Evaluation of the prevalence of disability and knowledge on prevention of disability among leprosy patients managed in the Dermatology Unit at the National Hospital of Sri Lanka during the period of years 2006 to 2008: An eye opener

S V Paranavithane[1], N P Madarasinghe[2], K Satgurunathan[3]

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Background

In leprosy, functional impairment due to nerve involvement can result from the disease or its reactions and can affect the eyes, hands and feet. It can lead to significant disability and impair the quality of life.

WHO classification of disability is as follows:

Nerve impairment
↓
Functional impairment/Disability
↓
Handicap
↓
Destitution

Simple measures that could be practiced by patients to prevent the progress of impairment to disability are available. This includes, verbal advice and interventions like splinting, chiropody, etc.

Grading of disability in leprosy patients[1]

Eye Grade 0 – no disability

Grade 2 – redness, impaired vision, blindness, lagophthalmos

Hand Grade 0 – no disability

Grade 1 – numbness only

Grade 2 – visible disability (weakness, deformity, ulcers, loss of tissue)

Foot Grade 0 – no disability

Grade 1 – numbness only

Grade 2 – visible disability (weakness, deformity, ulceration, loss of tissue)

Prevention of disability in leprosy includes, early detection of sensory impairment, prompt treatment of reactions, educating patients about disability preventive measures and directing needy patients for special care.

Objectives

We conducted this study with the objectives of determining the prevalence of disability among leprosy patients and assessing the knowledge on prevention of further injury in patients with disability.

Method

We conducted a retrospective observational study. Our study population comprised all patients registered for leprosy treatment at the Dermatology Unit in the National Hospital of Sri Lanka during the period of years 2006 to 2008 (a total of 335). Out of them, 124 patients, who were willing to participate, were interviewed. An interviewer administered questionnaire, patients records and when necessary, clinical examination, were used as data collection tools.

Assessment of level of knowledge

A score was given for knowledge on disability prevention activities with relevance to the existing impairment. Items included in the WHO Guidelines[1], with relevance to each subcategory of disability. (numbness, weakness, deformity, ulcers), was taken as the standard. The mean score of knowledge for the subcategory was calculated.

(e.g. for eye – out of 4, for numbness of hand – out of 5).

It was expressed as a percentage of expected level of knowledge.

[1,2]*Senior Registrar*, [3]*Consultant Dermatologist, National Hospital of Sri Lanka.*

Results

Epidemiological features

Majority of patients were between 20-60 years of age (76%), had tuberculoid (TT) type of leprosy (63%), had completed treatment at the time of study (67%), received PB treatment (51%). Gender distribution was equal, and 69% have had secondary education. Tuberculoid type of disease was evidenced in 63%. Defaulters comprised 3.6%.

Prevalence of disability

The prevalence of disability in the sample was 59% (Figure 1) with eye, hand and foot disability being 7.2%, 37.8% and 37.2% respectively. Prevalence of Grade 1 disability was 46% and Grade 2 disability was 30.6%. Mean Eye Hand Foot (EHF) disability score was 3.6 (out of 12).

Among patients with Grade 1 disability, 87% had Grade 1 disability at diagnosis and 13% have developed Grade 1 disability after the diagnosis.

Among patients with Grade 2 disability, 95% had Grade 2 disability at diagnosis, 4% developed Grade 2 disability after the diagnosis while 1% had progression of Grade 1 disability (present at diagnosis) to Grade 2 disability.

The prevalence of Grade 1 disability in hand and were 29% and 17.7% respectively. Corresponding figures for Grade 2 disability in hand and foot were 8.8% and 14.5%.

We observed that in some patients (31%) the disability grade has diminished after the diagnosis. When disability grade at diagnosis and that at the time of study are compared, 8% have diminished from Grade 2 to Grade 0, 7% have diminished from Grade 2 to Grade 1 and 15% have diminished from Grade 1 to Grade 0.

There was no significant difference in gender, year of initiation of treatment, type of leprosy, or age distribution between patients with disability and the sample population. Sixty percent (60%) of patients with disability have been treated with MB treatment. The prevalence of disability among defaulters was 50% and comprised two patients with eye involvement.

Assessment of level of knowledge on disability prevention[1]

In the sample population, 14%, 48% and 53% respectively were aware that, complications in the eye, hand and foot can occur. Among patients with disability, corresponding figures were 12%, 53%, and 55%.

Among patients with disability, percentage of knowledge relevent to eye, hand and foot[2] were calculated. Mean score was calculated compared to the expected score of knowledge. Percentage of knowledge for each subgroup was verified.

Sixty six percent (66%) of patients with eye involvement, 29.7% of patients with Grade 1 hand disability and 40.9% with Grade 1 foot disability, were not aware of any measure to prevent further injury.

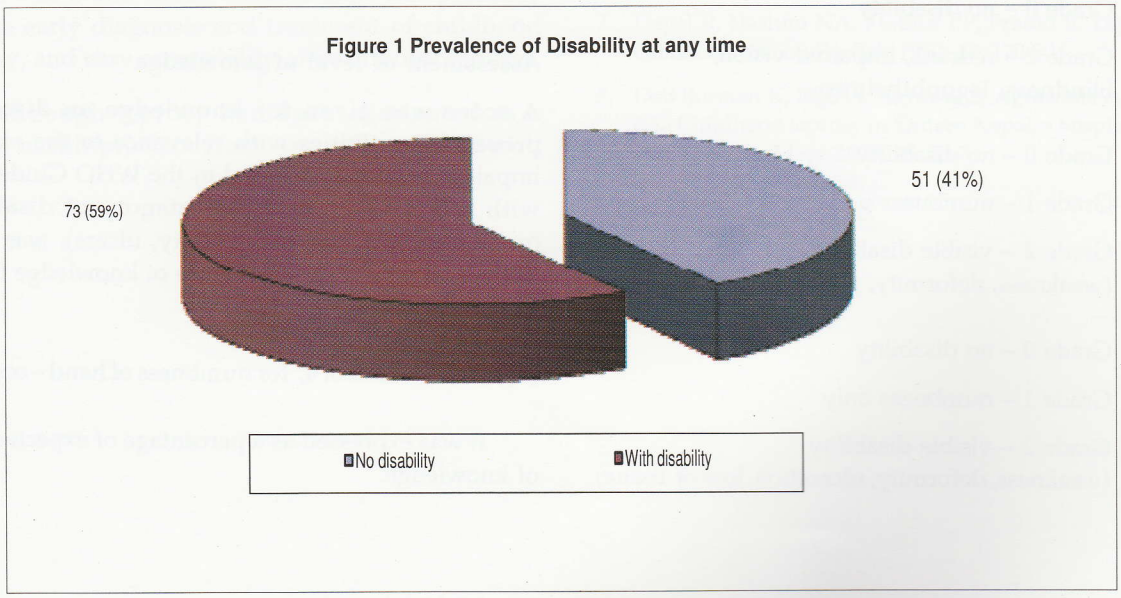

Figure 1

Among patients with Grade 2 disability of hands, percentage of mean scores of knowledge on preventive measures for specific impairments were 28% for numbness, 71% for weakness, 100% for deformity and 65% for ulcers. Corresponding figures for foot were, 21.6%, 30%, 0% and 53.3%.

Conclusions

Prevalence of disability in our study population is significant. However, the level of expected knowledge for prevention of further injury, in relation to the existing disability is unsatisfactory. Majority of patients with eye involvement and a significant proportion of patients with Grade 1 hand and foot disability were not aware of any preventive measure.

Improving knowledge on disability prevention activities in this group can contribute to prevent future morbidity.

Discussion and Recommendations

The prevalence of disability in our sample is higher than the National figure (Grade 1 disability rate 18.89%, Grade 2 disability rate 7.98%) for the year 2008. It is also higher than regional figures (16-42% in India[3], 9.61% Grade 1 disability, and 5.97% Grade 2 disability in Bangladesh[4]) and WHO statistics (25%)[5].

Direct data collection from the patients with the aid of records and clinical examination could have contributed to this figure. The national figures are formulated by analysing notification forms which are collected at the end of treatment. There are many lapses in filling and sending notification forms that lead to an underestimation of prevalence of disability.

Eighteen percent (18%) of patients with disability, developed the disability after diagnosis. However, 31% of patients with disabilty at diagnosis had their grading diminished at the time of study indicating the effective treatment of reactions and health education.

Sixty six percent (66%) of patients with eye disability not knowing any measure to prevent further injury depicts a large shortcoming in health education. Although hand and foot involvement in leprosy is well known to the public, many patients are unaware that the eye can be affected in leprosy which can ultimately lead to blindness. Sensory loss in the eye is not obvious to the patient (silent nerve impairment) and it may be undetected by clinicians unless specifically looked for. This can result in irreversible damage to the eye. It is very important to examine the eye in patients who have lesions in the face especially around the eye.

Almost half the patients (46%) in our sample have Grade 1 disability. In patients with Grade 1 disability (numbness of hands or feet), disability prevention activities are most important to prevent them from progressing to Grade 2 disability (weakness, deformity, ulceration). Health education would prevent morbidity and loss of quality of life to the patient as well as save cost of rehabilitation.

We have identified several factors that could have contributed to inadequate health education of leprosy patients on disability prevention.

There is no proper training programme for clinicians on disability prevention activities. The WHO Guidelines are not freely available in adequate numbers, for reference.

Our study shows that verbal advice alone is not effective in educating leprosy patients on disability prevention activities. A busy clinic leaves little time for proper evaluation of detection. In the busy clinic set up certain points may be missed. This could be overcome by written advice in the form of a leaflet or booklet.

A checklist to be filled initially as well as periodically, would assist in detection of nerve function impairment. The existing facilities (physiotherapy, chiropody, health education booklets on care of feet intended for diabetic patients, etc.) should be utilized maximally. Patients with nerve function impairment, who complete MDT should be further followed up periodically, at least at primary health care units for continuation of disability prevention measures.

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