

## **A scale to assess activities of daily living in persons affected by leprosy**

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*Summary* The aim of this study was to develop a scale for identifying disability among people in the rural areas of developing countries. The studies were carried out in the Green Pastures Hospital and the leprosy field programme of the Western Region of Nepal. With the help of staff experienced in working with people with disability, a 68-question questionnaire was made, based on the International Classification of Impairments, Activities and Participation (ICIDH-2). A survey was carried out of 269 people affected by leprosy who had impairments, as well as a sample of those who were unimpaired. The survey results were used to develop the questionnaire into a scale, using standard scale development methods. This included checking of criterion validity, discrimination and reliability and stability using weighted kappa statistics. Of the 68 questions, 38 were included in the second draft of the instrument. Eight questions were added to identify difficulty in relationships, about the use of aids and about occupation and employment. The sum score of the scale against the expert score gave a Spearman correlation coefficient of 0.72. Intra- and inter-interviewer reliability coefficients were 0.77 (95% CI 0.73–0.81) and 0.61 (95% CI 0.56–0.67), respectively. The stability test gave an overall kappa of 0.76 (95% CI 0.70–0.82). Four questions with particularly poor results were omitted from the final draft of the instrument. An interview-based instrument was developed for identifying limitations in activities of daily living (disability) in people living in a rural setting in a developing country—the Green Pastures Activity Scale (GPAS). The scale performed well during validity and reliability testing. It consists of 34 activity questions, five relationship questions, and three questions on the use of aids, occupation and employment.

### **Introduction**

Leprosy often causes impairment of autonomic, sensory and motor nerve function.<sup>1–3</sup> This in

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turn leads to secondary impairments or deformities of the eyes, face, hands and feet.<sup>4,5</sup> Too often these become irreversible before the affected person receives appropriate treatment. Impairments and deformities (visible impairments) may cause limitation of activities of daily living (disability) and adverse social reactions (restriction of participation).

The International Classification of Impairments, Activities and Participation (ICIDH-2):<sup>6</sup> defined impairment as 'a loss or abnormality of body structure or of a physiological or psychological function, e.g. loss of a limb, loss of vision'.

*Activity* is defined as 'the nature and extent of functioning at the level of the person, e.g. taking care of oneself, maintaining a job' In the field of rehabilitation, limitation of activities is commonly called 'disability'.

*Participation* is 'the nature and extent of a person's involvement in life situations in relation to Impairment, Activities, Health Conditions and Contextual Factors, e.g. participation in community activities, obtaining a driving license'. Restriction in participation was called 'handicap' in the first edition of the ICIDH.

As a result of fixed-duration multidrug therapy (MDT), the number of leprosy cases on treatment has decreased considerably in recent years.<sup>7</sup> Thus, attention is shifting to the needs of those 'cured' with MDT, but left with residual impairments, activity limitation or participation restrictions.<sup>8</sup> These cause long-term problems for the individual and place a demand on community resources. The global number of people with irreversible deformities due to leprosy is estimated to be between 1 and 2 million—up to twice the number of cases currently registered for MDT.<sup>9</sup>

Aware of the rehabilitation needs of people affected by leprosy, several authors have pointed out the advantages of applying the ICIDH concepts in leprosy.<sup>8,10-12</sup> The first edition of the ICIDH, published by the WHO in 1980, has been succeeded by the second edition, the ICIDH-2.<sup>6</sup> It is important that the outcome of rehabilitation be assessed in terms of disability and handicap.<sup>13</sup> The concepts described in the ICIDH(-2) may help in this.

Information on the impairment and activity status of people affected by leprosy may be used for: (i) decision making and management concerning (physical) rehabilitation of individual patients, (ii) assessing the effectiveness of a leprosy programme in preventing the development of (further) impairments and activity limitations, and treatment of pre-existing ones, and (iii) planning of resources needed for treatment and care of patients with impairments and activity limitations, before and after release from drug therapy.

No 'instrument' has been developed for identifying limitation in activities of daily living (ADL) suitable for use with people affected by leprosy in developing countries. Many disability scales are available in Western countries,<sup>14-18</sup> but none appeared suitable for use with people living under conditions common in rural areas of leprosy-endemic countries.

With increasing emphasis on rehabilitation, such a tool is needed to assess adequately the rehabilitation needs of those affected by leprosy and to evaluate the results of rehabilitation interventions. Using standard scale development techniques, we designed such an instrument: the Green Pastures Activity Scale (GPAS). This paper describes the development of the GPAS.

## Materials and methods

The studies were carried out in the Green Pastures Hospital of the International Nepal Fellowship in Pokhara and in the leprosy field programme of the Western Region of Nepal.

## STEPS IN THE SCALE DEVELOPMENT PROCESS

Standard procedures for scale development were used.<sup>19</sup> First, suggestions for activities of daily living to be included in the assessment were collected during a group consultation of Nepali staff members experienced in working with people with leprosy, or who had had leprosy themselves. Second, a questionnaire was drawn up in English, translated into Nepali and back translated to check the translation. The third step was pilot testing of the questionnaire on 26 subjects. Questions answered affirmatively (endorsed) less than 10% of the time or more than 90% were omitted. The remaining questionnaire was checked for face validity. Extensive validity and reliability testing was not done at this stage, because this instrument was only a precursor of the eventual activity assessment.

Fourthly, using this questionnaire, 269 people affected by leprosy who had impairments and a sample of unimpaired patients were surveyed. All subjects were interviewed about their common daily activities. As far as possible, the interview was conducted in the person's vernacular language, with interviewers of the same sex as the interviewees. They were asked to rank a list of activities on a scale of difficulty of performing them (never do this, same as before, some difficulty, much difficulty, only possible with help or impossible).

In the scale development process, the results of the survey were used for the fifth step. Questions with an endorsement of more than 20% on the 'don't do' category and questions where fewer than 15 people reported 'much difficulty' (or worse) with the activity were excluded. The remaining questions and a few additional ones, each with a five-point response scale, were rearranged into a new questionnaire, the first draft of our eventual scale. Using the method of Laman and Lankhorst,<sup>20</sup> an attempt was made to include an additional question for each activity to assess the perceived importance of that activity to the person concerned. The resulting questionnaire was again translated and back-translated to check the understanding of the wording.

The sixth step was the running of a series of pilot studies to check the criterion validity, discrimination, intra- and inter-interviewer reliability and stability of the draft scale. Criterion validity was checked by comparing the sum score of the scale with a sum of scores given by a panel of experienced staff in a sample of 37 patients. Using three groups of people with different severity of impairment, divided according to the 'maximum WHO disability grade method',<sup>21</sup> we checked the discriminative ability of the scale. Intra- and inter-interviewer reliability was assessed with paired interviews on 29 patients. Four different interviewers were involved. Stability over a period of a week was evaluated in a similar way.

The remaining steps in the GPAS development are checking for responsiveness to change and determining the optimal scoring and summary method.

## STATISTICAL METHODS

The percentage 'endorsement' was used to quantify how many respondents gave a positive answer to a given question, or who indicated that they didn't do that particular activity.<sup>19</sup> Criterion validity between the sum scores of the draft scale and the expert score was quantified using the non-parametric Spearman rank correlation coefficient.<sup>22</sup> The chance-corrected percentage of agreement between occasions (intra-tester reliability and stability) and interviewers (inter-tester reliability) was calculated using Cohen's weighted kappa statistic ( $j_w$ ) for categorical scales.<sup>23</sup> Kappa values are given with their 95% confidence intervals. The kappa value ranges from 0 (agreement no better than by chance alone) to 1

(perfect agreement). Values of 0.40 or less may be interpreted as poor agreement, 0.41–0.60 as 'moderate', 0.61–0.80 as 'good' and values above 0.80 as very good agreement.<sup>24</sup> The percentage direct agreement between occasions or interviewers is also given. The significance of the difference between two kappa values was tested with an appropriate z-test.<sup>23</sup>

## Results

The group consultation resulted in a long list of possible activities to be questioned. After eliminating activities that were not common enough to be of use in an assessment instrument, a pilot questionnaire with 95 items was drawn up. The endorsement pilot study led to elimination of 24 items, leaving a survey questionnaire consisting of 68 questions (with three additional questions specific for men or women). These questions were based on the Activity domain of the ICIDH-2. The survey showed that severe limitation of activity was not uncommon among people affected by leprosy who had at least some clinically detectable impairment. The detailed results of this survey have been reported elsewhere.<sup>25</sup>

The results of the survey were used to refine the questionnaire further for validity and reliability testing as described under Materials and methods. Of the original 68 questions, 38 were included in pilot-2 draft of the instrument. Five questions were added to identify difficulty in relationships, one question about the use of aids and two about occupation and employment. These eight questions were added to collect relevant information, but were not intended to be part of the actual scale.

Figure 1 shows the correlation between the sum score of the activity scale and the expert sum score. The Spearman correlation coefficient was 0.72. Discrimination testing showed significant differences in GPAS sum score between people with WHO impairment grade 0 (no impairment) and grade 2 (visible deformity; results not shown). Table 1 shows the results of the reliability testing. Intra-interviewer reliability was good. The overall kappa for all questions pooled together was 0.77 (95%CI 0.73–0.81). The percentage direct agreement was 95.5%. As expected, inter-interviewer reliability was less good, with an overall kappa value

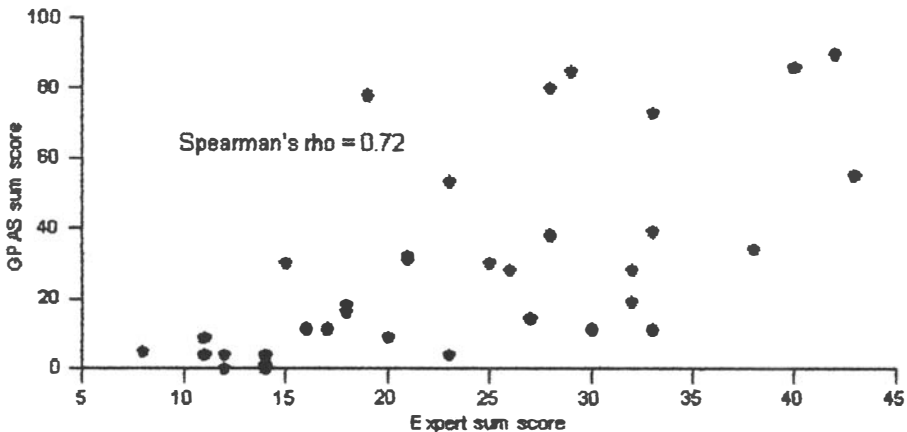


Figure 1. Correlation between the sum score of the Green Pastures Activity Scale and the expert sum score.

**Table 1.** Results of reliability testing of the pilot-2 draft of the Green Pastures Activity Scale

	Difficulty questions				Importance questions			
	<i>n</i> <sup>a</sup>	<i>k<sub>w</sub></i>	95% CI <sup>b</sup>	% DA <sup>c</sup>	<i>n</i>	<i>k<sub>w</sub></i>	95% CI	% DA
Intra-tester agreement	1199	0.84	0.73–0.81	95.9	877	0.60	0.53–0.67	93.1
Inter-tester agreement	1235	0.61	0.56–0.67	92.7	918	0.36	0.30–0.42	85
Stability	1061	0.76	0.70–0.82	95.6	792	0.66	0.59–0.73	91.6

*k<sub>w</sub>* = weighted kappa, <sup>a</sup>*n* = total number of questions included in the calculations, <sup>b</sup>95% confidence interval for *k<sub>w</sub>*, <sup>c</sup>percentage direct agreement.

of 0.61 (95% CI 0.56–0.67). Direct agreement was still 92.7%. The stability test resulted in an overall kappa of 0.76 (95% CI 0.70–0.82), with direct agreement in 95.6% of questions.

The results were also analysed by interviewer, by question and by interviewee. One interviewer appeared to do less well than the others, with significant differences between the overall kappa values (data not shown). Four questions that gave particularly poor results (weighted kappa <0.40) were omitted from the final draft of the instrument.

The results of the reliability testing were much poorer for the 'importance questions' than for the 'difficulty questions' (see Table 1). Feedback from the interviewers suggested that many interviewees had difficulty understanding the concept of asking 'How important is it to you to . . .?' During the drafting and translating of the questionnaire, this problem had already been encountered. We tried rephrasing these questions and put the least misunderstood version in the pilot-2 scale. However, after reviewing the results of the reliability testing, we decided to omit these questions altogether, thereby shortening the questionnaire considerably.

The final draft of the instrument was named the 'Green Pastures Activity Scale' (GPAS). The English translation of the scale is shown in the Appendix.

## Discussion

Irreversible impairments and deformities are the main causes of the complex of negative social reactions attached to leprosy, commonly known as 'stigma'.<sup>26,27</sup> Many investigators have studied the types of impairment occurring in leprosy and their prevalence, often using the term 'disabilities'.<sup>28–31</sup> Others have described the management of impairments<sup>4,5,32</sup> and their incidence and associated risk factors.<sup>33–36</sup> However, few studies have addressed disability (activity limitation) as defined in the ICDH.<sup>6</sup>

People with impaired sensation of the hands, weakness of muscles and deformities of hands and feet may have difficulty with many activities. However, in case management leprosy workers often do not consider the difficulties people experience in activities of daily life. Reconstructive surgery of hands, feet and face, in an attempt to replace lost muscle function, dates back to the pioneering work of Dr Paul Brand and others, more than 4 decades ago.<sup>37,38</sup> Nevertheless, a holistic approach to rehabilitation, including physical, psychological, spiritual and socioeconomic aspects, has been lacking.

In assessing the outcome of treatment or rehabilitation, measures of activity (disability) and social participation (handicap) are much more meaningful for the person involved and thus for clinical decision making.<sup>39,40</sup> However, ADL and participation (handicap) scales

used in Western countries are not appropriate to identify the problems experienced by people living in developing countries, particularly not those of people living in rural areas. We developed the Green Pastures Activity Scale (GPAS) in an attempt to provide a tool suited to this task, especially for use with people affected by leprosy. The GPAS is an interview-based instrument to identify difficulty experienced in activities of daily living. This will potentially allow the instrument to be used under field conditions as well as in referral centres. The structure of the scale is based on the 'Activity' concept of the ICDH-2. Validity, discrimination and reliability testing in a series of pilot studies showed very acceptable results.

We included questions about perceived importance of the various activities in the questionnaire to subjectively weight reported disability.<sup>20</sup> However, the pilot testing showed that such questions were not sufficiently well understood to be reliable. They were therefore omitted from the final scale. Although interviewers were instructed in interview techniques for the GPAS, inter-interviewer reliability can perhaps be further improved through additional training. Responsiveness to change and the best way to summarize the scale into a single index are still under investigation. The GPAS will be made available for general use. An English copy of the scale and instructions for its use can be obtained from the corresponding author.

#### AN EXAMPLE

Mr S. is a 27-year-old self-employed tailor referred to the clinic for rehabilitation. He has extensive impairments on both hands: complete bilateral ulnar/median palmar anaesthesia and motor paralysis with mobile clawing of four fingers on his right hand. He also has a partial footdrop on the left. All impairments are over 3 years old. He has completed 24 months of MDT, but says he is unable to do his job, because he cannot thread or hold a needle anymore. The GPAS interview identified severe difficulty with mobility, because he lives in a hillside village and cannot lift his foot high enough when walking uphill. In addition, he reported severe limitations with activities requiring fine dexterity, scoring 'very difficult' on items like opening containers or bottles (13), cutting nails (24), using buttons, hooks or pins (28) or making knots (29).

He underwent surgical correction of his footdrop and claw hand, which resolved the walking limitation, but not the dexterity problem. Therefore, at his request, weaving training was arranged, followed by a micro-credit loan to buy a hand loom. This proved successful, as weaving requires less fine dexterity than tailoring.

Use of the GPAS forced the staff to take time to talk with Mr S. and to listen carefully to the difficulties he experienced, as opposed to what they assumed he might have, based on his impairments. They were then able to identify specific areas of activity limitation and offer problem-oriented interventions to help him reintegrate as a contributing member of his community.

#### CONCLUSIONS

An instrument was developed for identifying activity limitations in people living in rural areas of a developing country—the Green Pastures Activity Scale. The scale performed well during validity and reliability testing. The GPAS consists of 34 activity questions; in addition, five questions explore difficulty in relationships and three questions the use of aids, occupation and employment status.

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## Appendix

## Green Pastures Activity Scale

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 Name of the patient:

Card number:

Reason for assessment: Admission/Discharge/Home visit/Other:

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Question	Something I have to do	Not difficult	A bit difficult	Very difficult	Something I can't do because of the disease
A. Walking					
1. For you, walking outside the house is					
2. For you, climbing stairs is					
3. For you, walking uphill is					
4. For you, walking downhill is					
B. Sitting and getting up					
5. For you, squatting is					
6. For you, sitting with crossed legs is					
7. For you, getting up is					
C. Seeing					
8. For you, recognizing people from far away is					
9. For you, seeing small things at a short distance (e.g. reading or putting a thread through a needle) is					
D. Preparing meals					
10. For you, cutting vegetables is					
11. For you, putting pots on the stove is					
12. For you, stirring food is					
13. For you, opening containers or bottles is					
E. Activities in the house					
14. For you, sweeping is					
15. For you, opening a door is					
F. Activities around the house or in the fields					
16. For you, opening a tap is					
17. For you, cutting grass or rice with an asi is					
18. For you, weeding grass or rice is					
19. For you, planting seedlings is					
26. For you, going to the toilet is					
27. For you, cleaning yourself after toilet is					
H. Dressing					
28. For you, using buttons, hooks or pins is					
29. For you making knots or tying laces (or bows) is					
30. For you, putting on shoes or sandals is					
31. For you, putting on clothes is					
I. Eating and drinking					
32. For you, eating with the hand is					
33. For you, drinking water from a container or glass is					
34. For you, peeling fruit is					

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Question	No problems	Some problems	Many problems	To live separately	No such relation
J. Relations					
35. Because of leprosy, in the relationship with your spouse, do you have					
36. Because of leprosy, in the relationship with your children, do you have					
37. Because of leprosy, in the relationship with your family, do you have					
38. Because of leprosy, in the relationship with your neighbours, do you have					
39. Because of leprosy, in formal relationship (eg. employer or village head), do you have					

Question	Not necessary	Not difficult	Difficult	Very difficult
K. Assistive devices: Do you use (an) assistive device(s)? YES/NO				
If yes, which:				
40. For you, the use of a device(s) is				
L. Occupation: Do you have any difficulty in your job/daily work? YES/NO				
41. What is your occupation?				
42. Do you do it /daily/sometimes/rainy season/winter season/unemployed?				

Name of the interviewer

Date of the interview: