LEPROSY AMONG ADOLESCENTS IN KOLKATA, INDIA

A.S. John 1, P.S.S. Rao 2, R. Kundu 3, M.S. Raju 4

Leprosy, manifesting during adolescence when significant physical and emotional changes are taking place, poses further stress and strain both on the individual and on the family. Based on hospital records, focus group discussions and in-depth interviews, data on 258 adolescent leprosy patients seen at a leprosy referral hospital in Kolkata, India, are presented. The male-female sex ratio was 1.93:1, 56.6% were multibacillary patients and 13.2% had grade 2 disability. At the time of final follow up, 10% of PB and 33% of MB patients had already discontinued treatment. The commonest complication was reaction (14.5%). Adolescents were still dependent on their parents for health matters. Data obtained from questionnaires confirmed the role of social stigma in hiding, delay in starting of MDT and defaulting. Frequent hospital admissions resulted in loss of jobs and disruption of studies and caused psychological disturbances. It is critical to identify and treat adolescent leprosy on a priority basis. Health education and counselling programmes must be more focussed and acceptable. Further research is necessary.

INTRODUCTION

Leprosy, a chronic debilitating disease caused by M. leprae, has an insidious onset and an obscure epidemiology (Fine, 1982; WHO, 1997). Children are considered most vulnerable to infection (Browne, 1965; Rao et al, 1972; Dayal & Bharadwaj, 1995) and with a long incubation period, leprosy generally manifests during adolescence or young adulthood.

While leprosy in children has been adequately described (Selvasekar et al, 1999; Nadkarni et al, 1988; Prasad, 1998; Lue et al, 2000; Rao et al, 1989), data on adolescent leprosy are scarce. This paper presents the highlights from a study on adolescent leprosy patients seen at a leprosy hospital in Kolkata (Calcutta), India.

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Adolescence is a period of significant physical and emotional changes (Chaturvedi et al, 1996; WHO, 2001) and the manifestation of leprosy during this period poses further stress and strain, both on the individual and on the family members (Hammond et al, 1999).

METHODS AND MATERIALS

Essential demographic, socio-economic and clinical details were taken from the outpatient records of all adolescent leprosy patients between the ages of 10 and 20 years, who newly registered for anti-leprosy treatment (MDT) during the period 1998 to October 2003 at the Premananda Memorial Leprosy Mission Hospital in Kolkata. Additional social and clinical data were collected prospectively on patients registered during 2002-2003.

Four focus group discussions were conducted in the local language separately with boys and girls, as well as with their parents. In-depth interviews were carried out with a few key informants.

FINDINGS

1434 leprosy patients were newly registered for anti-leprosy treatment during the study period; of these 258 (18%) were in the age-group of 10-20 years.

The proportion of adolescents among the newly registered cases remained the same during each year of the study period. 96.5 per cent of patients were from Kolkata or other parts of West Bengal.

The age and sex distribution of these patients are shown in Table 1.

<table>
<thead>
<tr>
<th>Age</th>
<th>&lt;10 years</th>
<th>10-20</th>
<th>&gt;20</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>37 (29.7%)</td>
<td>170 (65.9%)</td>
<td>881 (79.1%)</td>
<td>1088</td>
</tr>
<tr>
<td>Females</td>
<td>25 (40.3%)</td>
<td>88 (34.1%)</td>
<td>233 (20.9%)</td>
<td>346</td>
</tr>
<tr>
<td>Total</td>
<td>62 (4.3%)</td>
<td>258 (18%)</td>
<td>1114 (77.7%)</td>
<td>1434</td>
</tr>
<tr>
<td>M : F ratio</td>
<td>1.48:1</td>
<td>1.93:1</td>
<td>3.78:1</td>
<td>3:1</td>
</tr>
</tbody>
</table>

The male-female ratio is nearly equal (1.48:1) in children under 10 years which increased to 3.78:1 in the adults; while it is intermediate (1.93:1) among adolescents.
Clinical details of 83 adolescents registered during 2002-2003 for intensive study are summarized in Table 2. 56.6% of the adolescents were diagnosed as having multibacillary leprosy. The bacterial index (BI) was negative for 70% of MB patients; of the remaining, 15% had a BI of 3+ or more. For 22% of adolescents, it was the complications that made them report to the hospital—the commonest complication being reactions. For 13.2%, it was the appearance of grade 2 disabilities. Among the boys, there were eye, hand and foot deformities, and among the girls, 3 had developed deformities of the hand.

MDT was initiated for all the patients. At the time of final follow up, 10% of the PB and 33.3% of the MB patients had defaulted.

<table>
<thead>
<tr>
<th>Findings</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total patients</td>
<td>83</td>
<td>100</td>
</tr>
<tr>
<td><strong>Type of leprosy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PB</td>
<td>36</td>
<td>43.4</td>
</tr>
<tr>
<td>MB</td>
<td>47</td>
<td>56.6</td>
</tr>
<tr>
<td><strong>Grade 2 Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Hand</td>
<td>8</td>
<td>9.6</td>
</tr>
<tr>
<td>Foot</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td><strong>Bacterial Index</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 2</td>
<td>7</td>
<td>14.9</td>
</tr>
<tr>
<td>3 – 4</td>
<td>7</td>
<td>14.9</td>
</tr>
<tr>
<td><strong>Complications – All</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reaction</td>
<td>12</td>
<td>14.5</td>
</tr>
<tr>
<td>Deformity</td>
<td>4</td>
<td>4.8</td>
</tr>
<tr>
<td>Anaesthesia</td>
<td>2</td>
<td>2.4</td>
</tr>
</tbody>
</table>

During focus group discussions, the adolescents stated that they had to depend on their parents to seek appropriate care for their symptoms and had no say in the matter. They were less concerned about the disease *per se*, but, when frequent, debilitating complications occurred, they were confused and ashamed of their disabilities. This affected their social interactions, education and for some, their jobs. Unmarried adolescents were
reluctant to marry and those married would rather not reveal their disease to their parents-in-law.

Parents were protective of their children, but were not motivated to seek help or early care at a leprosy hospital. They would rather explore folk or indigenous medicine before going to the right place for treatment. They seemed as yet unaware of the advantages of modern therapy for leprosy, and the importance of early reporting. Social stigma was quite strong, and there was a general tendency to hide the disease as long as possible from relatives and neighbours. Both adolescents and their parents expressed the view that as long as the disease is hidden, there were no social problems, distancing or discrimination. After disclosure, the behaviour of certain family members changed, and they tended to isolate the affected persons. Once complications set in, and especially when there were frequent visits to hospitals or in-patient admissions, there were psychological and emotional problems as well as discontinuation of studies or loss of jobs. This led to despair and helplessness.

In-depth interviews confirmed the dilemma of the adolescents, and the feeling of insecurity. They expressed the need for counselling and support in addressing and coping with their problems. Despite a sense of despondency, they looked forward to becoming well, independent and self-reliant.

One typical case history summarizes the help-seeking behaviour of the parents, as well as the despair and hopes of the adolescents.

**CASE HISTORY**

WA, a 16-year-old boy from a poor economic background, lost his father when he was an infant. His mother remarried when he was 5 years. The parents could not manage to send the boy to high school, so he started working as a helper in a local tea stall, but lost the job because of frequent hospitalization.

When WA developed leprosy, he had reaction and swollen feet, which were mistaken by his family as snake bite and taken to an *ofha* (local healer), then to a local *vaidya* (traditional medicine practitioner) who sent him to TLM Hospital. Only then the boy came to know that he had leprosy. He has now completed the MDT, but is getting admitted frequently into the hospital for lepra reaction. Presently, both his hands are anaesthetic and weak; he also has cataract probably due to the use of steroids.
All his family members and some neighbours were aware of his illness, but WA notices no change in their behaviour. Only his stepfather does not want him to stay with the family or share food or linen. During his hospitalization, only his mother and elder sister visited him, and that too only when called to meet the doctors.

Before coming to the hospital, the boy had no knowledge about leprosy. Now he knows that it is caused by bacteria, affects nerves causing anaesthesia. He also knows that with regular treatment, leprosy is curable, but due to his frequent reaction and pain, he started feeling that he has to take medicines life-long and he will never be cured. He wants to stay alone and does not want get married. Now he would like to get some training or a job to become self-reliant.

**DISCUSSION**

Adolescents in the age-group of 10-20 years constitute one-fifth of India’s population (Registrar-General, 1998). Although it is injudicious to infer epidemiological trends from a hospital-based study, 20% of the newly-detected leprosy patients in this study were adolescents. Population-based surveys will probably throw up more adolescents with early leprosy, especially among young women who are under greater stress due to puberty and possibly impending early marriages (Caldwell et al, 1998). In a study done in Maharashtra, initial delay in seeking treatment was higher for females than for males, and, even after identifying the symptoms, women were observed to depend exclusively on non-medical treatment for a longer period than males (Rao et al, 1996). There is, therefore, a need to address the problem of early detection of leprosy among adolescents. Epidemiological studies indicate that infection with *M. leprae* probably takes place during childhood, and the disease manifests itself during adolescence or later depending on the immunity of the individual (Selvasekar et al, 1999; Rao et al, 1989). The sex ratio of leprosy in children is nearly equal and becomes heavily skewed towards the males among adults (Rao et al, 1972; Selvasekar et al, 1999). Whether this is biological or operational has not been conclusively proved, although women, in general, are poorly represented in hospital statistics, attributed largely to socio-economic and cultural difficulties. The sex ratio among adolescents in this study was 1.93:1, closer to that of children, but starts to show the dominance of males. Naturally, the proportion of adolescents, by sex, will show an over-representation among all female patients attending the hospital. This imbalance needs further investigation and correction, if needed.
It is disconcerting to note a significantly larger proportion of multibacillary patients among the adolescents, as compared to that seen in children (Selvasekar et al, 1999). The implications of undetected multibacillary leprosy in transmission of the disease are quite serious, (Van Beers et al, 1999), especially since adolescents move very closely with children.

Although adolescents are old enough and better educated, they are still dependent on their parents for health matters. The findings from the present study clearly show the dilemma of the adolescents and their helplessness, as the disease progresses to physical and social disabilities, as a result of preventable delay in seeking the right treatment. Adolescence is a critical period in the life of an individual when personalities develop and expectations are high, but it is also a time when risks are underestimated and the vulnerability cannot be easily admitted (Lancet, 2004). Obviously, the underlying factors in hiding the disease, and delaying reporting to a leprosy centre are the prevailing stigma and negative attitudes despite leprosy education (Raju & Kopparty, 1995; Nicholls et al, 2003; Richardus et al, 1999). The health system thus should be more responsive, especially to the problem of adolescent leprosy patients, either in early detection or reducing the frequency or duration of hospital admissions, which interfere with schooling or occupation (Van Dijk et al, 2003). Once deformities set in, there seem to be no effective strategies to prevent social restrictions or dehabilitation. Given the modern powerful drugs for managing leprosy and its complications, it is imperative that information, education and communication (IEC) activities be revamped to address the needs of adolescents and younger adults, who form the crux of the next generation (Crook et al, 1991, ILA, 2002; Da Silva Souza & Bacha, 2003, Withington & Samsujoja, 2000). Further research on these aspects is needed.

REFERENCES


