SHORT REPORT

Disability aid compliance in people affected by leprosy in urban and rural Maharashtra, India – a need for comprehensive study

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Introduction

If the predictions of Richardous1 are correct, then leprosy is the biggest cause of preventable disability in India today. Data from the National Leprosy Eradication Programme, (NLEP), also indicates rising numbers of Grade II deformities in newly detected cases since 2005.2 In a recent communication, the draft Leprosy Strategy 2016 to 2020 from the World Health Organisation (WHO) also underlines the need for a global research agenda to reduce the disability burden in communities affected by leprosy.3 Key to this is the assessment of disability aid compliance in such communities, a research topic which unfortunately shows a paucity of up to date and relevant data. As a result we believe that there is a greater need for more research on this subject and hence we present our preliminary findings arising out of a recent assessment in Maharashtra, India.
Materials and Methods

As part of leprosy patients’ ongoing treatment, monitoring and follow-up, an informal questionnaire was designed to assess disability aid compliance. Patients were interviewed at the Referral centre and satellite clinics of the Bombay Leprosy Project (BLP) operations in both urban and rural locations. For the purpose of this assessment and due to the paucity of information, we defined disability aid compliance as patients who have taken up a disability aid or aids and report whether there was a positive outcome of the intervention. Conversely, patients who reported on non-usage or no positive outcome were classified as non-compliance. Patients were asked how often they used the disability aids, how long the aids were used for and whether they felt they had helped to improve their symptoms. Patients were also asked if they had any difficulties with the disability aids.

Results

Seventy interviews were carried out in rural and urban areas with a 3:1 male to female ratio, aged between 15 and 81, with mean age 44 years. The results are based on 64 responders as six people did not answer the questionnaire. Among the patients interviewed a large majority of them (87%), have been affected by leprosy for 3 years or more and 81% of them showed Grade II deformities. The remainder of patients had been affected by leprosy for less than 3 years and had Grade I deformities. The disability and disability aid information collected is summarised in Table 1.

Over 90% of patients answered questions relating to frequency and time of aid use, and whether they felt the intervention had improved their functional ability. Overall, 60% reported that this was a positive intervention using the aid during the daytime, (MCR footwear) or once per day for 10–20 minutes for FLS, (finger loop splints). Some patients used the FLS for up to three times a day and were generally the younger patients on the assessment. Uniformly, the AD, (abductor band), was used at night during sleep.

Some 32% of patients felt there was no improvement in their symptoms and had limited their use of the aid as a result. Many patients reported pain as a limiting factor, especially with FGS, (finger gutter splints), or the fact that the aid was broken, lost or unavailable. Some identified lack of time to use the aid, due to work and family caring commitments.

A small number of patients didn’t like the aid and preferred to wear normal footwear, had not taken up the treatment even though it was given, or had not requested replacement of damaged or lost disability aids. A small number of patients with multiple deformities reported non-compliance, where their illness had lasted 7 years and less than 6 months; 8% of patients were uncertain about the question or did not answer.

Discussion

The majority of patients using disability aids showed good compliance leading to an improvement in their symptoms. This suggests they were committed to self-care and understood the education they were given, correlating with the observations of Joshi and Revankar. The 60% compliance rate shows patients reporting with fixed to mobile claw correction and greater hand dexterity or feet free of ulceration and showing foot drop
improvements. When patients take up the services voluntarily and understand how to use them the result is generally positive - a fact also noted by Ganapati et al.\textsuperscript{5}

This assessment has also shown that non-compliance in using disability aids remains relatively common, both in rural and urban districts, through all ages and by people new to the disease, or those that have been affected by leprosy for many years. Joshi \textit{et al.}\textsuperscript{6} reported a compliance rate of less than 50\% in 2000, supporting the 32\% non-compliance revealed in this assessment. While this may be due to a lack of patient motivation or difficult personal circumstances, it also shows the need for continued education and training for people affected by leprosy set against a backdrop of structured long-term care management.

Ganapati \textit{et al.}\textsuperscript{7} indicated that the problem posed by leprosy patients with disabilities is highly challenging and without further research into this issue, we may not know how challenging it may be. However, it is certain that research into disability aid compliance is needed to reduce the rate of non-compliance discovered and to improve the prevention of disability among leprosy affected people.

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References


\textbf{Table 1. Disability aid compliance}

<table>
<thead>
<tr>
<th>Disability</th>
<th>No of disabilities reported</th>
<th>Disability aid used</th>
<th>No. of Disability aids utilised</th>
<th>Compliance rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile Claw</td>
<td>29 FLS</td>
<td>25</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Plantar Neuropathy</td>
<td>32 MCR footwear</td>
<td>32</td>
<td>62</td>
<td></td>
</tr>
<tr>
<td>Plantar Ulcer</td>
<td>15 MCR footwear</td>
<td>15</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Hand Neuropathy/Muscle Atrophy</td>
<td>8 AB</td>
<td>2</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Claw Toe</td>
<td>3 MCR</td>
<td>3</td>
<td>65</td>
<td></td>
</tr>
<tr>
<td>Fixed Claw</td>
<td>3 FLS</td>
<td>2</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Foot Drop</td>
<td>2 FDS</td>
<td>1</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Abductor Deformity</td>
<td>4 AB</td>
<td>4</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Chronic Deformity/Surgery</td>
<td>8 MCR</td>
<td>8</td>
<td>62</td>
<td></td>
</tr>
</tbody>
</table>

Note: Many patients reported multiple disabilities and disability aids used. % compliance calculated by the number of disability aids utilised and whether a positive outcome was reported for example, 29 people reported having a mobile claw deformity and 25 reported using a finger loop splint. 60\% reported a positive outcome.

FLS – Finger Loop Splint; FGS – Finger Gutter Splint; AB – Abductor Band; MCR – Micro-cellular Footwear; FDS – Foot Drop Splint.


