LETTER TO THE EDITOR

Sources of anxiety amongst leprosy patients in urban treatment setting in Hyderabad, India

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People with leprosy in the Indian Subcontinent are reported to have a lower quality of life and poorer mental health compared to control groups. The cause of these inequalities is usually attributed to a combination of stigma and physical disability. While addressing the impact of these factors among leprosy patients is important, the increase in early diagnosis and treatment of leprosy, particularly in cities, has led to a group of patients with relatively concealed symptoms, who have not been forced to disclose their status publically. The concerns of this group of patients are therefore different to that of long-term leprosy patients, and greater knowledge of their concerns relating to leprosy is necessary to ensure compliance to treatment and improve quality of life.

Objective

Research into the mental health repercussions of leprosy in India have tended to focus on the effects of leprosy stigma and self-perceived stigma on patients’ mental health among patients with severe and obvious disabilities, often in the context of leprosaria. This small-scale study focused instead on patients attending urban leprosy clinics, with Grade 0, Grade I or Grade II disabilities (according to the WHO leprosy disability grading system), and sought to investigate whether these patients had specific concerns regarding their diagnosis and ramifications of the disease, and what these were.

Methodology

The study was carried out between August and September 2013 across three urban outpatient clinics (run by the non-government organisation LEPRA) specialising in the treatment of leprosy and its complications in Hyderabad, India. Patients attending these free clinics were
either on multi-drug therapy (MDT) for leprosy, or had previously been treated for leprosy and were now being treated for reactions to leprosy (erythema nodosum leprosum, reversal reactions, neuritis) or ulcer care. A random sample of 30 patients was taken across all three clinics. After completing their consultation with the medical staff, all patients being treated for leprosy or its side-effects were asked to participate in a short semi-structured interview (in the local language Telugu) to discuss whether they had any concerns or anxieties relating to their diagnosis of leprosy or its ongoing effects. Those who admitted to anxiety concerning leprosy were asked to identify sources of anxiety. There were no set prompts for determining these sources: each patient was simply asked to list concerns about their disease at the current point in time. All sources of anxiety were recorded, along with age, sex, reason for attending clinic and grade of disability. Consent was gained prior to interview from all patients. All results were anonymised.

Results

Our sample consisted of 23 males and seven females. The average age of the 30 participants was 44 years, with a range of 25 to 87. The majority of patients (60%) had Grade II disabilities, and similar numbers attended the clinic for either MDT (37%) or leprosy reactions (40%) (Figure 1).

Fourteen patients (47%) did not admit to any anxiety concerning their diagnosis. Of these fourteen, two had no leprosy related disabilities, six had Grade I disabilities and six had Grade II disabilities (see Figure 2). Sixteen patients (53%) stated that they did have anxieties concerning their leprosy diagnosis. Among this group there was a higher incidence of Grade II disabilities.

Most patients reported several causes of anxiety (in total 23 were listed), and all causes of anxiety are reported in Table 1, with concerns regarding leprosy split into five categories.

Discussion

The most striking finding of this study was that only half the patients surveyed admitted to anxiety relating to leprosy: many patients were unable to identify any concerns relating to their disease. This is suggestive of successful diagnosis and treatment prior to disabling symptoms becoming evident, improved education into the curability of leprosy, and
decreasing concern over its stigma. In part this may be a result of the setting: patients are receiving treatment for leprosy or its complications, and therefore may be less anxious than if they were not being treated. Furthermore the urban setting allows anonymity of diagnosis, which may be responsible for the low numbers of patients with concerns about stigma.

In terms of those who admitted to anxiety relating to leprosy, this study shows that sources of anxiety in this setting are varied, but that practical concerns feature strongly. Complications and employment concerns account for approximately 60% of all sources of anxiety mentioned by patients. Concerns relating to curability and reoccurrence of leprosy were evident in patients who had hard-to-treat leprosy reactions or had not been adequately treated for leprosy on initial diagnosis. Those patients with anxiety relating to drug

Table 1. Sources of anxiety among patients presenting at LEPRA clinics in Hyderabad

<table>
<thead>
<tr>
<th>Source of Anxiety</th>
<th>Number of patients reporting source of anxiety</th>
<th>Percentage of total reported sources of anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leprosy complications (leprosy reactions,</td>
<td>8</td>
<td>35%</td>
</tr>
<tr>
<td>clawing, blindness, ulcers)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment concerns/effect of</td>
<td>6</td>
<td>26%</td>
</tr>
<tr>
<td>leprosy on work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Curability/re-occurrence</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>Drug side effects</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>Stigma/self-perceived stigma</td>
<td>2</td>
<td>9%</td>
</tr>
</tbody>
</table>

Figure 2. Disability grading of patients with no concerns relating to leprosy and with concerns relating to leprosy.
side-effects (three patients) all cited skin discolouration due to clofazimine (part of MDT) as their concern, and these patients went on to explain that it had forced them to disclose their leprosy status unwillingly, affected their mental health, and, in one case, damaged their prospects of marriage. There has been little research into this particular side-effect of MDT, and it may be of interest to healthcare professionals working with leprosy that 10% of our sample, and 27% of the sample currently receiving MDT, considered this a concern.

Acknowledgements

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References