Health care utilisation in Indian leprosy patients in the era of elimination

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Summary
Objectives: The health care utilisation pattern among Indian leprosy patients accessing a tertiary care centre over an 18 month period was studied.
Design: A study was conducted at the Dermatology Outpatient Clinic at the Christian Medical College, Vellore, from January 2005 to June 2006. The profile of patients was assessed and a subgroup was interviewed on their healthcare use, including any delays and costs incurred.
Results: 198 patients presented of which 115 patients (58.1%) were on treatment for leprosy or a leprosy reaction (active) including 35 new patients (17.7%), and 83 (41.9%) patients were not on active treatment (inactive). 81 patients were interviewed in depth, 14 (17.3%) were new patients included among 54 (66.7%) patients with active disease, and 27 (33.3%) with inactive disease. The average delay from the onset of symptoms to starting treatment in those interviewed was 13.4 months, 7.9 months of which was a patient-related delay and 5.4 months of which was the health care system-related delay. In patients who had been released from treatment, 78.6% (22/28) required care after cure.
Conclusions: Improved awareness is required to reduce patient-related delays and systems for sustained training need to be in place to tackle the problem of health care system-related delays. Care after cure is a felt need for many patients released from treatment.
Introduction

The recently published data on leprosy shows that the case load has fallen by around 90% in the past two decades.\textsuperscript{1,2} The number of countries with a prevalence above elimination levels has fallen from 122 in the mid eighties to just four as of June 2007.\textsuperscript{3}

Delays in diagnosis and in starting treatment are not good for the patient because of the risk of adverse consequences, nor are they good for the community because of the risk of prolonged transmission.\textsuperscript{4–6} Available data suggests that delays longer than 6 months were detrimental to the clinical outcome.\textsuperscript{5,7} In a study from Brazil, 71\% had a delay of 7 months or more and this was significantly associated with nerve function impairment.\textsuperscript{8} It has been found that under diagnosis is more common among the borderline lepromatous and the lepromatous group.\textsuperscript{4} The importance of early detection and effective treatment in the elimination of leprosy cannot be over emphasised.

Patients continue to access referral services at tertiary care hospitals although leprosy care is available at Primary Health Centre level. We assessed the clinical profile and healthcare utilisation patterns of patients presenting over an 18-month period to determine factors that lead to delay in diagnosis and treatment.

Material and Methods

A study was done at the Dermatology Outpatient Department (OPD) at the Christian Medical College, Vellore from January 2005 to June 2006. All newly registered patients diagnosed with currently or previously having leprosy were eligible for inclusion in the study; consecutive patients who consented to participate in detailed interviews were enrolled. Patients who had been diagnosed previously and treated at Christian Medical College were excluded.

The demographic and clinical features, past history, history of contact with leprosy, diagnosis and disability status were recorded, and each patient classified as multibacillary (MB) or paucibacillary (PB) according to NLEP (National Leprosy Eradication Programme) guidelines.\textsuperscript{9} The diagnosis of leprosy and classification was primarily clinical; all patients had skin smears tested and skin or nerve biopsies as necessary.

Patients were questioned about their symptoms, contacts with the health care system, costs incurred, presence of visible deformity at the time of presentation, occurrence of deformity during or after treatment, history of reactions and knowledge about their diagnosis. The overall delay was classified as patient-related delay and health care system-related delay. Patient-related delay was defined as the interval between the first onset of symptoms to the time of presentation to any health care facility. The health care system-related delay was defined as the sum of the intervals from presentation to diagnosis, and from diagnosis to starting treatment. The contacts with the health care system and the total number of physician patient contacts noted. Any instance of seeking alternative medicine was also recorded. In patients released from treatment (RFT), details of self-medication, and any symptoms post RFT were recorded in the proforma. The costs of medical care were traced and the cost incurred over the previous year was noted to minimise recall bias.

Categorical variables were analysed using the Chi square test. Relationships between variables were assessed using the Pearson’s product moment correlation and Spearman’s rho. Comparisons of continuous variables between categorical levels were conducted using
independent sample ‘t’ tests and analysis of variance, though the Mann-Whitney and Kruskal-Wallis tests were used when the required assumptions were not met. The study was approved by the Institutional Review Board, Christian Medical College, with institutional funding.

Results

A total of 198 patients with leprosy were seen in the Dermatology OPD during the study period, 162 (81.8%) were males. The reasons for attendance are summarised in Table 1. Of these patients, 115 (58.1%) were on treatment for leprosy or a leprosy reaction including 35 new patients (17.7%); 83 (41.9%) patients were not on active treatment for leprosy or for reaction.

Utilisation Profile

Eighty one of the 198 patients consented to participate in the detailed interviews on healthcare use. This group of 81 was not statistically different from the clinic attendee group of 198 with respect to age, sex, religion, state, MB/PB status and WHO disability grades; 93.2% of the study population was literate, of which 24 (32.9%) were graduates.

The majority of patients – 54 (66.7%) – had active leprosy. The clinical diagnosis in the group interviewed was borderline tuberculoid leprosy in 33 (40.7%) patients, lepromatous leprosy in 15 (18.5%), borderline lepromatous leprosy in 11 (13.6%), pure neuritic leprosy in seven (8.6%), tuberculoid leprosy in five (6.2%) and mid-borderline leprosy in three (3.8%). Seven patients had treated inactive leprosy which could not be classified. Grade 2 disabilities were noted in 33 (40.74%) patients and Grade 1 in 13 (16.05%) patients.

Disability

Fourteen out of 18 were newly diagnosed cases of leprosy, and 67 had been previously diagnosed. Sixty-four of these 67 known cases of leprosy were able to give details of disability at the onset of their illness, and any disabilities which developed later. At the time

<table>
<thead>
<tr>
<th>Presenting features at the time of study</th>
<th>All patients n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opinion on treatment adequacy</td>
<td>42 (21.2)</td>
</tr>
<tr>
<td>Deformity</td>
<td>38 (19.2)</td>
</tr>
<tr>
<td>Trophic ulcer</td>
<td>20 (10.1)</td>
</tr>
<tr>
<td>Patch</td>
<td>20 (10.1)</td>
</tr>
<tr>
<td>Type 1 reaction</td>
<td>19 (9.6)</td>
</tr>
<tr>
<td>Type 2 reaction</td>
<td>18 (9.1)</td>
</tr>
<tr>
<td>Paresthesias</td>
<td>11 (5.6)</td>
</tr>
<tr>
<td>Swelling of the hands and/or feet/infiltrations</td>
<td>10 (5.1)</td>
</tr>
<tr>
<td>Dermatological problem unrelated to leprosy</td>
<td>8 (4.0)</td>
</tr>
<tr>
<td>Sensory loss</td>
<td>6 (3.0)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (3.0)</td>
</tr>
<tr>
<td>Total</td>
<td>198 (100.0)</td>
</tr>
</tbody>
</table>
of onset of their illness, 41 (64·1%) had no disability, 10 (15·6%) had a Grade 1 disability and 13 (20·3%) had a Grade 2 disability. Among the 41 patients who had no disability, three patients developed a Grade 1 and 12 patients developed a Grade 2 disability. Out of the 10 patients who had a Grade 1 disability at the onset of illness, six developed a Grade 2 disability subsequently. Out of the 13 patients who had a Grade 2 disability, one patient acquired a new Grade 1 disability, and three patients, new Grade 2 disabilities. At the time of presenting 48·4% (31/64) patients had Grade 2 disability.

Thirty-two (40·5%) had a past history of reactions, and 21 had a resultant deformity. There was no statistical significance in disability whether or not the patients had received steroids for their reaction ($P = 0·59$).

**DELAY**

Sixty-four out of 81 patients were able to recall information on the delay between the onset of their symptoms and starting any anti-leprosy treatment. Among these 29 (45·3%) had a delay of up to 6 months, and 35 (54·7%) had a delay equal to or more than 7 months. Complete data on patient and health care system-related delays were available in 58 out of the 64 patients. The distribution of delays is shown in Table 2.

The overall delay tended to be longer in patients aged 35 years or less, as compared to those above 35 years ($P = 0·64$), and in women as compared to men ($P = 0·35$). There were no statistically significant differences between paucibacillary cases and multibacillary cases, patients without a history of reaction compared to patients who have had reaction in the past, and in patients who had used alternative medicine in terms of delay.

**NUMBER OF PHYSICIANS CONSULTED**

Seventy-six patients in the interview group were able to give details of the number of physicians they had consulted for treatment; the median was two, and the maximum was nine. The number of doctors was more in patients with past history of reactions ($P < 0·001$), with multibacillary leprosy ($P = 0·025$) and with use of alternative medicine ($P = 0·001$). There were no significant differences between the duration of the disease and the number of physicians consulted or the gender of the patient.

**AWARENESS ABOUT DIAGNOSIS**

Seven (10·6%) of the patients interviewed were not aware of their diagnosis, even though five of them had received MDT, and four of them could definitely identify the blister packs; 59 (89·4%) were aware of their diagnosis.

**Table 2. Delay characteristics (delay in months)**

<table>
<thead>
<tr>
<th>Delay</th>
<th>Mean</th>
<th>Median</th>
<th>Range</th>
<th>Std. deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>From onset of symptoms to presentation (patient-related delay)</td>
<td>7·9</td>
<td>3</td>
<td>48</td>
<td>10·46</td>
</tr>
<tr>
<td>From presentation to diagnosis</td>
<td>3·8</td>
<td>0</td>
<td>60</td>
<td>10·41</td>
</tr>
<tr>
<td>From diagnosis to starting treatment</td>
<td>1·6</td>
<td>0</td>
<td>72</td>
<td>9·60</td>
</tr>
<tr>
<td>From presentation to starting treatment (health care system delay)</td>
<td>5·4</td>
<td>0</td>
<td>108</td>
<td>16·77</td>
</tr>
<tr>
<td>From onset of symptoms to starting treatment (overall delay)</td>
<td>13·34</td>
<td>7</td>
<td>109</td>
<td>19·68</td>
</tr>
</tbody>
</table>
PREVIOUS TREATMENT

Fifty-nine patients gave details of their previous treatment. One patient had defaulted after hearing of the diagnosis and was not on any treatment, one was diagnosed but not treated, and the rest could not recall exact details. Thirty-five out of 59 patients had taken only WHO MDT, 15/59 had other regimens of antileprosy treatment and 9/59 had taken both. The average duration of anti-leprosy treatment was 28.3 months, of which the average duration of WHO MDT was 11.4 months and that of other anti-leprosy treatment regimens was 16.9 months.

SYMPTOMS AFTER RELEASE FROM TREATMENT (RFT)

There were 29 patients who had been released from treatment. Details of the presence or absence of treatment after RFT were available in 28 patients. Among these six (21.4%) patients had no complaints after RFT, the rest (78.6%) had complaints that necessitated a physician’s care; seven of these were re-started on treatment for leprosy. The reasons for seeking a physician after RFT in these 22 patients were: persistent sensory loss in six patients (27.3%), persistent motor weakness in four (18.2%), reactions and trophic ulcers/callosities in five (22.7%) and new patches and generalised malaise in one (4.5%). All patients who had sensory loss were not aware of the possible irreversible nature of their disability.

COSTS

Out of 81 patients details of the economic impact on them was available in 62. Complete details regarding the direct and indirect costs were available in 60 patients, and are shown in Table 3. Patients spent an average of $20.05 ± 29.88% of their annual earnings on health care. Twelve (19.4%) were forced to lose or change their jobs.

Discussion

Leprosy is on the decline according to national and international statistics. Leprosy services are fully operational under the Governmental health care services and are free; unrestricted access to medical care has been promised. However, the needs as felt by the patients themselves may not always be captured by incidence or prevalence rates. In order to cater to the needs of the patients as much as possible, it is necessary to know their health care utilisation. In fulfilling the commitment towards early case detection and prompt treatment, we need to know the delays in diagnosis and treatment.

Table 3. Costs in rupees over the past 1 year

<table>
<thead>
<tr>
<th>Cost</th>
<th>Direct cost</th>
<th>Indirect cost</th>
<th>Total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>4309.52</td>
<td>4748.89</td>
<td>7871.18</td>
</tr>
<tr>
<td>Median</td>
<td>2112.50</td>
<td>0</td>
<td>2720.00</td>
</tr>
<tr>
<td>Std. deviation</td>
<td>7906.986</td>
<td>12491.536</td>
<td>16173.074</td>
</tr>
<tr>
<td>Minimum</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Maximum</td>
<td>44400.00</td>
<td>63900.00</td>
<td>92400.00</td>
</tr>
</tbody>
</table>

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SOCIO DEMOGRAPHIC PROFILE

In this study a total of 198 patients with leprosy accessed our centre during the study period of 18 months. Only 18.2% were females; this could reflect a gender bias in health seeking practices. Overall, patients from nine states other than Tamil Nadu accessed our centre.

DISEASE CHARACTERISTICS

Overall, 74.3% (26/35) of new cases could have been easily diagnosed by a trained health worker at Primary Health Centre level. These findings could reflect a referral bias or a lack of awareness of the local availability of leprosy services, cases being missed at primary level or stigma preventing patients from accessing centres closer to their places of residence. Strengthening awareness, both among patients and their families, and better training and orientation programmes for all health workers is recommended.

The percentage of people with Grade 2 deformity in this study was as high as 40.7% (33/81), though the national rate for Grade 2 disability is 2.25%. This rate is about twice that found by Kumar et al. in a tertiary care centre in Agra and by Pimentel in Brazil. This could be due to the fact that established reconstructive services are available at our centre. Among the known cases of leprosy, the disability rates had risen from 20.3% (13/64) to 48.4% (31/64), which was in stark contrast to a study from Brazil, in which the disability rates actually decreased through treatment and follow up. This probably reflects the level of efficacy of prevention of disability measures available to patients. Strengthening this component needs to be undertaken along with the strengthening of facilities for chemotherapy and early diagnosis. Males had more deformities than females (P = 0.013) in keeping with earlier studies.

HEALTHCARE UTILISATION PROFILE

Patient-related delays, and health care system-related delays were considered. The patient-related delay in our study was 7.9 months. The overall delay was 13.3 months which is twice as high as the suggested maximum of 6 months. The health care system-related delay was 5.4 months, less than that in a study from Nigeria (10 months) where patient-related delay was 4.5 months; 45.3% had a delay less than 6 months, which is shorter compared to earlier studies from India and from other endemic countries. Females had a longer delay than males, consistent with earlier studies from West Bengal, Bangladesh and Maharashtra, although a recent study from Delhi showed otherwise. The use of alternative medicine was associated with a longer health care system-delay (17.6 months in those who used alternative medicine compared to 1.4 months in those who did not); this was in accordance with available data. Although the number of patients in the group using alternative medicine was small, this is an important pointer to the need for better awareness regarding the disease, its treatment and the free availability of such treatment. The delay was less in patients with a past history of reactions as suggested by Nicholls et al. In our study the delay was greater in paucibacillary patients compared to multibacillary cases in contrast to earlier studies. The difference here was attributable primarily to the health care aspect of the delay in our study, i.e. failure to diagnose paucibacillary cases early. The average number of physicians consulted was 2.5 (±1.8), which was remarkably similar to a study done 25 years ago.
A delay between presentation and diagnosis indicates the need to strengthen the training of medical personnel to facilitate early diagnosis, while a delay between diagnosis and treatment needs to be addressed by improving both patient and physician participation and cooperation. In this study, we found that 45.4% (10/22) of patients had trophic ulcers or reactions, both of which need quality medical care.

Delays in diagnosis and treatment are associated with adverse clinical outcomes and increased disease transmission. Continued emphasis on early detection and prompt treatment are key to leprosy control, and addressing these delays is important. Improved awareness with resultant improved health seeking behaviour, and better training and continued orientation of health care workers is recommended.

References

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