

Epidemiology of Disability in Leprosy

I. A General Study of Disability Among Male Leprosy Patients Above Fifteen Years of Age¹

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Epidemiologic data on disability in leprosy patients are few. With the advances made in the use of physiotherapy and corrective surgery toward physical rehabilitation, and increasing interest in social rehabilitation, getting dependable information on the problem of disability becomes necessary.

Information on disability in leprosy, in the past, has come mostly from leprosaria and outpatient clinics. Often, however, such information does not reflect the true situation as it exists, since the groups are highly selected. For a correct picture we need information collected from well organized field studies. Such information on disability is essential for planning effective rehabilitation measures on a large scale.

This paper is the result of analyses of data collected from the field and is based on a planned survey. It is believed to represent the true situation regarding the various factors associated with disability.

METHODS AND MATERIALS

Selection of sample. The present study was conducted in the Chingleput taluk of Madras State, India. This area was chosen because it has been surveyed earlier for leprosy, and basic information on all leprosy patients was available. The area had 300 villages with a total population of about 200,000 persons, among whom were about 4,150 leprosy patients, of whom 2,174

were males above 15 years of age. It did not appear necessary to study all 2,174 patients for the purpose of the present investigation, and so it was decided to conduct a sample survey. A representative 20 per cent sample of the 300 villages was selected, and all the male leprosy patients above 15 years of age were included in the study. This sample had 62 villages with 484 such patients. Of these 484 patients, 465 (96%) were actually studied. Only male patients above 15 years were chosen for this study, since these belonged to the wage-earning group and disability among them was likely to have a serious effect on their relations with society.

Method of survey. Information for this study was collected by an experienced field worker. Patients included in the sample were interviewed individually and examined by the field worker on the basis of a preplanned proforma. The proforma had been "pretested" earlier on a small population, and suitable alterations had been made so that the information obtained was comparable and reliable. The information collected by the field worker was verified further by one of us by means of a 20 per cent sample check. The survey took four months to complete.

Variables studied. Information on the following variables was collected and studied:

Disability. This was the main subject of the present study. Data on the other variables were collected so as to relate them to disability or its components. The disability among leprosy patients was classified as (a) social disability and (b) phys-

¹Received for publication October 21, 1965.

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TABLE 1. Components of disability in cases studied.

Disability	Patients	
	No.	%
Physical	73	15.7
Social	9	1.9
Combined social & physical	83	17.8
None	300	64.5
Total	465	99.9

ical disability. Information on social disability was based on replies by the patients to certain questions on discrimination against them. Physical disability was determined by examination of patients and by using a method of scaling specially prepared for this purpose. The details of the scale are given later.

Age in years. This was based on patients' statements.

Type of leprosy. Leprosy was classified in three main groups: lepromatous (L), nonlepromatous (N), and intermediate (N?L). This system was based on the classification followed by the Indian Association of Leprologists (1).

Duration of disease. The record was based on each patient's statement and rounded off to the nearest year.

Caste. Caste status was one of the variables studied. Only the main castes were taken into account. Numerically minor castes were grouped as "others." Thus the

sample was composed of Naickers, Harijans, Mudaliars, Naidus, Pillais, Chettiars and "others."

Treatment status. The information recorded was based mainly on treatment records of the Mobile Unit of the Central Leprosy Institute, and treatment was classified as "regular treatment" (attendance at at least 50% of the clinics), "irregular treatment" (attendance at less than 50%), and "no treatment." The treatment referred to here is treatment with DDS. The maximum dose given was 600 mgm. per week.

Occupation status. Information was collected on occupation of the patients, both before and after they acquired leprosy. If the occupation after leprosy developed was different from that before advent of the disease, inquiry was made as to the reasons for change of occupation. The various occupations were classified with respect to heavy work or light work and skilled or unskilled jobs. The details of this classification are given later.

Economic worsening. In the questionnaire part of the proforma the patients were asked if they had worsened economically after acquiring leprosy, and if the deterioration was due to disability, either physical or social.

FACTORS INFLUENCING DISABILITY

Of the 465 patients studied, 300 had no record of disability; 165 had disability of some kind. The disability rate was thus

TABLE 2. Disability and age.

Age in years	Patients				Total
	Disabled		Not disabled		
	No.	%	No.	%	
15 - 19	1	5.9	16	94.1	17
20 - 24	7	17.5	33	82.5	40
25 - 29	16	27.1	43	72.9	59
30 - 34	20	33.3	40	66.7	60
35 - 39	19	37.2	32	62.8	51
40 - 44	20	40.0	30	60.0	50
45 - 49	26	41.9	36	58.1	62
50 - 54	18	48.6	19	51.4	37
55 - 59	18	54.5	15	45.5	33
60 & over	20	35.7	36	64.3	56
Total	165	35.5	300	64.5	465

TABLE 3. Disability and caste.

Caste	Patients				Total
	Disabled		Not disabled		
	No.	%	No.	%	
Naicker	48	31.0	107	69.0	155
Harijan	34	25.6	99	74.4	133
Mudaliar	31	46.3	36	53.7	67
Naidu	13	46.4	15	53.6	28
Pillai	9	52.9	8	47.1	17
Chettiar	9	60.0	6	40.0	15
Others	21	42.0	29	58.0	50
Total	165	35.5	300	64.5	465

TABLE 4. Disability and treatment status.

Treatment status	Patients				Total
	Disabled		Not disabled		
	No.	%	No.	%	
No treatment	13	9.8	119	90.2	132
Irregular treatment	62	41.9	86	58.1	148
Regular treatment	90	48.6	95	51.4	185
Total	165	35.5	300	64.5	465

35.5 per cent. The disabled persons were classified as (1) with physical disability, (2) with social disability, and (3) with both physical and social disability (Table 1). Most patients with disability had either physical disability alone or physical disability together with social disability. Those who had social disability without physical disability were few, whereas a considerable number of patients had physical disability without any social disability. This shows that physical disability in this leprosy population is more important than social disability.

Age. The influence of the age of the patient on disability is shown in Table 2. It can be seen that the disability rate increased as the age increased. As shown later (Table 6) this was found to be due mainly to the longer duration of disease in patients in the later age groups. It can be seen also that persons over 60 years of age showed a lower disability rate than those of the preceding age groups; this could be due to the decreased rate of survival among the very aged disabled persons.

Caste. Disability rates among patients belonging to the different castes are shown in Table 3. It can be seen that the disability rate was not the same for all castes and showed wide variations. Harijans, as a caste, showed a statistically significant low disability rate in comparison with that of the other castes ($t = 3.01$; $p < 0.01$).

Type of leprosy. Of the patients studied, 102 were lepromatous, 343 were nonlepromatous and 20 were intermediate; the disabled among them were 71 (69.6%), 84 (24.4%) and 10 (50.0%) respectively. Thus disability among the lepromatous patients was found to be about three times as common as among the nonlepromatous. This is understandable, because lepromatous leprosy is generally progressive and as such is potentially capable of producing disability, whereas a great proportion of nonlepromatous cases have localized and often nonprogressive disease.

Treatment status. Disability rates among patients with different treatment status are shown in Table 4. It is seen that the disability rate among patients with no treatment was very low, and only about one-

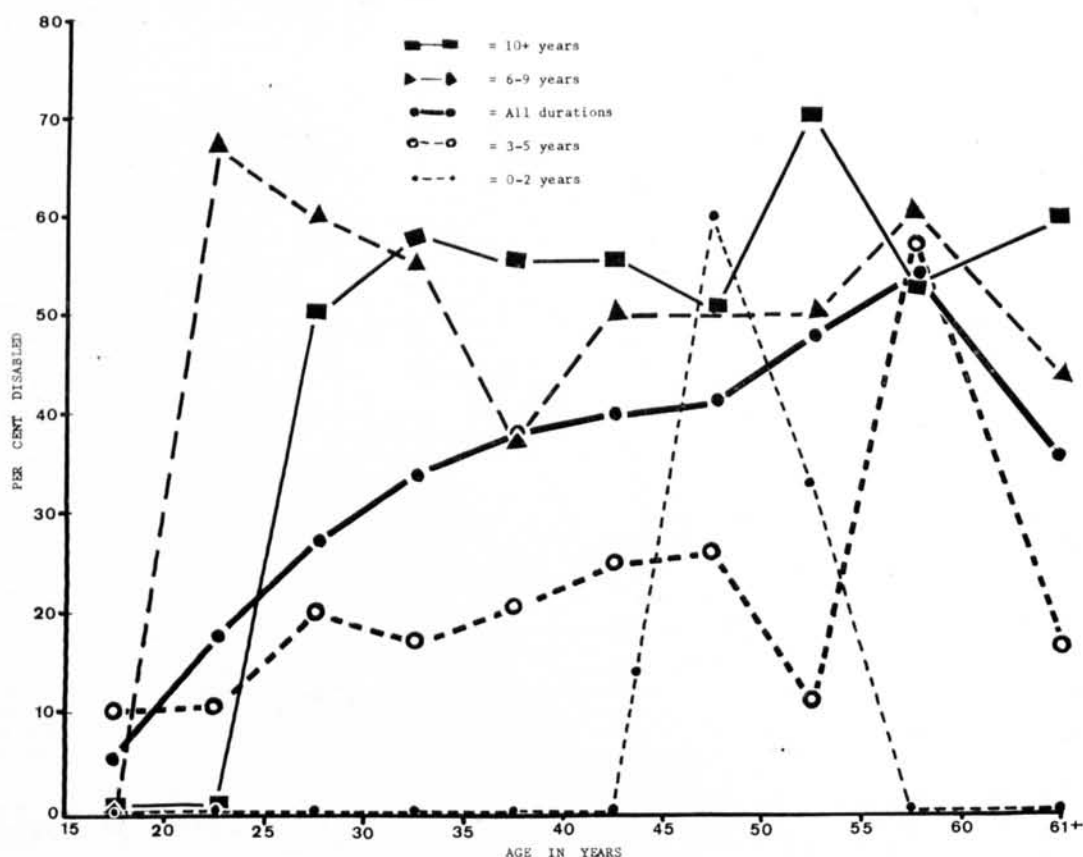


FIG. 1. Disability rates according to age and duration of disease.

fifth of that among those with treatment, regular or irregular. The difference is statistically significant ($t = 9.50$; $p < 0.001$). This finding will be discussed in a subsequent paper.

Duration of leprosy. Table 5 shows disability rates among patients grouped according to duration of the disease. The disability rate is seen to increase with increasing duration of the disease. The mean

duration of leprosy for the disabled was 9.2 years, and 5.7 years for the nondisabled. The influence of duration in relation to certain other variables associated with disability was studied in some detail.

Disability rates in relation to duration and age are shown in Table 6 and Figure 1. From these it appears that duration of disease was more important than age of the patient, as in all age groups the chances

TABLE 5. Disability and duration of disease.

Duration of disease in years	Patients				Total
	Disabled		Not disabled		
	No.	%	No.	%	
0 - 2	4	8.7	42	91.3	46
3 - 5	39	19.7	159	80.3	198
6 - 9	45	52.9	40	47.1	85
10 & over	77	56.6	69	43.4	136
Total	165	35.5	300	64.5	465

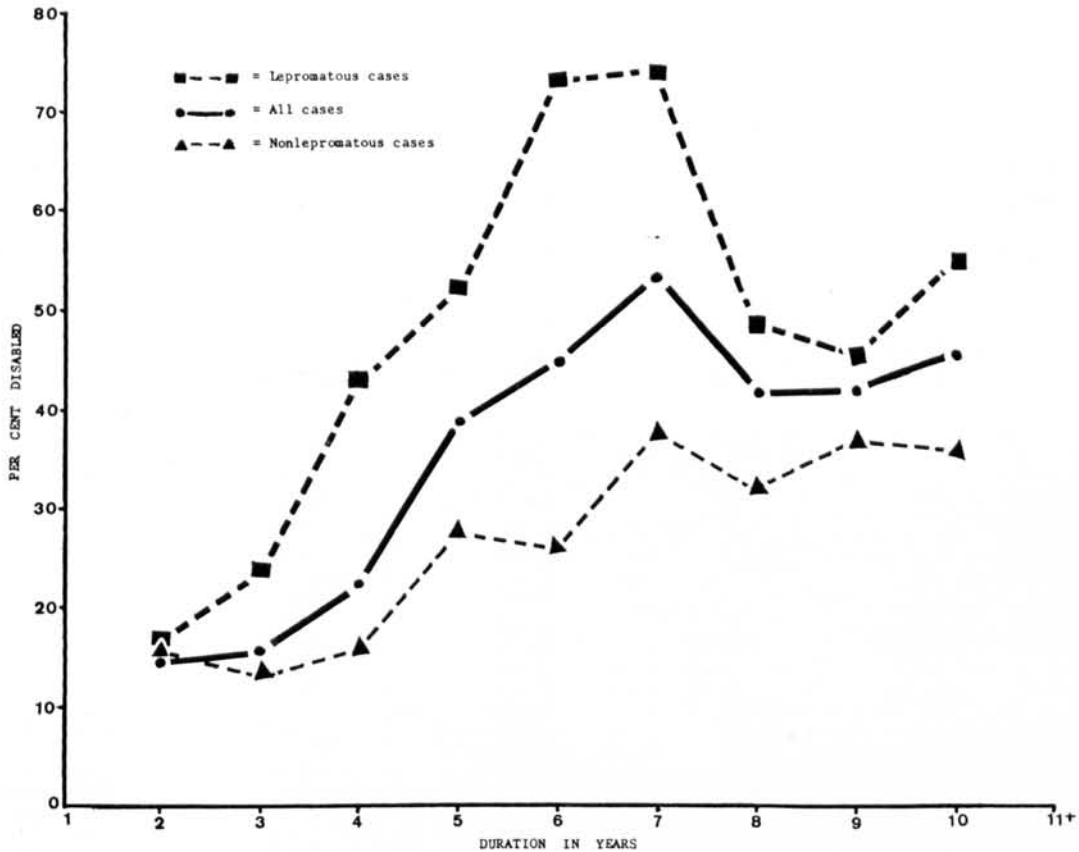


FIG. 2. Disability rates according to duration of disease and type of leprosy. (The disability rates are worked out on the basis of a three-year moving mean.)

of leprosy patients becoming disabled as a result of disease appeared far greater in cases of duration of more than five years than in cases with duration of less than five years.

Figure 2 shows disability rates according to duration and type of leprosy. It can be seen that for all duration categories, the disability rates are considerably greater for lepromatous than for nonlepromatous cases. The mean durations of disease for the disabled among L, N, and N?L types were 10.1, 8.6 and 7.9 years respectively; for the nondisabled they were 6.6, 5.6 and 6.2 years respectively. The data show that the disabled had a longer duration in each type than the nondisabled, and that both duration and type of leprosy are important in influencing the disability rate.

Disability rates in relation to duration and treatment status are given in Table 7 and Figure 3. It is evident that, although disability rates in treated patients increased with duration of the disease, this was not true for those who had no treatment. Duration of disease apparently had no influence on disability rates among those who had no treatment.

Occupation status. On the basis of the nature of work, i.e., heavy or light, and the requirement or not for manual skill, the occupational status of the patient was classified as shown in Table 8. Only the past occupation was considered for this analysis, as it was more relevant than the current occupation. Only 63 patients (13.5%) had changed or lost their occupations as a result of leprosy.

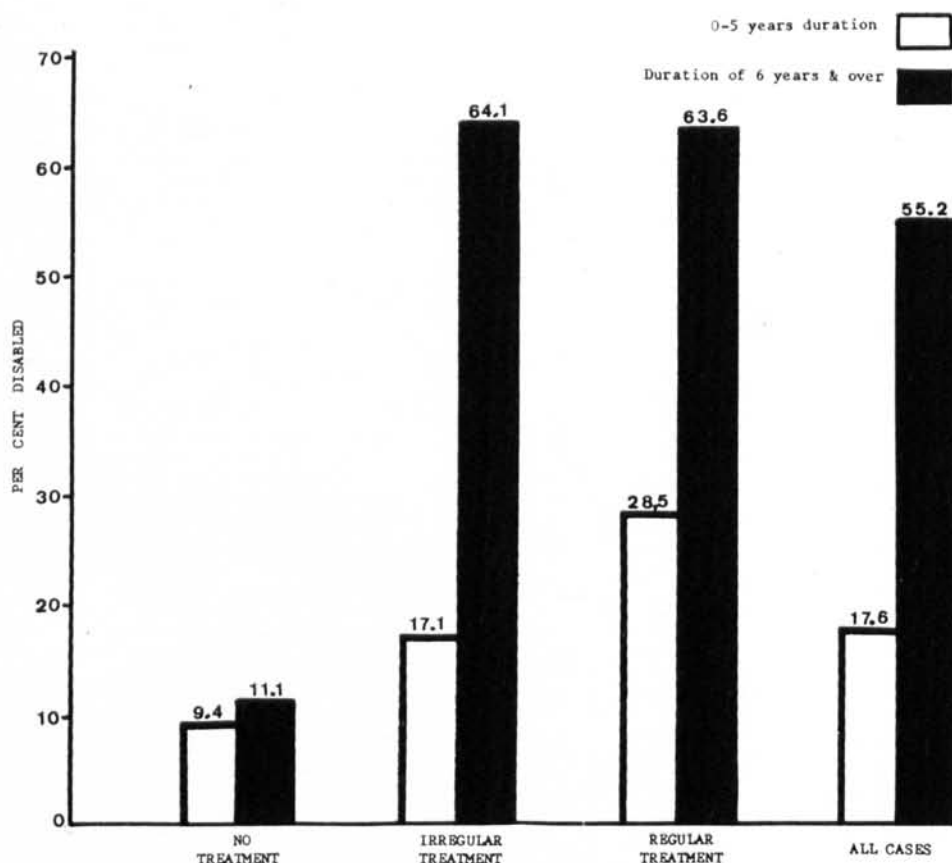


FIG. 3. Disability rates according to treatment status and duration of disease.

Table 9 gives the disability rates among the different occupational groups. It is seen that disability was maximum among patients doing heavy work, whether skilled or unskilled. Disability was found to be least in skilled light occupations and in agricultural work. The disability rate among agricultural workers compared with that among others was significantly low ($t = 2.44$; $p < 0.02$).

Economic worsening. The disability rate among those who were economically worsened as a result of leprosy was found to be very high, 86.3 per cent (120 out of 139). It was found to be low among those who had not worsened economically, 13.8 per cent (45 out of 326). Similarly, economic worsening was seen in 72.7 per cent, or 120 out of 165 among the disabled, and in only 6.3 per cent, or 19 out of 300 among those

who were not disabled. This shows that disability and economic worsening go together.

DEFORMITIES OF HANDS AND FEET

Up to this point variables were studied for disability as a whole, which included social as well as physical disability. Physical disabilities in hands, feet and eyes will now be considered and taken up individually.

Study of deformities in groups of persons presents certain problems of comparison of data. These difficulties are due to the variations in site, type and extent of deformities, and the numerous possible combinations of these that may occur and hinder comparison between groups. To overcome these difficulties a special method of scaling was used. In this method

TABLE 6. *Disability according to age and duration of disease.*

Age in years	Disability rates among various disease duration groups				Total %
	0 - 2 years %	3 - 5 years %	6 - 9 years %	10 years and over %	
15 - 19	0.0 (0/4)	10.0 (1/10)	0.0 (0/2)	0.0 (0/1)	6.0 (1/17)
20 - 24	0.0 (0/6)	10.7 (3/28)	66.7 (4/6)	0.0 (0/0)	17.5 (7/40)
25 - 29	0.0 (0/11)	20.0 (6/30)	60.0 (6/10)	50.0 (4/8)	27.1 (16/59)
30 - 34	0.0 (0/5)	17.2 (5/29)	55.6 (5/9)	58.8 (10/17)	33.3 (20/60)
35 - 39	0.0 (0/3)	21.7 (5/23)	37.1 (4/7)	55.6 (10/19)	37.3 (19/51)
40 - 44	0.0 (0/4)	25.0 (4/16)	50.0 (5/10)	55.5 (11/20)	40.0 (20/50)
45 - 49	60.0 (3/5)	26.1 (6/23)	50.0 (7/14)	50.0 (10/20)	41.9 (26/62)
50 - 54	33.3 (1/3)	11.1 (1/9)	50.0 (4/8)	70.6 (12/17)	48.6 (18/37)
55 - 59	0.0 (0/1)	57.1 (4/7)	60.0 (6/10)	53.3 (8/15)	54.5 (18/33)
60 & over	0.0 (0/4)	17.4 (4/23)	44.4 (4/9)	60.0 (12/20)	35.7 (20/56)
Total	8.7 (4/46)	19.7 (39/198)	52.9 (45/85)	56.6 (77/136)	35.5 (165/465)

Note: Figures in parentheses indicate number disabled in relation to total for each cell.

TABLE 7. *Disability according to treatment status and duration of disease.*

Duration of disease in years	Disability rate in patients of different treatment status			
	None %	Irregular %	Regular %	Total %
0 - 2	4.2 (1/24)	0.0 (0/14)	37.5 (3/8)	8.7 (4/46)
3 - 5	11.1 (8/72)	21.4 (12/56)	27.1 (19/70)	19.7 (39/198)
6 - 9	0.0 (0/14)	55.2 (16/29)	69.0 (29/42)	52.9 (45/85)
10 & over	18.2 (4/22)	69.4 (34/49)	60.0 (39/65)	55.6 (77/136)
Total	9.8 (13/132)	41.9 (62/148)	48.6 (90/185)	35.5 (165/465)

Note: Figures in parentheses indicate number disabled in relation to total for each cell.

TABLE 8. *Classification of occupation.*

Category	Nature	Occupation groups included
Unskilled	Heavy	Laborers, fishermen, railway gangmen, woodcutters
Unskilled	Light	Landowners, shopkeepers, shepherds, cleaners, watchmen, clerks, teachers
Unskilled	Special	Agricultural workers
Skilled	Heavy	Carpenters, goldsmiths, masons, potters, foremen, military servicemen, cart drivers
Skilled	Light	Tailors, barbers, dhobies, maistries
Skilled	Special	Weavers

TABLE 9. *Disability and occupation.*

Occupation classification	Patients				Total
	Disabled		Not disabled		
	No.	%	No.	%	
Unskilled heavy	23	47.9	25	52.1	48
Unskilled light	39	34.5	74	65.5	113
Unskilled agriculture	58	29.3	140	70.7	198
Skilled heavy	13	68.4	6	31.6	19
Skilled light	7	33.3	14	66.7	21
Skilled weaving	21	36.8	36	63.2	57
Unemployed	4	44.4	5	55.6	9
Total	165	35.5	300	64.5	465

TABLE 10. *Deformity scale.*

Type of deformity	Score	
<i>Hand</i>		
Anesthesia	2 per finger	1 for dorsum and 1 for palmar anesthesia
Paralysis	5 per finger	
Absorption	2 for little finger	Half the score for absorption of less than half the digit
	4 for ring finger	" " " " "
	6 for midfinger	" " " " "
	8 for index finger	" " " " "
	20 for thumb	" " " " "
<i>Foot</i>		
Ulcers	1 for each toe tip	
	5 for each ulcer elsewhere	
Absorption	2 for each toe	
	30 for fore-foot absorption	
Drop-foot	30 per foot	

each particular deformity in a hand or a foot was given a numerical score and the total scores for that limb were added up. The scores for the right and left hands and for the right and left feet were added up separately. Thus deformity scores for the hands and for the feet were obtained separately for each patient.

The deformity status of each patient was then determined separately for his hands and for his feet from the scores obtained as above and expressed in terms of grades. Four grades of deformity status were used, designated respectively A, B, C, and D. Grade A repre-

TABLE 11. Grading of deformity status.

Hands		Feet	
Grade	Aggregate score	Grade	Aggregate score
A	0 - 5	A	0 - 4
B	6 - 20	B	5 - 20
C	21 - 70	C	21 - 70
D	over 71	D	over 71

among 930 hands). Among the claw hands the order of decreasing frequency by the number of fingers involved was as follows: two fingers (63 out of 183), one finger (51 out of 183), five fingers (46 out of 183), three fingers (12 out of 183), and lastly four fingers (11 out of 183). In the case of absorption of digits, one and two fingers were more often involved (28 and 25 re-

TABLE 12. Association between deformity status of hands and feet.

Feet	Hands				Total
	Grade A	Grade B	Grade C	Grade D	
Grade					
A	309	30	29	2	370
B	15	18	25	6	64
C	3	4	14	9	30
D	0	0	0	1	1
Total	372	52	68	18	465

($\chi^2 = 172.6$; $p < 0.001$)

sented practically no deformity, and grades B, C and D represented increasing severity of deformity in this system of measurement. The details of the scale are given in Tables 10 and 11.

Among the 465 patients studied, 165 had deformities (35.5%). Sixty-one patients had hand deformities only, 18 had foot deformities only, and 77 had combined deformities of hand and foot. Thus 138 patients (29.7% of total patients) had deformities of a hand, either alone or in association with deformities of a foot, and 95 patients (20.4% of total) had deformities of a foot, either alone or in association with deformity of a hand. These figures show that hand deformities were more common than foot deformities.

As can be seen from the above, patients who had deformities of a hand did not necessarily all have deformities of a foot and *vice versa*. But a certain amount of correlation in the occurrence of the two was found (Table 12). Out of 465 patients, 342 had the same grades of deformity for hands and feet.

Type of deformity. *Hands.* Clawing of digits was more common than absorption, viz., 19.7 per cent as compared with 8.3 per cent (183 instances of clawing as compared with 77 instances of absorption

respectively out of 77 hands) than three, four or five fingers (8, 10 and 6 respectively among 77 hands).

Feet. Ulcers of feet were more common than absorption. Out of 930 feet 146 (15.7%) had ulcers, whereas only 78 (8.4%) showed absorption. Drop foot was seen in only 8 feet (0.9%).

Eyes. Six patients had lagophthalmos of one or both eyes (4 and 2 patients respectively), and none of the 6 was blind. Another 6 patients were blind in one or both eyes (4 and 2 respectively) and none of these 6 had lagophthalmos. The figures indicate a blindness rate of 12.9 per 1,000 for male leprosy patients over 15 years of age in this area. The blindness rate for the whole male rural population for the Chingleput district has been estimated by the census department, in a special survey conducted in 1963, as 6.9 per 1,000 (²).

The 12 patients with eye disability were not analyzed separately, as all of them had associated hand or foot deformities.

Variables influencing hand and foot deformities. *Age.* On analysis of deformities of hands and feet separately it was found that in both cases the deformities increased with increasing age of the patient.

Type of leprosy. Deformities of hands as well as feet were more common among

the lepromatous cases than the nonlepromatous. The difference in deformity rates between lepromatous and nonlepromatous cases was more striking for hand than for feet. The hand deformity rate for lepromatous cases was 57.8 per cent and for nonlepromatous cases 20.4 per cent, i.e., a difference of about three times; foot deformity rates in the two types were 35.3 per cent and 15.5 per cent respectively, a difference of a little over two times.

Duration of disease. No difference was found between hands and feet with regard to the influence of duration of disease on deformity rates. In both cases deformity rates increased with increasing duration of disease.

Occupation status. Deformities of hands were most common among skilled and unskilled heavy workers and least common among skilled light workers and agricultural workers. Deformities of feet were most common among skilled heavy workers and weavers. They were least common among agricultural workers.

Thus in both hands and feet the various factors influencing deformities operate to about the same extent.

SUMMARY

About a third of the 465 patients studied had some disability. Social disability was not as important as physical disability in this population. Disability increased with increasing age and increasing duration of disease. It was least among nonlepromatous cases of leprosy.

Disability was least among Harijans, patients who did not take treatment, and agricultural workers. Disability generally led to economic worsening. The influence of the different variables on deformities of hands and feet was approximately the same.

The influence of age, duration, and type of leprosy on disability can be explained from the present understanding of the disease. But the influence of the other three factors, occupation, treatment and caste status is not explainable on the basis of

present understanding. These three factors need a more detailed analysis than the one presented here and will be taken up in a subsequent paper.

RESUMEN

Alrededor de un tercio de los 465 pacientes estudiados mostraron alguna incapacidad. La incapacidad social no ha sido tan importante como la incapacidad física. La incapacidad aumentó con el aumento de edad y el aumento de la duración de la enfermedad. Fué menor entre los casos no lepromatosos de lepra.

La incapacidad fué menor entre los Harijans, los pacientes que no tuvieron tratamiento y los trabajadores agrícolas. La incapacidad generalmente llevó al empeoramiento económico. La influencia de las diferentes variables sobre deformidades de las manos y pies fué aproximadamente la misma.

La influencia de la edad, duración y tipo de lepra sobre la incapacidad, puede ser explicada con el presente entendimiento de la enfermedad. Pero la influencia de los otros tres factores, ocupación, tratamiento y casta no es explicable sobre la base del entendimiento actual. Estos tres factores necesitan un análisis mas detallado que el presentado aquí y serán tomados en un trabajo subsecuente.

RÉSUMÉ

Un tiers environ parmi 465 malades qui ont été étudiés présentaient un certain degré d'invalidité. L'invalidité sociale dans cette population n'était pas aussi importante que l'invalidité physique. L'invalidité augmente avec l'âge et avec la durée de la maladie. Elle était moins fréquente parmi les cas de lèpre non-lépromateuse.

L'invalidité était moindre parmi les Harijans, les malades qui n'étaient pas soumis au traitement, et les travailleurs agricoles. Généralement l'invalidité mène à une détérioration du niveau économique. L'influence de ces différents facteurs sur les déformations des mains et des pieds était approximativement la même.

L'influence de l'âge, de la durée de la maladie et du type de lèpre sur l'invalidité peut être expliquée sur la base de notre connaissance actuelle de l'affection. L'influence des trois autres facteurs, occupation, traitement et caste, ne peut toutefois pas être expliquée sur la base de notre connaissance actuelle. Ces trois facteurs requièrent une analyse plus détaillée que celle présentée ici et sera entreprise dans une communication ultérieure.

Acknowledgment. Statistical help for this study was provided by Sri K. V. N. Prasad, Statistician, and Sri K. P. Ganesan, formerly Statistical Assistant, Division of Epidemiology and Statistics, Central Leprosy Teaching and Research Institute, Chingleput.

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