Clinical aspects of nerve damage in leprosy
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Psychiatric Morbidity in People affected by Leprosy in Nepal assessed with the WHO Self-Reporting Questionnaire (SRQ-20)

From: Psychiatric Morbidity in People affected by Leprosy in Nepal
Wim J. Theuvenet, Paul W. Roche, Sanju Ruchal, Sakalananda Shrestha and C. Ruth Butlin
Submitted for publication
SUMMARY

In 1999/2000 a cohort of 146 leprosy patients enrolled from 1996 on for MDT treatment at Anandaban Leprosy Hospital, Kathmandu was interviewed using a questionnaire, which included the WHO SRQ-20 questions. These measure 'non-psychotic' disorders and have been validated in Nepal.

The findings show a high level of psychiatric morbidity among leprosy patients, with 46/146 (31.5%) attaining a significant score. In a community survey in the same area the score was 10%.

It seems therefore that being diagnosed with leprosy adds considerably to psychiatric morbidity. Patients who were female, older than 40, had established disability, were illiterate or lacked formal education were more likely to have higher scores. Patients' experience of rejection by their families was also associated with high scores. Patients' beliefs were important determinants of morbidity as well. Patients with feelings of sadness, fear or loneliness had high scores. Patients with negative views of the future, or who did not believe they would be cured, were also more likely to have a high score. There were significant differences in the frequency of positive answers to the 20 questions between men and women. A simple logistic regression model showed the strongest determinants of morbidity to be age and sex, with strong negative associations with education, literacy and family acceptance.

These results were compared with those collected from an earlier cohort of patients in 1990/1 at Anandaban Leprosy Hospital and two other leprosy centres in Nepal using the same questionnaire. The prevalence of high SRQ scores had increased significantly in the later cohort and, while some important differences were noted between the two groups, many of the major determinants of morbidity were the same.

This survey identifies some clinical, social and psychological determinants of psychiatric morbidity and documents that after ten years of intensive health education about leprosy, patients are still the victims of ostracism and resultant mental stress.

It is well known that mental stress is a causative factor in defaulting and non-compliance in leprosy elimination programmes. We plan to use this test as a first screening of undue mental stress as this latter may thus affect the efficacy of our Prevention of Impairment and Deformity (POID) and Rehabilitation programmes.

INTRODUCTION

Between 1989 and 1999 more than ten million people were cured of leprosy but there is still a problem to solve as more than 700,000 new cases have been registered annually. Since 1998 there remain today an estimated two to three million people with significant disabilities. The successful introduction of MDT has had a major impact on all aspects of leprosy work and now in many leprosy control programmes the focus of attention is turning towards better prevention of impairment and disabilities and towards rehabilitation. However, the sheer complexity of the physical, psychological, social and economical impact
of leprosy makes the task difficult. Unless patients can identify with the aims of these programmes and become participants, they will not be fully committed and non-compliance will remain a breaking point. In 1983 Wartman stated that a possible predictor of non-compliance could be the patients' level of mental stress, and the attitudes and beliefs of significant people in their environment. In this there will be different cultural perspectives and therefore an instrument that recognised this factor was required when wanting to assess mental stress factors in leprosy at Anandaban Hospital, Nepal.

We sought to measure mental stress by means of the WHO SRQ-20 in leprosy patients.

METHODS AND MATERIALS

Interviews
The WHO Self-Reporting Questionnaire for Adults was selected as this is designed to identify psychiatric morbidity across different cultures. It is a 24-item inventory that has been translated into a number of languages. The questionnaire has 20 questions designed to detect non-psychotic disorders. Validation data are available from a number of countries. There is a considerable variation in the optimal cut-off point on the scale, which results from substantial differences in the response rates. Nevertheless, by careful translation and administration acceptable levels of sensitivity and specificity have been obtained for the clinical assessment of non-psychotic mental stress. Another reason for selecting this test was that it had already been used in Nepal by Wright in 1987 for screening psychiatric morbidity in a village health post and a district hospital. In this study it was shown that Nepali individuals with 11 or more of the 20 questions answered in the affirmative were likely to show symptoms of depression, this with a 91% specificity and 74% sensitivity. Hence the same cut-off of >=11 positive answers was used in both the surveys. The translation was produced by a team of Nepali leprosy health workers and checked for accuracy by trying the questions on a group of leprosy hospital staff and on villagers during a field survey. The same Nepali translation of this questionnaire was used in both surveys. The questionnaire (in English) is shown in the Appendix. A number of questions were added with regard to the patients' perception of their social framework and their illness.

Patient populations
In the 1990/1 cohort were 411 patients from three centres (Anandaban Leprosy Hospital, Green Pastures Leprosy hospital and a large out-patient clinic), who were attending as both out- and in-patients.

The 2000/1 cohort included 146 patients: 67 in-patients and 79 outpatients of Anandaban Leprosy Hospital.
RESULTS

**Responses to the WHO SRQ questions:**

1. **The year 2000/1 cohort:**
   The answers of the 146 leprosy patients of this cohort are shown in Table 1. In 31% a positive score of greater than 11 of the 20 questions was found. In our study there were significant differences in the proportions of responses to each question between male and female patients. Women were more likely than men to say they felt more frightened or nervous, had trouble thinking, found it difficult to make decisions, felt unable to be useful and had thoughts of ending their lives. More women than men had positive answers to 11 or more of the SRQ questions (24/49 versus 22/97, p<0.01). The most common questions answered affirmatively were also different between men and women (Table 1 and 2).

   There was a clear trend for increased psychiatric morbidity in older patients (Table 2), with prevalence rising from 18% in patients under 20 years to more than 50% among patients aged more than 60 (trend test p<0.05).

   There was also a clear trend for greater psychiatric morbidity among patients with increasing amounts of disability, rising from 22% among patients free from disability to 43% among those with visible disability (WHO grade 2; trend test, p<0.05, Table 2).

   Among the strongest “protective factors” against psychiatric morbidity were education and literacy (Table 2). The patient’s own outlook on their disease and their future was associated with a high risk of psychiatric morbidity. This association persisted after adjustment by other factors, suggesting a causal link as well as a logical association as a product of psychiatric morbidity.

   Patients with families who reportedly treated them well and with a belief in their own eventual cure were at significantly lower risk of developing psychiatric morbidity: this effect, however, was removed after adjusted Odds ratios were calculated (Table 2).

   Other factors such as leprosy type, duration of symptoms or treatment, the number of admissions, occupation, marital status, and social acceptance in the village did not have significant influence on the risk of developing psychiatric morbidity.

2. **Comparison with the 1990/1 cohort:**
   We were interested to see what the effect of ten years of leprosy health education had been on the patients’ attitudes and their social acceptability. We had surveyed 411 Nepali leprosy patients in 1990-1991 using the same questionnaire and compared the current results with this unpublished data.

   It was surprising that the prevalence of psychiatric morbidity had apparently risen in the 2000 cohort (31.5%) compared with the 1990/1 cohort (16.3%, p<0.05).

   The responses of the two cohorts to questions about social circumstance and attitudes (Table 3) were compared and some significant differences were noted.
The 1990/1 cohort had more disabled patients (82% versus 55%) with a longer duration of disease (52% versus 30%) and more patients treated for multibacillary leprosy (64% versus 48%). Social circumstances seemed to have improved by 2000, with a higher proportion of patients (83% versus 68%) telling their families about their disease and living with their own families (79% versus 67%): this implies less social rejection than the earlier patients experienced. Nevertheless, there were more patients whose family avoided them (33% versus 19%), and more patients in the latest cohort reported difficulties in going to the shops (24% versus 15%) while less patients faced problems in going to a temple (14% versus 23%) than in the earlier group. Perhaps as an over-all consequence more patients in the latter group (78% versus 60%) felt negatively (with sadness, fear or alienation) about their disease than those in the earlier cohort.

Patients' beliefs about their disease showed some changes over ten years, with more patients in 2000 giving "germs" as the cause of disease (32% versus 16%). However, more also believed their disease was a consequence of sin (7% versus 2%), a belief held perhaps more often by older patients. Importantly, despite evidence to the contrary, fewer patients in 2000 believed they would be cured.
Table 1. Breakdown of positive answers to the SRQ-20 questions among leprosy patients by sex.

<table>
<thead>
<tr>
<th>SRQ question</th>
<th>Total positive responses (%)</th>
<th>Males positive responses (%)</th>
<th>Females positive responses (%)</th>
<th>Significance of difference male &amp; female*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Do you often have headaches?</td>
<td>35 (21%)</td>
<td>19 (18%)</td>
<td>16 (33%)</td>
<td>ns</td>
</tr>
<tr>
<td>2 Is your appetite poor?</td>
<td>41 (28%)</td>
<td>22 (23%)</td>
<td>19 (39%)</td>
<td>ns</td>
</tr>
<tr>
<td>3 Do you sleep badly?</td>
<td>43 (29%)</td>
<td>27 (28%)</td>
<td>16 (33%)</td>
<td>ns</td>
</tr>
<tr>
<td>4 Are you easily frightened?</td>
<td>64 (44%)</td>
<td>33 (34%)</td>
<td>31 (63%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>5 Do your hands shake?</td>
<td>55 (38%)</td>
<td>34 (35%)</td>
<td>21 (43%)</td>
<td>ns</td>
</tr>
<tr>
<td>6 Do you feel nervous, tense or worried?</td>
<td>83 (51%)</td>
<td>47 (48%)</td>
<td>36 (73%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>7 Is your digestion poor?</td>
<td>44 (27%)</td>
<td>33 (34%)</td>
<td>11 (22%)</td>
<td>ns</td>
</tr>
<tr>
<td>8 Do you have trouble thinking clearly?</td>
<td>73 (45%)</td>
<td>41 (42%)</td>
<td>32 (65%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>9 Do you feel unhappy?</td>
<td>90 (62%)</td>
<td>54 (56%)</td>
<td>36 (73%)</td>
<td>ns</td>
</tr>
<tr>
<td>10 Do you cry more than usual?</td>
<td>31 (21%)</td>
<td>19 (20%)</td>
<td>12 (24%)</td>
<td>ns</td>
</tr>
<tr>
<td>11 Do you find it difficult to enjoy your daily activities?</td>
<td>35 (24%)</td>
<td>22 (23%)</td>
<td>13 (27%)</td>
<td>ns</td>
</tr>
<tr>
<td>12 Do you find it difficult to make decisions?</td>
<td>60 (41%)</td>
<td>33 (34%)</td>
<td>27 (55%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>13 Is your daily work suffering?</td>
<td>54 (37%)</td>
<td>35 (36%)</td>
<td>19 (39%)</td>
<td>ns</td>
</tr>
<tr>
<td>14 Are you unable to play a useful part in life?</td>
<td>87 (60%)</td>
<td>50 (52%)</td>
<td>37 (76%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>15 Have you lost interest in things?</td>
<td>63 (43%)</td>
<td>40 (41%)</td>
<td>23 (47%)</td>
<td>ns</td>
</tr>
<tr>
<td>16 Do you feel you are a worthless person?</td>
<td>0 (48%)</td>
<td>42 (43%)</td>
<td>28 (57%)</td>
<td>ns</td>
</tr>
<tr>
<td>17 Has the thought of ending your life been on your mind?</td>
<td>51 (35%)</td>
<td>25 (26%)</td>
<td>26 (53%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>18 Do you feel tired all the time?</td>
<td>55 (38%)</td>
<td>32 (33%)</td>
<td>23 (47%)</td>
<td>ns</td>
</tr>
<tr>
<td>19 Do you have uncomfortable feelings in your stomach?</td>
<td>37 (25%)</td>
<td>28 (29%)</td>
<td>9 (18%)</td>
<td>ns</td>
</tr>
<tr>
<td>20 Are you easily tired?</td>
<td>100 (68%)</td>
<td>63 (65%)</td>
<td>37 (76%)</td>
<td>ns</td>
</tr>
</tbody>
</table>

*Significance of differences in response rates between men and women tested by the Chi-square test
Table 2. The relation between the incidence of stress (SRQ score>=11) and clinical and social factors in leprosy patients

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. SRQ+ (%) /total positive</th>
<th>No. SRQ+ (%) /total negative</th>
<th>Unadjusted</th>
<th>Odds ratio( 95% CI ) Adjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female gender</td>
<td>24/49 (49%)</td>
<td>22/97 (23%)</td>
<td>3.3 (1.6-6.8)**</td>
<td>3.3 (1.1-6.7)*</td>
</tr>
<tr>
<td>Age greater than 40 years</td>
<td>28/62 (45%)</td>
<td>18/84 (21%)</td>
<td>3.0 (1.5-6.2)**</td>
<td>2.7 (1.3-8.4)*</td>
</tr>
<tr>
<td>Established physical disability</td>
<td>32/81 (40%)</td>
<td>14/65 (22%)</td>
<td>2.4 (1.1-5.0)*</td>
<td>1.4 (0.6-3.4)</td>
</tr>
<tr>
<td>Any education</td>
<td>6/54 (11%)</td>
<td>39/90 (43%)</td>
<td>0.2 (0.06-0.4)***</td>
<td>0.6 (0.1-2.8)</td>
</tr>
<tr>
<td>Literate</td>
<td>12/69 (17%)</td>
<td>34/77 (44%)</td>
<td>0.3 (0.1-0.6)***</td>
<td>0.7 (0.2-2.4)</td>
</tr>
<tr>
<td>Patient's family treats them well</td>
<td>32/112 (29%)</td>
<td>12/29 (41%)</td>
<td>0.3 (0.1-0.8)**</td>
<td>0.5 (0.2-1.2)</td>
</tr>
<tr>
<td>Patient believes they can be cured (of leprosy)</td>
<td>31/123 (25%)</td>
<td>12/18 (67%)</td>
<td>0.18 (0.07-0.4)***</td>
<td>0.3 (0.09-0.8)*</td>
</tr>
</tbody>
</table>

*p<0.05, ** p<0.01, *** p<0.001
### Table 3. Differences in rates of responses in two cohorts to questions about social ostracism and attitudes to leprosy.

<table>
<thead>
<tr>
<th>Factor</th>
<th>1990 rate (%)</th>
<th>2000 rate (%)</th>
<th>Significance *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>132/411 (32%)</td>
<td>49/146 (33%)</td>
<td></td>
</tr>
<tr>
<td>Age &gt;40</td>
<td>203/411 (49%)</td>
<td>62/146 (42%)</td>
<td></td>
</tr>
<tr>
<td>MB leprosy</td>
<td>191/298 (64%)</td>
<td>71/146 (48%)</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>Duration of disease &gt;5y</td>
<td>215/411 (52%)</td>
<td>44/146 (30%)</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>Disability grade &gt;0</td>
<td>245/300 (82%)</td>
<td>81/146 (55%)</td>
<td></td>
</tr>
<tr>
<td>Farmers</td>
<td>173/293 (59%)</td>
<td>53/146 (36%)</td>
<td></td>
</tr>
<tr>
<td>No Education</td>
<td>130/197 (66%)</td>
<td>90/144 (63%)</td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>176/303 (58%)</td>
<td>77/146 (53%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>249/308 (81%)</td>
<td>113/145 (78%)</td>
<td></td>
</tr>
<tr>
<td>Living with own family</td>
<td>200/297 (67%)</td>
<td>115/146 (79%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Family knows patient has leprosy</td>
<td>205/300 (68%)</td>
<td>118/143 (83%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Patient's family looks negatively on leprosy</td>
<td>73/286 (26%)</td>
<td>43/146 (29%)</td>
<td></td>
</tr>
<tr>
<td>Patient's family helps patient</td>
<td>240/299 (80%)</td>
<td>115/144 (80%)</td>
<td></td>
</tr>
<tr>
<td>Patient's family avoids patient</td>
<td>56/300 (19%)</td>
<td>49/142 (33%)</td>
<td>p&lt;0.01</td>
</tr>
<tr>
<td>Problems going to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shops</td>
<td>41/275 (15%)</td>
<td>33/139 (24%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Schools</td>
<td>39/198 (20%)</td>
<td>5/27 (18%)</td>
<td></td>
</tr>
<tr>
<td>Another's house</td>
<td>55/281 (19%)</td>
<td>34/141 (24%)</td>
<td></td>
</tr>
<tr>
<td>Do business</td>
<td>40/245 (16%)</td>
<td>14/54 (26%)</td>
<td></td>
</tr>
<tr>
<td>Get a job</td>
<td>51/216 (24%)</td>
<td>20/82 (24%)</td>
<td></td>
</tr>
<tr>
<td>Go to temple</td>
<td>63/265 (23%)</td>
<td>20/137 (14%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Get married</td>
<td>62/203 (29%)</td>
<td>20/55 (36%)</td>
<td></td>
</tr>
<tr>
<td>Feels negatively about disease</td>
<td>185/305 (60%)</td>
<td>114/146 (78%)</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>Views future negatively</td>
<td>118/305 (39%)</td>
<td>61/146 (42%)</td>
<td></td>
</tr>
<tr>
<td>Cause of disease is:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Curse of God</td>
<td>14/406 (3%)</td>
<td>5/146 (3%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Sin</td>
<td>8/406 (2%)</td>
<td>10/146 (7%)</td>
<td></td>
</tr>
<tr>
<td>Bad times</td>
<td>31/406 (8%)</td>
<td>17/146 (11%)</td>
<td></td>
</tr>
<tr>
<td>Germs</td>
<td>65/406 (16%)</td>
<td>47/146 (32%)</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>Blood</td>
<td>50/406 (12%)</td>
<td>25/146 (17%)</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td>193/406 (47%)</td>
<td>32/146 (22%)</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>Other</td>
<td>45/406 (11%)</td>
<td>10/146 (7%)</td>
<td></td>
</tr>
<tr>
<td>Family treats patient kindly</td>
<td>321/403 (80%)</td>
<td>112/140 (80%)</td>
<td></td>
</tr>
<tr>
<td>Villages treat kindly</td>
<td>296/406 (73%)</td>
<td>112/141 (79%)</td>
<td></td>
</tr>
<tr>
<td>Patient believes they will be cured</td>
<td>373/399 (93%)</td>
<td>123/141 (87%)</td>
<td>p&lt;0.05</td>
</tr>
<tr>
<td>Patient believes deformity will be prevented</td>
<td>374/397 (93%)</td>
<td>139/146 (95%)</td>
<td></td>
</tr>
</tbody>
</table>

*Significance of differences between two study groups tested by Chi-square test.
### Table 4. SRQ scores in different communities* in Nepal

<table>
<thead>
<tr>
<th>Author** (year)</th>
<th>Community</th>
<th>No. Studied</th>
<th>Prevalence of psychiatric morbidity*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wright(1990)</td>
<td>Population around Kathmandu area</td>
<td>101 (aged 16 or over)</td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>Lalitpur health post attendees</td>
<td>146 (aged 16 or over)</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>Patan hospital out-patients</td>
<td>150 (aged 16 or over)</td>
<td>28%</td>
</tr>
<tr>
<td>Pol (1998)</td>
<td>Patan urban health project: Community survey</td>
<td>252</td>
<td>11%</td>
</tr>
<tr>
<td>Adhikari &amp; Denison (1999)</td>
<td>South Lalitpur: community survey</td>
<td>362</td>
<td>10%</td>
</tr>
<tr>
<td>Theuvenet et al (1990)</td>
<td>Leprosy in- and out-patients in 3 referral hospitals</td>
<td>411</td>
<td>16.3%</td>
</tr>
<tr>
<td>Theuvenet et al (2000)</td>
<td>Leprosy patients</td>
<td>146</td>
<td>31.5%</td>
</tr>
<tr>
<td></td>
<td>Hospital visitors</td>
<td>167</td>
<td>61.7%</td>
</tr>
</tbody>
</table>

* All studies used the same SRQ and the same cut-off point

** References
### Medico-Social Questionnaire

**Anandaban Leprosy Hospital 1999**

<table>
<thead>
<tr>
<th>Sample</th>
<th>1 = In-patient</th>
<th>2 = Outpatient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>0 = male; 1 = female</td>
<td></td>
</tr>
<tr>
<td>Type of leprosy</td>
<td>0 = TT; 1 = BT; 2 = BB</td>
<td>3 = BL; 4 = LL; 5 = PN; 6 = IND</td>
</tr>
<tr>
<td>Duration of disease (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of treatment (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of admissions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>0 = Nil; 1 = Leprosy only</td>
<td>2 = Leprosy plus prednisone; 3 = Prednisone only</td>
</tr>
<tr>
<td>Disability (WHO)</td>
<td>0 = 0; 1 = 1; 2 = 2</td>
<td></td>
</tr>
<tr>
<td>Interviewer</td>
<td>1 = Madan; 2 = Sanju</td>
<td></td>
</tr>
</tbody>
</table>

1. **Occupation:**
   - 0 = Farmer
   - 1 = Office work
   - 2 = Business
   - 3 = Other

2. **Education.** Which is the highest class the patient has passed?
   - Class 1-10; code as 1-10; SLC = 11
   - Intermediate 1st year = 12; intermediate 2nd year = 13 etc.

3. Can the patient read and write?:
   - 0 = No; 1 = Yes

4. Is the patient married?
   - 0 = No; 1 = Yes

5. If married, is the patient living with spouse in the house?
   - 0 = No; 1 = Yes
   
   If not living with spouse is the reason:
   - 0 = spouse died
   - 1 = spouse left

6. With whom does the patient live?
   - 0 = own family; 1 = parent-in-law
   - 2 = alone; 3 = children; 4 = other

7. How many children does the patient have?

8. Does the patient’s family know that the patient has leprosy?
   - 0 = No; 1 = Yes

   How is the patient’s family looking on leprosy?
   - 0 = neutral; just a disease; 1 = negatively

   Does the patient’s family help the patient?
   - 0 = No; 1 = Yes

   Is the patient’s family avoiding him/her?
   - 0 = No; 1 = Yes
9. Is the patient accepted by his/her villagers? 0 = No; 1 = Yes

Is there any problem for the patient to:

a. Go to the shops 0 = No; 1 = Yes
b. Go to school 0 = No; 1 = Yes
c. Go to another's house 0 = No; 1 = Yes
d. Do business 0 = No; 1 = Yes
e. Get a job 0 = No; 1 = Yes
f. Go to the temple 0 = No; 1 = Yes
g. Get married 0 = No; 1 = Yes

10. How does the patient look upon his/her disease? Does he/she:

1 = Feel angry; 2 = Feel sad; 3 = Feel afraid
4 = Feel lonely; 0 = Have no special feeling

11. How does the patient see his/her future?

1 = Good; 2 = Bad; 3 = Does not care; 4 = Does not know

WHO Questionnaire

1. Do you often have headaches? 0 = No; 1 = Yes
2. Is your appetite poor? 0 = No; 1 = Yes
3. Do you sleep badly? 0 = No; 1 = Yes
4. Are you easily frightened? 0 = No; 1 = Yes
5. Do your hands shake? 0 = No; 1 = Yes
6. Do you feel nervous, tense or worried? 0 = No; 1 = Yes
7. Is your digestion poor? 0 = No; 1 = Yes
8. Do you have trouble thinking clearly? 0 = No; 1 = Yes
9. Do you feel unhappy? 0 = No; 1 = Yes
10. Do you cry more than usual? 0 = No; 1 = Yes
11. Do you find it difficult to enjoy your daily activities? 0 = No; 1 = Yes
12. Do you find it difficult to make decisions? 0 = No; 1 = Yes
13. Is your daily work suffering? 0 = No; 1 = Yes
14. Are you unable to play a useful part in life? 0 = No; 1 = Yes
15. Have you lost interest in things? 0 = No; 1 = Yes
16. Do you feel you are a worthless person? 0 = No; 1 = Yes
17. Has the thought of ending your life been on your mind? 0 = No; 1 = Yes
18. Do you feel tired all the time? 0 = No; 1 = Yes
19. Do you have uncomfortable feelings in your stomach? 0 = No; 1 = Yes
20. Are you easily tired? 0 = No; 1 = Yes
21. What do you think is the cause of your disease?
   1 = Spell of God; 2 = Sin; 3 = Bad times
   4 = Germs; 5 = Blood; 6 = Don't know; 7 = Other
22. Are the people of your family treating you differently since you have had leprosy?
   1 = Less kind; 2 = Kinder; 3 = Same
23. Are your villagers treating you differently since you have had leprosy?
   1 = Less kind; 2 = Kinder; 3 = Same

24. Do you think you can be cured?
   0 = No; 1 = Yes

25. Do you think that further deformity can be prevented?
   0 = No; 1 = Yes
DISCUSSION

Psychiatric morbidity measured by the WHO SRQ test varied from 10.6% in Sudan, 10.8% in Colombia, and 16.3% in the Philippines, 17.7% in India, 22.7% in Brazil and 29% in Kenya. The wide variation in cut-off points used in different countries makes one hesitant to conclude that a positive score above this point justifies the conclusion of “psychiatric caseness” and in general the SRQ test is merely used as the first filter for wider screening of a patient's mental stress.

In 1990/1 amongst 411 leprosy in- and outpatients in the Central, Eastern and Western Region a positive score was found of 16.3%, while in the general population around Kathmandu a score of 9% was found.

Ten years later, in 1999 and 2000 (Table 4), the WHO SRQ test scored a 10% psychiatric morbidity in the community of South Lalitpur District in the Central Region and 13.1% in the Western Rural Nepal community survey respectively while in 2000 and 2001 amongst leprosy patients visiting Anandaban Hospital, Lalitpur District, a positive score of 31.5% was found.

Both in the 1990/1 as well the 2000/1 cohort the positive scores amongst leprosy patients was much higher than in the general population, this until late 2001 when we conducted a survey amongst 167 Anandaban Hospital visitors and a surprising positive score of 60% was found. The strong increase in positive scores amongst the population of Lalitpur district between 1999 (10%) and 2001 (60%) can perhaps be attributed to the sharp increased Maoist guerrilla activity at the end of 2001.

We were interested to see what the effect of ten years of leprosy health education had been on the patients' attitudes and their social acceptability. We were initially surprised to find that it had risen in the 2000 cohort to 31.5% (p<0.05). This is perhaps explained by the significant changed proportion of illiterate patients (176/411, 43% versus 77/146, 53%).

When we further compared the responses of the two cohorts significant differences were noted. The 1990/1 cohort had more disabled patients with a longer duration of disease and treatment. Social circumstances seemed to have improved by 2000, with a higher proportion of patients telling their families about their disease and living with their families; this implies less social rejection than the earlier patients experienced. Nevertheless there were also more patients whose families avoided them, and more patients in the latest cohort reported difficulties in going to the shops and the temple than in the earlier group. Perhaps as a consequence more patients in the latter group felt negatively (with sadness, fear or alienation) about their disease than those in the earlier cohort. Patients' beliefs about their disease showed some changes over ten years, with more patients in 2000 giving “germs” as the cause of the disease. However, more also believed that their disease was a consequence of sin, but there was also greater optimism about cure among patients in 2000 than in 1990.
Less women than men were interviewed in both the 1990/1 and in the 2000 cohorts (32% and 33% respectively) This may be explained by the fact that in the cultural milieu of Nepal women do not enjoy the same geographical mobility as men. If this causes a selection, it may explain why women presenting gave more positive answers to 11 or more of the SRQ questions than men, in both the 1990/1 cohort (35/132 versus 45/279, p<0.05) and 2000 cohort (24/49 versus 22/97, p<0.01). This finding corresponds with earlier studies in Nepal [4], Saudi Arabia [10] and Brazil [11] but is in contrast with a Nigerian [9] and Kenyan [12] study where no sex differences in positive score were found.

In our first 1990/1 study women complained significantly more than men about poor appetite, poor digestion, headaches, the tendency to cry more often, to feel frightened, and that their hands shake, while in the 2000 follow-up this had shifted to complaints of feeling frightened, nervous, having trouble thinking, finding it difficult to make decisions, feeling unable to play a useful part and having thoughts of ending their lives. This suggests a shift from psychosomatic to mental problems for which we have found no explanation yet.

We feel that the SRQ is a useful instrument to assess the causative factors and the degree of mental stress in individual leprosy patients in Nepal. It deserves further study to demonstrate whether with the knowledge gained by this test, the compliance rate, the feasibility of preventing disability and impairment and the outcome of rehabilitation programmes can be enhanced.

References:
1. Guidelines for the social and economic rehabilitation of people affected by leprosy.
2. Wartman SA. et al.,
   Patient understanding and satisfaction as predictors of compliance.
3. Harding TW et al.,
   The WHO Collaborative Study on Strategies for Extending Mental Health Care, II: The Development of New Research Methods.
4. Wright C, Nepal MK and Bruce Jones WDA.
   Mental Health Patients in Primary Health Care Services in Nepal; 1987.
5. Pol K, Nakarmi B, Thapa B and Ackland S.
   Yalla Urban Health Project: A Mental Health Study.
6. Adhikari KP and Denison BDB.
7. Adhikari KP, Huttunen J. and Kiljunen R.
   Mental Health in Nepal: A Community Survey of Anandaban Village in Western Region of Nepal.
8. Kortmann F and Ten Horn S.
   Deficiencies of the Self-Reporting Questionnaire: The validity of a WHO psychiatric screening instrument.
9. Ohaeri JU and Odejide J.
10. Al-Subaie AS et al.
11. Lima MS, Beria JU et al.
12. Dhadphale M, Ellison RH et al.