

## WHO DISABILITY GRADING

Sir,

I have some questions and suggestions regarding WHO disability grading, and would be interested to hear the views of other readers as to its use and usefulness.

I am using the term 'deformity' to mean change of form, and thus to cover deformity due to paralysis (lagophthalmus, clawing, dropfoot) and deformity due to absorption. I am using the term 'disability' to cover *also* loss of sensation.

### WHO purposes for disability grading

In its booklet *OMSLEP Recording and Reporting Systems for Leprosy Patients, second edition* (1983), WHO states that 'an information system should be seen in a decision-making context' and gives two purposes for its disability grading.

The first stated purpose is as an index 'which can be *used to assess the delay in case-detection*. This index should be close to zero when case-finding is early and when screening coverage is high'.

WHO ask in their suggested Individual Patient Form and Detection Form, for the number of newly registering patients having 'WHO grade < 2 disability (bone absorption, claw hands and dropfoot)—omit anaesthesia'.

Thus they require only two categories: with and without deformity or ulceration; and only the highest grading for any one patient: eye, hand or foot.

*Comment.* For this purpose the grading could be greatly simplified. WHO need ask for only two grades in newly registering patients: deformity and/or ulceration in either eye, hand *or* foot; or no deformity or ulceration.

A second overall purpose for records described by WHO is that of 'evaluation of the efficiency of programmes'. WHO's main purposes in regard to leprosy are a reduction in the number of patients with active disease and eventual disease eradication. However, under a heading 'Cohort Analysis' WHO give as one index that can be observed any *increase* in disability grading *from* 0·1 or 2 to 2 or 3 '*so that occurrence of new disability can be observed*'.

*Comment.* Those working towards disability control in leprosy patients would like to know: (a) the number of patients suffering decreasing nerve function; and (b) the number of patients suffering worsening secondary deformity.

However, I think it important to recognize that WHO grading in its present form is *not appropriate* for this purpose, despite the fact that attempts are sometimes made to use it in this way. I myself have tried to do so but one cannot determine either of the above properly. For example: the hand with slight sensory loss and clawing of the little finger will be graded as 2. If subsequently the hand shows complete ulnar and median nerve lesions, plus several wounds and open cracks, the grading will remain at 2. Yet if the *only* added problem is little stiffening then the grading will change to 3. If the area of sensory loss of a foot increases from one toe to the whole sole, the WHO grading will remain unchanged at 1.

I have followed up some Ethiopian and Tanzanian patients whose WHO disability grades had changed from 0 to 1 or from 1 to 0. I found that almost all changes were due not to real ones but either to differences in testing *method* (some used cotton wool, others pressed hard with a ballpoint pen) or in test *area* (some tested the hand and foot dorsum, others did not). Neither area nor method are specified in WHO grading keys.

### **ILEP purposes for disability grading**

In their form B, ILEP ask for numbers of *registered* patients having WHO grade < 2 disability. The purpose of collating this information *only* for patients registered for chemotherapy is not clear to me.

*Comment.* In patients having nerve lesions affecting eyes, hands and/or feet deformity may well increase over the years. Apart from paralysis, WHO grades 2 and 3 disability problems are those *secondary* to nerve damage. They do not cease when the patients are released from chemotherapy control and their names are removed from the register. Patients having sensory and/or strength loss may need continuing care, education and supply of protective devices. It would be useful to include patients needing such continuing support in any national disability statistics.

Under the present ILEP recording system many patients with an increasing disability problem are *never* included in disability statistics. For example: A patient's foot may lose sensation before he is released from control—this grade 1 disability will not appear on ILEP statistics. During the years that *follow* his release from control the patient may suffer increasing grades 2 and 3 ulceration and absorption but because his name has been removed from the register these will not appear in statistics.

Under the present ILEP system the shorter the treatment course becomes on multidrug therapy the better the disability statistics will appear!—whether or not they have in fact changed. There will be no purpose in comparing statistics from year to year if treatment durations have changed.

If ILEP, WHO or national authorities wish to know the extent of the continuing disability problem amongst patients released from chemotherapy control, then it will presumably be necessary for them: (a) to have patients who attend for support listed in a 'disability problems' section of the attendance register; or (b) to define criteria for removing patients' names from this register—for 'release from disability control'. Such criteria might for example be: either 'has not attended for support for the whole year' or 'has attended but has had no increase in disability for two years and needs no continuing supply of protective devices'.

### **Disability records needed by those responsible for disability prevention activities**

Those planning and evaluating disability prevention activities would like to know:

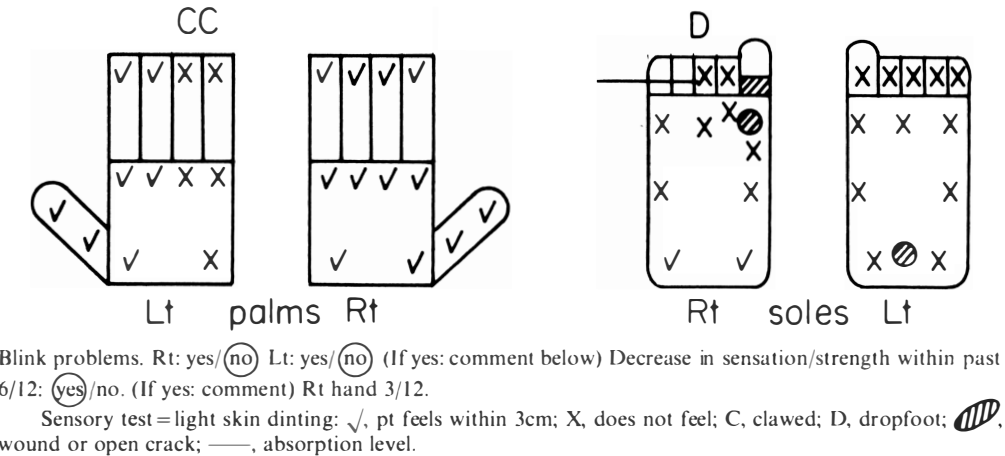
(a) Number of patients, registered either for chemotherapy or for disability control, having nerve lesions (WHO grade < 1): (i) affecting eyes; (ii) affecting hands; and (iii) affecting feet. These numbers will be useful for assessing needs for teaching and for protective devices.

(b) Numbers of patients having decreased sensation or strength during the year. This information is important in patients with active leprosy and in multidrug therapy programmes. However, it can only be determined where strength loss and area of sensory loss are given in some detail (see Figures 1 and 2) and *reliably*.

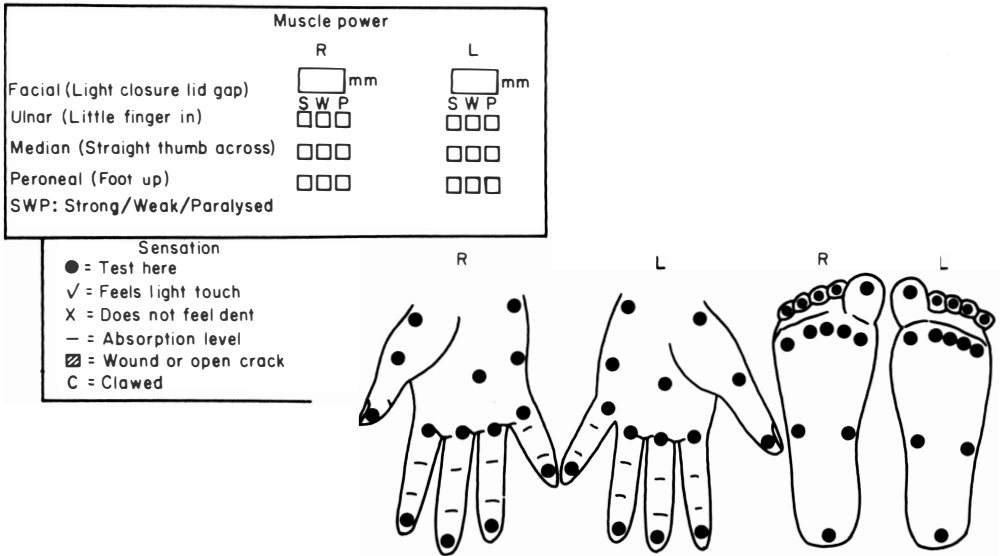
(c) Numbers of patients having wounds or open cracks during the year or increased absorption/reduced vision where records give such detail.

(b) and (c) can be used for the purposes of identifying patients needing action to halt increasing disability, and of evaluating effectiveness of this action.

Examples of records usable for these purposes are given in Figures 1 and 2. In my opinion hand and foot maps showing areas of sensory loss and other information illustrated, and having a key, are a vital part of useful disability records. Any changes can be recorded on new, hand-drawn diagrams. Many national leprosy casesheets already incorporate outline maps of hands and feet. At present these are often ill-used because they lack keys and because staff lack training in proper use of them but they could *become* useful.



**Figure 1.** Suggested use of sensory hand and foot maps with blink comment.



**Figure 2.** Disability record including strength detail (from Zambia Individual Patient Form).

## **Conclusions**

I suggest:

(a) That a system of WHO +/– deformity grading is substituted for the present 0–3 grading and that only one grade per patient is recorded on the Individual Patient Form if this is all that WHO and ILEP use.

(b) That WHO encourages the use of disability records similar to those shown above, and usable for purposes of identifying patients in need and evaluating their progress. I would like to see use of the WHO expanded ‘form for recording disabilities from leprosy’, which appears in their ‘A Guide to Leprosy Control’ discouraged. I see its use, in several African countries that I visit, as effectively blocking the introduction of a disability record useful for the purposes as stated.

(c) That WHO sanction the use of disability records from selected areas in which testing and recording are reasonably *reliable* for national returns made to them. This seems to me more helpful than the present method of including information from a large number of largely inaccurate returns.

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