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Prevalence of Deformities and Disabilities Among Leprosy Patients in an Endemic Area

Part I. General Findings[1, 2]

P. S. S. Rao, S. Karat, A. B. A. Karat and M. A. Furness[3]

Disability and deformity in leprosy patients, despite adequate antileprosy treatment, constitutes a major problem in the management of the disease. There is a need not only to quantify the magnitude of this problem, but also to determine the etiology of the various disabilities and deformities that occur in leprosy either as part of the disease process or due to lack of adequate patient care. The part played by antileprosy therapy in complicating this problem also needs to be elucidated. Epidemiologic studies of the prevalence of disabilities sponsored by the World Health Organization have been undertaken in Nigeria, Cameroon, and Thailand (4). Similar prevalence studies have been carried out in a few parts of India (1, 3, 5, 6). Comparative studies, or application of the estimates from these various studies, are difficult because of differences in the criteria used for defining and classifying disability. The methods used for detection and grading have also varied widely. If the extent of the disabilities are to be assessed, and compared in different areas it is essential not only to develop criteria which are acceptable and reproducible for classifying disability but to indicate objective and precise methods of assessment.

The leprosy control program carried out by the Schieffelin Leprosy Research Sanatorium, Karigiri, caters to the needs of nearly 8,500 patients residing in Gudiyatham Taluk (population approximately 400,000) which is one of the administrative units of North Arcot District, in Madras State, South India. The program provided opportunity to undertake a comprehensive study of disabilities and deformities. The major objectives of this study were to determine:

(a) The magnitude of the problem of disability (prevalence).

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2 This work was carried out under the sponsorship of Schieffelin Leprosy Research Sanatorium, Karigiri, Tamilnadu, India, and was supported by funds received from Social and Rehabilitation Service, Washington, D.C., U.S.A., under research Project No. SRS-IND-32 and from the Swedish Red Cross, Stockholm.

3 P.S.S. Rao, M.A., M.P.H., F.S.S., Consultant Biostatistician; M. A. Furness, M.C.S.P., Chief Physiotherapist, Schieffelin Leprosy Research Sanatorium, Karigiri, via Katpadi, North Arcot District, South India; Mrs. S. Karat, M.B., F.R.C.S. (Edin.); A.B.A. Karat, B.Sc., M.B., M.R.C.P. (Lond.), Church of South India Hospital, Bangalore Cantonment, Bangalore 2, Mysore State, India. *Requests for reprints* should be addressed to Mrs. S. Karat.

(b) The number of new cases of disability that arise each year (incidence).
(c) The relationship of the disability to the classification of leprosy, and to disease and treatment status.
(d) The extent of disability that can be directly related to the disease process *per se* quite apart from the disabilities that occur due to inadequate patient care in relation to the preservation of anesthetic and paralytic limbs.

In this paper the methods of assessment used and some of the general findings regarding the prevalence of the disabilities in relation to the disease process are presented and their significance discussed.

MATERIALS

The over-all prevalence of leprosy in this area is 29 per thousand and of lepromatous leprosy six per thousand. The characteristics and some of the epidemiologic features of these patients have been described in an earlier communication (2). Seventy per cent of the patients are adults and 30 per cent are children.

For the purpose of this study, all the patients registered in a geographically defined area, which forms one-third of the Gudiyatham Taluk, are considered. Of the 2,156 patients who were registered in the area during 1962-1966, only 1,780 were considered bona fide residents. Of these 59 could not be contacted by the team of assessors in spite of repeated visits to their homes. The total number of patients assessed is therefore 1,721 which forms 97 per cent of the resident patients. The basic demographic characteristics of the 59 patients who could not be contacted did not reveal any significant difference when compared with the group who have been assessed. The type of leprosy among the 1,721 patients and their age and sex pattern are shown in Table 1. Three of the patients with purely neural forms of leprosy could not be classified.

METHODS AND CRITERIA OF ASSESSMENT

Primary disabilities and deformities that occur in the limbs and face are categorized in three major groups:

A. Those due to peripheral nerve involvement.
B. Those due to deformities and disabilities in the face, including eye complication.
C. Those due to primary lepromatous involvement or lepra reaction in the hand.

Patients with no deformity or disability were designated as a fourth group (D). It is necessary to comment briefly on the first three groups mentioned above:

A. Peripheral nerve involvement. No consistent relationship has been found between thickening, pain or tenderness of a segment of peripheral nerve trunk and its functional integrity.

The sole criteria for recognition of motor nerve involvement was the presence of

TABLE 1. *Details of cases assessed according to classification of leprosy.*

Type of leprosy	No. observed			Total
	Male	Female	Children	
Lepromatous	235	83	25	343
Tuberculoid	351	325	376	1,052
Borderline	87	47	21	155
Indeterminate	41	43	84	168
Purely neural (unclassified)	2	—	1	3
Total	716	498	507	1,721

nerve dysfunction as evidenced by weakness or paralysis of the individual muscles supplied by the nerve.

The nerves considered were the ulnar, median, radial, lateral popliteal and the facial. A standard sample group of muscles supplied by each nerve were tested individually by using "manual muscle test" and graded 0 to 5. A large number of patients showing early nerve dysfunction, as evidenced by minimal weakness of the muscles tested, were further confirmed by faradic testing using strength duration curves and sometimes by electromyography.

Posterior tibial nerve paralysis was not included in this survey, as reliable clinical testing of intrinsic function in feet is not possible.

Deformities "typical" of a nerve deficit were also not considered as reliable evidence of nerve dysfunction. For example, clawing that occurs as a result of ulnar nerve paralysis may be simulated by contractures of the proximal interphalangeal joints as a result of injury or scarring in anesthetic hands. Clawing may also be simulated by deep fascial contracture and Landsmeer ligament contracture resulting in flexion deformity of the proximal interphalangeal joint due to local lepromatous infiltration or lepra reaction. On the other hand, paralytic clawing is not evident in fingers where the distal two phalanges are lost. Also, when there is aberrant median nerve innervation of all the four lumbricals, there may be no clawing in spite of the fact that the ulnar nerve is paralyzed.

No. 5 nylon was used to test peripheral anesthesia that occurs independently or concurrently with motor paralysis.

Since there may be loss of sensation in testing with No. 5 nylon in normal calloused feet of people who walk barefooted, only those feet which showed definite evidence of past or present plantar ulceration were accepted as having definite loss of sensation.

B. Deformities and disabilities of the face. This group includes those with skin involvement resulting in gross infiltration, nodularity of the ears and loss of eyebrows. Nasal involvement was considered present when there was history of obstruction and/or epistaxis or when there was perforation of the septum or collapse of the nasal bridge. Eye involvement as evidenced by corneal anesthesia, corneal ulcer, circumcorneal injection, irregular or contracted fixed pupil was recorded.

C. Complications due to primary lepromatous infiltration or lepra reaction in the hands. This group consisted of patients with nodular lepromatous infiltration of the hands, swollen and stiff fingers, necrotizing erythema nodosum leprosum (ENL), angular deformities due to subarticular, pathologic fractures of osteolytic lepromatous bone lesions, and stiffness and deformities as a result of chronic reaction resulting in fibrosis and acrosclerosis in lepromatous leprosy.

METHODS OF RECORDING

For detailed recording of observations a special series of forms was devised. These were filled in by a trained physiotherapy technician under the supervision of the consultant surgeon (Figs. 1, 2, 3). These assessments were carried out mostly at the peripheral clinics at which the majority of the patients receive outpatient treatment. In cases where the patients could not come to the clinic or did not keep appointments, home visits were made and the assessments were completed. Approximately a half to one hour was spent on each assessment.

The various deformities and disabilities that could occur due to primary nerve dysfunction, secondary complications that may occur in the limbs due to anesthesia or paralysis and deformities that could occur due to local lepromatous infiltrations were all individually listed. Each finger was assessed to record primary and secondary deformity that could occur in it. The scheme also included sketches of distal parts of the limbs so that areas with ulceration, scarring or loss of tissue could be accurately indicated.

Since this scheme was meant to be used at regular intervals for a longitudinal study, the first assessment recordings were made by indicating a figure 1 in the appropriate columns. The second and subsequent assessments were then indicated with 2, 3, etc., in the appropriate places. The dates of assessments against these numbers and

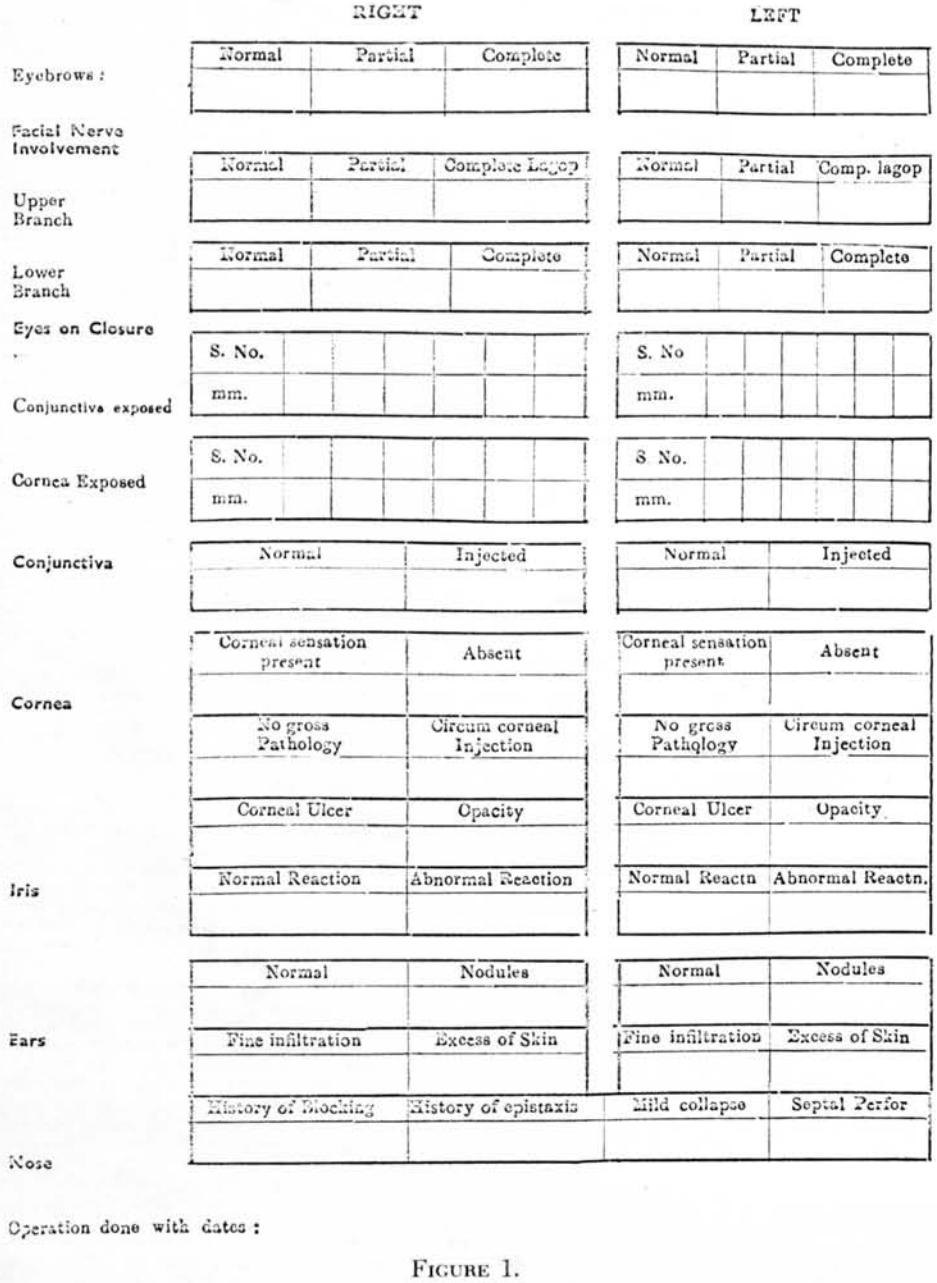

FIGURE 1.

identification details of each patient were entered on the first page. Data from these forms were transferred to 80-column punch cards and processed through I.C.L. data-processing equipment.

RESULTS

The number of patients who fall into the different groups of disability are shown in Table 2 according to classification of the disease. Both early motor paralysis and partially anesthetic hands are defined as having nerve involvement for the purpose of this study.

Thus 738 patients or 42.9 per cent of the total patients assessed were disabled. In the area where the prevalence of leprosy is 29 per one thousand, 42.5 per cent of

TABLE 2. *Disability observed among various types of leprosy patients.*

Disability Group: Classification of leprosy	Lep.	Tub.	Bord.	Ind.	Purely neural	Total
A: Involvement of nerves	245	245	100	30	2	622
B: No nerve involvement but deformity of face	30	61	12	13	—	116
C: No nerve involvement or disability of the face but disability due to primary lepromatous infiltration	—	—	—	—	—	—
D: No disability	68	746	43	125	1	983
Total observed:	343	1,052	155	168	3	1,721

disability would mean a prevalence rate of disability due to leprosy in the entire population of 12 per thousand.

Of the 738 patients who were disabled, 622 or 84.3 per cent had primary involvement of the peripheral nerve, forming the most serious form of disability. These 622 patients with nerve involvement constitute 36.1 per cent of the total patients assessed. They were further studied according to classification of leprosy and the findings are shown in Table 3. It was observed that while 18 per cent of indeterminate and 23.3 per cent among tuberculoid, were found to have paralysis and/or anesthesia, the percentages for borderline (intermediate) and lepromatous cases were 64.5 per cent and 71.4 per cent respectively.

Nerve involvement among adults and children were as indicated in Table 4.

The over-all percentage of disability among adults was 47 per cent while among the children it was only 10 per cent. The per cent disabled among adults was significantly higher when compared with children with the same type of leprosy.

Disabilities for male and female patients has been studied separately. Among the children there were not sufficient numbers of cases divided by sex to study the differences statistically except among those with the tuberculoid type of leprosy. The proportion of children in the tuberculoid group with nerve involvement in the two sexes was not significantly different.

Among the adults, the percentage with nerve involvement according to sex is given in Table 5. While 33.3 per cent of the women had paralysis or anesthesia, similar disability was seen in 56.6 per cent of the

TABLE 3. *Nerve involvement observed among various types of leprosy patients.*

Classification	Nerve involvement: Yes No.	Yes %	No No.	No %	Total studied
Lepromatous	245	71.4	98	28.6	343
Tuberculoid	245	23.3	807	76.7	1,052
Borderline	100	64.5	55	35.5	155
Indeterminate	30	17.9	138	82.1	168
Purely neural	2	66.7	1	33.3	3
Total	622	36.1	1,099	63.9	1,721

FEET : LATERAL POPLITEAL PARALYSIS

	Normal	Partial	Complete
Right Foot			

Angle of Dorsiflexion	S. No.								
	Deg								

	Nil	Present	Unable to Assess
Clawing :			

	Normal	Partial	Complete
Left Foot :			

Angle of Dorsiflexion	S. No								
	Deg								

	Nil	Present	Unable to Assess
Clawing :			

First Ulcer :	Site	Time	Footwear
Right Foot			
Left Foot			

Cause of First Ulcer :

History of Footwear :

1. Footwear before MCR :
2. Duration of MCR :
3. Any Change of pattern : Specify :

Recurrence of Ulcer After MCR :	Same as Before	Less Frequent	Nil
Right			
Left			

Foot Drop Operation :

Claw Toe Correction :

FIGURE 2.

men. This difference was statistically highly significant ($P < .001$). The male-female difference among borderline and indeterminate leprosy patients does not attain statistical significance, though similar trends for male preponderance are observed even in these groups.

DISCUSSION

Disability and deformity in leprosy are of two distinct categories, one related directly to the disease process and the other due to preventable secondary complications related largely to the level of patient care. Most of the attempts to classify and grade disabilities and deformities are based on the observed physical disabilities without distinguishing primary from secondary problems. It is essential to keep these two categories separate in evaluating primary disease process. For example, primary involvement in the hands with complete

TABLE 4. *Percentage with nerve involvement according to classification and age group.*

Classification	Adults		Children		Diff. between adults & children found disabled
	No. studied	% disabled	No. studied	% disabled	
Lepromatous	318	75.2	25	24.0	P< .01
Tuberculoid	676	32.1	376	7.4	P< .01
Borderline	134	69.4	21	33.3	P< .01
Indeterminate	84	25.0	84	10.7	P< .01
Purely neural	2	50.0	1	100.0	—
Total	1,214	47.0	507	10.1	P< .01

ulnar paralysis is the same whether or not they have severe secondary disuse contractures of the interphalangeal joints. In the same way, the variable extent of clawing that occurs in ulnar paralysis due to anatomic variations in ulnar and median nerve supply of the lumbrical muscles does not change the extent or the pattern of primary nerve involvement. Thus, in spite of the differences in the degree of physical disabilities produced by either secondary complications or anatomic variations, all these hands have the same type of primary problem in relation to the primary disease process. Again a totally anesthetic hand with no secondary trophic ulceration or shortening has essentially the same primary disablement as one that has sustained trauma and trophic ulceration resulting in loss of many phalanges and marked shortening.

It is also essential to keep the different varieties of primary involvement in distinct categories, grouped according to the primary pathologic process responsible for the disability. Such an attempt is made in this paper by classifying the problems arising primarily from nerve involvement as distinct from local lepromatous involvement of the hands.

It has already been stated that objective and careful testing for the presence of anesthesia in the limbs and the use of manual muscle testing of individual, selected muscles for detecting paralytic deformities are essential for accurate recording of nerve involvement. When such criteria of assessment are used, a much larger proportion of patients are likely to be found disabled. Detection and recording of early signs of nerve involvement are essential

TABLE 5. *Percentage with nerve involvement by sex in adults according to classification.*

Classification	Male		Female		Diff. between males & females found disabled
	No. studied	% disabled	No. studied	% disabled	
Lepromatous	235	79.2	83	63.9	P< .01
Tuberculoid	351	40.5	325	23.1	P< .001
Borderline	87	72.4	47	63.8	Not significant
Indeterminate	41	31.7	43	18.6	Not significant
Purely neural	2	50.0	—	—	—
Total	716	56.6	498	33.3	P< .001

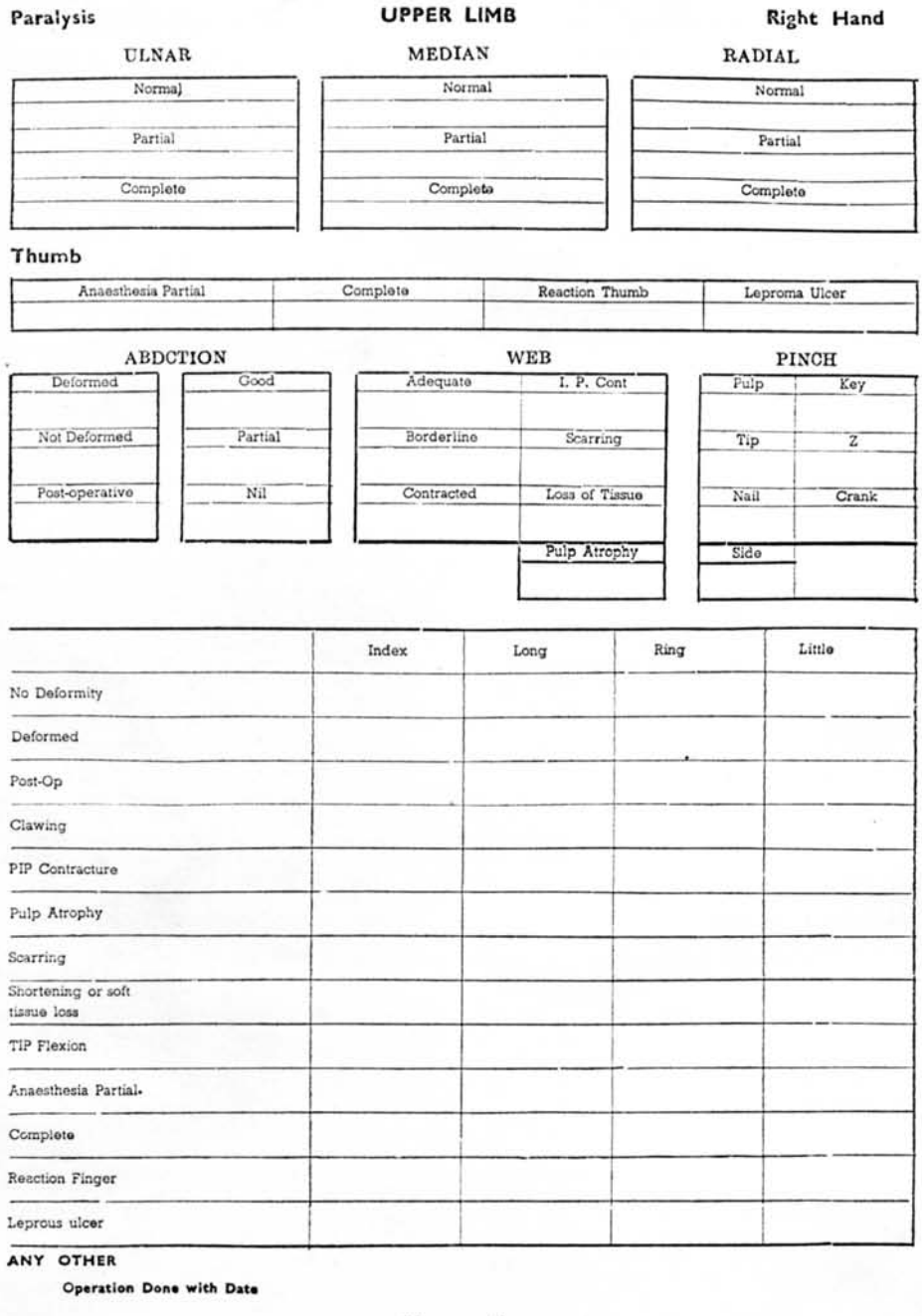

FIGURE 3.

both for longitudinal studies of an individual nerve affected as well as for accurate estimation of the incidence of nerve involvement. In our study 36.1 per cent of all the patients studied had functional nerve deficit of at least part of one limb. It is to be noted that the leprosy control program in this area had been active for four years prior to this investigation. Thus study of the relationship between the disability and treatment status or phases of the disease is not possible with this group.

Anesthesia (with or without paralysis) is a constant feature of nerve involvement. There is, therefore, a possibility for the development of trophic ulceration and loss

of digits resulting in disability and deformity in at least one-third of the patients. It is interesting to note that there was no lepromatous leprosy patient with deformity due to primary lepromatous infiltration of the hand who had not already developed either nerve dysfunction or deformity of the face.

There is a strikingly high incidence of nerve involvement in the lepromatous and borderline groups of leprosy. This significant difference in the incidence between the various types of leprosy is present even among children, though the percentage of lepromatous and borderline cases among the children is small. On the other hand, the pattern of disability among the adults and children was significantly different in each of the four major classifications. For example, it is significant that in children classified as tuberculoid, the incidence of disability was 7.4 per cent, whereas in the adult tuberculoid group it was 32 per cent. In general, while 47 per cent of all adults are disabled and have nerve involvement, only 10 per cent of the children are affected. This has great significance in diagnosis and initiation of treatment among children. Early control of the disease in children will minimize the disability. One cannot, however, presuppose that all adult patients represent cases where leprosy was not diagnosed or was neglected when it was present during their childhood.

The significantly lower incidence of the disability among women needs to be further studied. The significance of the polar groups showing this difference more than the borderline and indeterminate is not clear. However, the fact that this difference in disability among male and female was not found among the children makes it reasonable to postulate hitherto unrecognized factors, influencing the natural history and longitudinal pattern of the disease process. These highly significant differences are being studied prospectively in relation to duration of the disease, time of initiation of treatment, duration of treatment, and occurrence of reaction, and will be published later.

SUMMARY

Disability and deformity in leprosy despite adequate antileprosy therapy constitutes a major problem in the management of the disease. In a few studies on prevalence of disabilities, the criteria used for defining and classifying disability as well as the methods used for detection of disability have varied very widely. In this paper an attempt is made to present acceptable and reproducible criteria for defining disability and deformity. Based on these criteria, general findings are presented on the prevalence of disabilities and deformities among 1,721 patients who form 97 per cent of the total resident patient population in a geographically defined leprosy endemic area.

The primary disabilities and deformities were categorized into three major groups. Details of the deformities that occur under each of these groups are given and methods of assessments described.

A special proforma which was devised for use in a longitudinal study is presented. Of the 1,721 patients assessed 42.9 per cent (738 patients) were disabled and belonged to the first two groups mentioned above. Of the 738 patients who were disabled, 622 or 84.3 per cent had primary involvement of the peripheral nerve, forming the most serious form of disability. These 622 patients with nerve involvement constitute 36.1 per cent of the total number of patients assessed. In terms of classification of leprosy, 18 per cent of the indeterminate and 23.3 per cent among tuberculoid were found to have paralysis and/or anesthesia, while 64.5 per cent of the borderline and 71.4 per cent of the lepromatous leprosy patients were so affected. The over-all percentage of disability among adults was 47 per cent, while among the children it was only 10 per cent. The per cent disabled among adults was significantly higher when compared with children of the same type of leprosy. While only 33.3 per cent of the women had paralysis or anesthesia, similar disability was seen in 56.6 per cent of men. This difference was statistically highly significant ($P<.001$).

The problems involved in defining and classifying disability are briefly discussed. The differences noticed among various types of leprosy, between adults and children and between men and women are briefly commented upon.

RESUMEN

Las incapacidades y deformaciones producidas por la lepra a pesar de un tratamiento antileproso adecuado constituyen un problema importante en el manejo de la enfermedad. En algunos estudios sobre prevalencia de incapacidades, los criterios usados para definir y clasificar la incapacidad y asimismo los métodos usados para detectar la incapacidad varían enormemente. En este trabajo se ha tratado de presentar criterios aceptables y reproducibles para definir las incapacidades y deformaciones. Basados en estos criterios, se presentan resultados generales sobre la prevalencia de incapacidades y deformaciones encontradas en 1721 pacientes que forman el 97% del total de la población de pacientes residentes en un área endémica de lepra, geográficamente delimitada.

Las incapacidades y deformaciones primarias fueron clasificadas en tres grupos principales. Se dan detalles de las deformaciones que se presentan dentro de cada uno de estos grupos y se describen los métodos de estudio.

Se presenta una encuesta especial diseñada para ser utilizada en un estudio longitudinal. De los 1721 pacientes que se estudiaron, el 42.9% (738 pacientes) estaban incapacitados y pertenecían a los primeros dos grupos mencionados anteriormente. De los 738 pacientes incapacitados, 622, o sea el 84.3% tenían compromiso primario de los nervios periféricos, que representa la forma más grave de incapacidad. Estos 622 pacientes con compromiso nervioso constituían el 36.1% del número total de pacientes estudiados. En términos de clasificación leprológica, el 18 por ciento de los pacientes indeterminados y el 23.3% de los tuberculoides presentaban parálisis y/o anestesia, mientras que el 64.5% de los dimorfos y el 71.4% de los pacientes lepromatosos presentaban esas mismas lesiones. El porcentaje global de incapacidades entre los adultos era de 47%, mientras que en los niños era solamente de 10%. El porcentaje de incapacitados en adultos en comparación con el de los niños con el mismo tipo de lepra fué significativamente mayor. Mientras que sólo el 33.3% de las mujeres tenían parálisis o anestesia, esta misma incapacidad se presentaba en un 56.6% de los hombres. Esta diferencia tiene una alta significación estadística ($P < 0{,}001$)

Se discuten brevemente los problemas que presenta la definición y clasificación de incapacidades. Se comenta brevemente sobre las diferencias que se encuentran entre los distintos tipos de lepra, entre niños y adultos y entre hombres y mujeres.

RÉSUMÉ

L'incapacité et les difformités qui surviennent dans la lèpre malgré une thérapeutique spécifique adéquate constituent un problème majeur das l'organisation de la lutte contre la maladie. Dans un certain nombre d'études portant sur la prévalence des lésions entrainant de l'invalidité, les critères utilisés pour définir celles-ci et pour les classer en differents groupes, ont considérablement variés; il en est de de même des méthodes auxquelles on a eu recours pour dépister l'invalidité. Dans cet article, on a tenté de dégager des critères acceptables et reproductibles permettant de définir l'incapacité et la difformité. A partir de ces critères, on a présenté des observations générales concernant la prévalence des incapacités et des difformités parmi 1,721 malades, soit 97 pour cent de la population totale des malades résidant dans une région géographiquement définie et endémique pour la lèpre.

Les incapacités et les difformités primaires ont été classés en trois groupes majeurs. Les détails des difformités survenant dans chacun de ces 3 groupes sont fournis, et des méthodes sont décrites en vue de les évaluer.

Un formulaire spécial a été rédigé en vue de son utilisation dans une étude longitudinale. Ce formulaire est présenté. Parmi les 1,721 malades étudiés, 42.9 pour cent (738 malades) étaient invalides, appartenant aux deux premiers groupes mentionnés ci-dessus. Des 738 patients invalides, 622 (84.3 pour cent) présentaient une atteinte primaire d'un nerf périphérique, qui constituait la forme la plus grave de l'incapacité. Ces 622 malades présentant une atteinte nerveuse représentaient 36.1 pour cent du nombre total de malades qui a été étudié. Si l'on se réfère à la classification de la lèpre, 18 pour cent des sujets indéterminés et 23.3 pour cent des tuberculoides ont été trouvés porteurs, soit de paralysie, soit d'anesthésie, ou bien encore de ces deux symptômes ensemble; par contre, 64.5 pour cent des sujets

atteints de lèpre dimorphe et 71.4 pour cent des malades souffrant de lèpre lépromateuse, présentaient de telles lésions. Le pourcentage global d'incapacité chez les adultes s'élevait à 47 pour cent, alors que chez les enfants ce pourcentage atteignait seulement 10 pour cent. La proportion de personnes invalides parmi les adultes était significativement plus élevée, quand on la compare à celle observée chez les enfants souffrant du même type de lèpre. Alors que 33.3 pour cent seulement des femmes présentaient de la paralysie ou une anesthésie, des lésions de ce type étaient observées chez 56.6 pour cent hommes. Cette différence était statistiquement hautement significative ($P < 0.001$).

Les problèmes soulevés par la définition de l'incapacité, et par sa classification en divers groupes, sont brièvement discutés. Les différences relevées parmi les divers types de lèpre, ainsi qu'entre les adultes et les enfants, de même que d'après le sexe, sont brièvement commentées.

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REFERENCES

1. [Belgian Leprosy Center] Polambakkam. Report on the Activities, 1955-1958.
2. Karat, A. B. A., Sadananda Rao, G., Karat, S., Job, C. K. and Rao, P. S. S. Epidemiological studies in Gudiyatham Taluk—Part I: Leprosy Rev. **38** (1967) 77-82.
3. [Leprosy Centre] Polambakkam. Report on the Activities, 1955-1962.
4. Martinez Dominguez, V., Bechelli, L. M. and Patwary, K. M. WHO surveys of disabilities in leprosy in Northern Nigeria (Katsina), Cameroon and Thailand (Khon Kaen). Internat. J. Leprosy **34** (1966) 244-254.
5. Noordeen, S. K. and Srinivasan, H. Epidemiology of disability in leprosy. 1. A general study of disability among male leprosy patients above fifteen years of age. Internat. J. Leprosy **34** (1966) 159-169.
6. Wardekar, R. V. Sulphone treatment and deformity in leprosy. Leprosy in India **40** (1968) 161-178.