows the distribution of numbers of patients, by year of registration. The numbers registered per year varied from a high of 160 in 1975, soon after the initiation of LCP activities, to a low of 40 cases ascertained by passive detection during 1985, the year between LEP surveys. The total numbers

registered by the LCP fell during the years 1974–79, reflecting gradual ascertainment of patients which had accumulated in the district prior to the appearance of LEPRA. High numbers of cases were detected during the years 1980–84 and again in 1986–1987, reflecting active case detection by the LEP. The relatively low number recorded in 1982 reflects temporary interruption of fieldwork due to staff illness.

Figure 1(B) presents a breakdown of these patients by their disability status at registration. The percentage disabled at registration fell from approximately 20% during the era of passive case detection, to approximately 10% during the LEP survey, reflecting the early detection of cases by active case finding. It is notable that the percentages disabled at registration were highest in 1978, 1979 and in 1985, coinciding with small total numbers of patients, almost all of whom self-reported.

Figures 2(A)–(D) show the percentage breakdown of disability status by age at registration, sex and mode of ascertainment. Each of these variables is seen to have an important relation to the distribution of disabilities. First, there is a clear increase of percentage with disabilities with age at registration. Out of 114 children under age 10, only 2 had any disability at registration. Second, there were higher disability rates among males, for both the passively and the actively detected groups. Third, disability percentages were much higher among passively detected (self-reporting) cases than among those actively detected in the epidemiological survey. The percentage with any disability among actively detected females did not exceed 10% for any age group, whereas it rose to over 40% among the oldest group of self-reporting females. This difference is less marked among males than females.

Figure 3 shows disability status at registration by classification, for females and males separately. There is a tendency in each sex for the percentage with severe disabilities at registration to rise as one moves across the spectrum from tuberculoid to lepromatous groups.[17] The proportions with moderate disabilities were highest among the borderline

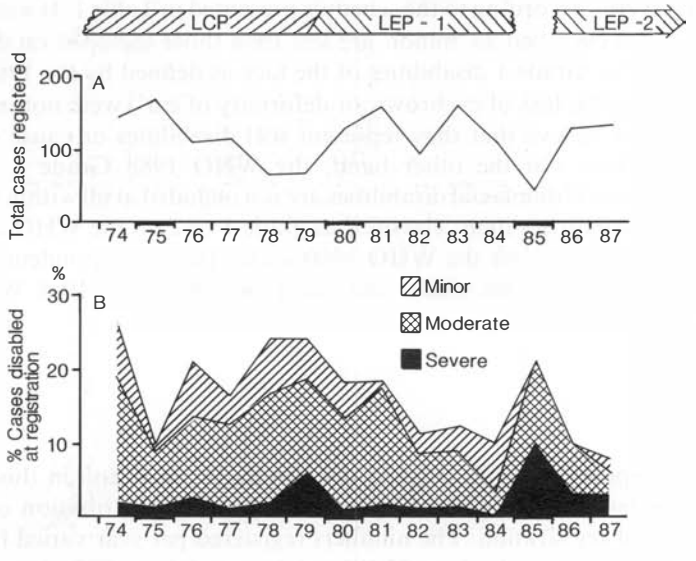

Figure 1. Annual numbers registered (A) and disability status (B) of 1654 confirmed leprosy patients registered in Karonga District, Northern Malawi, 1973–87.

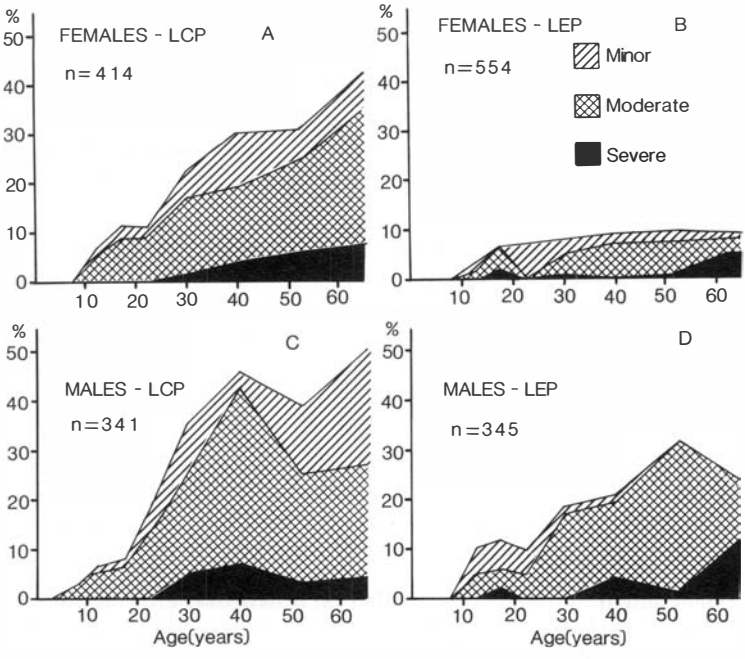

Figure 2. Percentages of leprosy cases with minor, moderate or severe disabilities, by age at registration, sex and mode of ascertainment. (LCP = Lepra Control Project, passive detection; LEP = Lepra Evaluation Project, active detection).

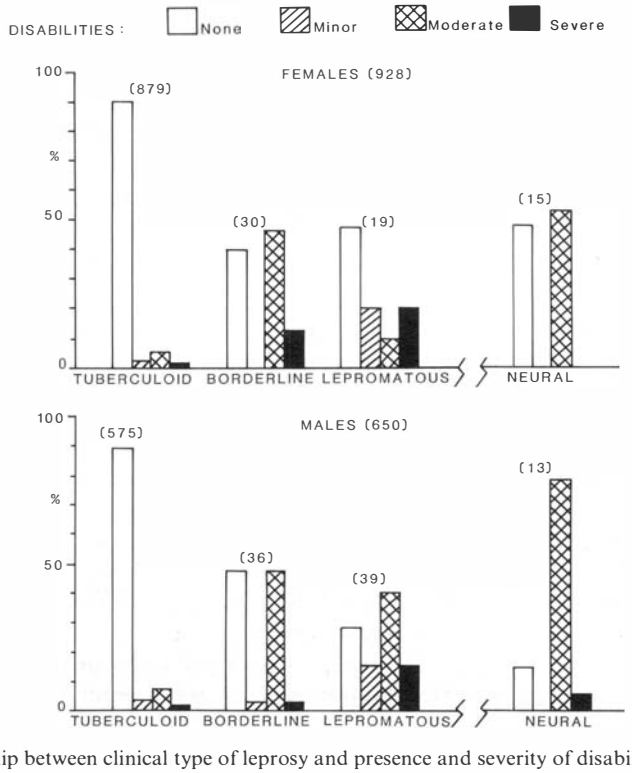

Figure 3. Relationship between clinical type of leprosy and presence and severity of disabilities at registration, separately for males and females. The Figure excludes 48 patients of uncertain classification.

Table 3. Risks of developing disabilities during and after treatment.

Sex	Number	Person years at risk	Numbers of new disabled (and rate per 1000 person years)	
			All disabilities	Moderate and severe
During treatment				
Females	750	2596	9 (3·5)	2 (0·8)
Males	479	1872	4 (2·1)	4 (2·1)
Total	1229	4468	13 (2·9)	6 (1·3)
After completion of treatment				
Females	498	1340	12 (9·0)	6 (4·5)
Males	329	916	6 (6·6)	5 (5·5)
Total	827	2256	18 (8·0)	11 (4·9)

patients, in particular in females. It may also be noted that although there were larger numbers of female patients overall, there were twice as many lepromatous males as lepromatous females (39 compared to 19). Out of 28 patients with neural leprosy, 19 (68%) had moderate or severe disabilities.

Table 3 presents the risks of developing disabilities either during treatment, or after discharge, among individuals with no recorded disabilities at time of initial registration, or at time of discharge from treatment, respectively. Incidence rates of disabilities after discharge were based upon new disabilities between discharge and the first recorded subsequent examination, and thus relate to a period of time during which the individuals were on no antileprosy treatment whatsoever. These data show a low risk of developing any disabilities during treatment—approximately 3 per 1000 persons per year (1·3/1000 for moderate and severe disabilities), but slightly higher risks, in the order of 8 per 1000 person years (4·9/1000 for moderate and severe disabilities) after completion of treatment. Each of these differences between pre- and post-treatment rates is statistically significant ($p < 0{\cdot}02$).

Discussion

This analysis of data on 1654 confirmed leprosy patients diagnosed in Karonga District, Northern Malaŵi, between 1973 and 1987, shows several clear patterns. The proportions with disabilities were appreciably higher for cases who self-reported than for actively detected cases. The actual differences observed necessarily reflect many things: the history and classification (e.g. proportion multibacillary) of leprosy in the population; cultural factors (e.g. health care seeking behaviour), availability of routine health services and the history and intensity of active case ascertainment.

Interpretation of the time trend in disability rates prior to the LEP, as shown in Figure 1, is complicated by the fact that our analysis has excluded individuals who were not seen, and hence not diagnostically confirmed, by the LEP. This criterion has probably meant the exclusion of some (severe?) leprosy cases who were registered by the LCP but

who died prior to being seen by the LEP, and perhaps also some (mild?) cases who were registered and treated by the LCP but whose lesions had so totally resolved by the time they were seen by the LEP that their original diagnosis could no longer be confirmed. As these potential biases are of unknown magnitude, and in opposite directions, their overall impact on the observed severity distribution (Figure 1(B)) is unclear. Such difficulties frequently arise in attempting to interpret data from routine control programmes.

The sex differences seen in these data are particularly interesting. Though leprosy is more frequent among females than males in this population,[26] it is more severe among males. These differences are seen in terms of percentages disabled (Figure 2) and also in the numbers and percentages of multibacillary forms of the disease (Figure 3). Though a general male predilection for lepromatous disease has been noted by other authors,[2,3,29,30] these data are unusual in that the overall prevalence of leprosy is appreciably higher among females in this population. A similar pattern was also found in a small study carried out in Kenya.[15] Consistent with the association of more severe and disabling forms of the disease with males we may also note a tendency for disability rates to fall among older males, but not older females (see Figure 2). This may be a chance observation, but it could also reflect selective mortality among more severely affected elderly males. We plan to explore this hypothesis in future analyses of LEP data.

The incidence rates of disability presented in Table 3 represent unusual statistics, as there are few comparable data in the leprosy literature. Several authors have reported incidence rates of disabilities during the course of treatment. For example Keeler & Ryan[31] reported onset of disabilities in 2 (0·6%) of 335 patients after several years of treatment on the islands of Trinidad and Tobago. More impressive are analyses presented by Radhakrishna & Nair on the incidence rates of 'deformities' among almost 6000 leprosy patients on dapsone therapy in Polambakkam, South India.[32] These authors found incidence rates of 'deformity' in the order of 14 per 1000 person years among nonlepromatous cases. Each of these studies used different criteria for disabilities or deformities, and neither reported on disabilities arising after the completion of chemotherapy. Of particular interest in our data is the suggestion of higher incidence rates of disabilities *after* rather than *during* treatment (e.g. 4·9 compared to 1·3 per thousand person years for disabilities classified as moderate or severe). We plan in the future to compare these data with ongoing follow-up studies of patients during and after discharge from short course multiple drug regimens.[27]

It should be emphasized that we have described the disabilities in this population in a manner which is analogous but not identical to systems used by other authors or to any of the WHO scales. This has been necessary because of the nature of the data available to us, and has seemed preferable in that it allowed us to adjust the severity grading to what appears to us to be appropriate for this African population. The concordance between our system and the various WHO scales is illustrated in Tables 1 and 2. Given that the literature now contains many different systems for classifying leprosy-attributable disabilities, there is a need for a critical review of these systems, preferably with reference to the International Classification of Impairments Disabilities and Handicaps as recommended by the World Health Organization.[23]

Acknowledgments

This study was carried out with support from LEPRA, the British Leprosy Relief

Association. The authors express particular thanks to Ms Rosie Hau for assistance in field work and data coding and Ms Carol Nelissen for help in preparing the typescript.

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