CHALLENGES IN PREVENTING DISABILITIES AMONG CHILDREN AFFECTED BY LEPROSY - FINDINGS FROM A REFERRAL HOSPITAL IN NORTH INDIA

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Introduction

• India had declared elimination of leprosy in December 2005 and leprosy services have been integrated into general health services
• There is still high incidence of disabilities in children which poses a major challenge to the society and leprosy services
• If the nerve function impairment (NFI) is < 6 months duration, further disabilities can be prevented by early intervention
Background

- **The Leprosy Mission (TLM) Community Hospital** established in 1984 is located in the north-eastern part of Delhi, India.
- Annually 300-400 new leprosy cases are detected and 5,000 people affected by leprosy are treated.
- It has an in-patient ward of 45 beds.
Objectives

• To estimate the burden of disabilities due to leprosy among untreated children brought to this referral hospital

• To Identify measures to prevent them
Material and Methods

- All untreated children affected by leprosy (<15 years) brought to the OPD in TLM Hospital Nandnagri Delhi, India during January 2009 to Dec 2012 were included.
- Patients were classified into WHO deformity Grade 0, 1 and 2.
- All data was collected, analysed through SPSS software.
Findings

34% patients with disabilities (grade 1 & grade 2) and 24.5% with grade 2 disabilities
Among the MB cases the disabilities increased with increasing age; there were no disabilities among children < 5 years of age.
Majority of disability cases were reported among BTHD patients.
It was noted that there were less number of cases with disability in children who had familial or extra familial contact.
Incidence of disabilities by reactions at the time of presentation

Percentage of patients with deformity

- Reaction
  - Grade 0: 48
  - Grade 1: 26
  - Grade 2: 26

- No Reactions
  - Grade 0: 73
  - Grade 1: 3
  - Grade 2: 24
The incidence of disabilities by number of nerve lesions

<table>
<thead>
<tr>
<th>Nerve involvement</th>
<th>Grade 0</th>
<th>Grade 1</th>
<th>Grade 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>9 (100%)</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>1</td>
<td>10 (100%)</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>&gt;1</td>
<td>43 (57%)</td>
<td>9 (12%)</td>
<td>23 (31%)</td>
<td>75</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>9</td>
<td>23</td>
<td>94</td>
</tr>
</tbody>
</table>

- There were no disability cases in patients with no nerve trunk involvement.
- Among the disability cases 65% had NFI >12 months duration, 15% had 6-12 months duration and 20% < 6 months duration.
Among all disability cases there was a direct relationship with multiple nerve trunk involvement.
It was noted that the disability cases had ipsilateral nerve trunk involvement.
Grade 2 disability in children

- Ulnar Clawing (70%)
- Plantar Ulcer (20%)
- Lagopthalmos (10%)

Hidden challenges
There was no relation of Grade 2 disability with number of skin lesions.
## Reasons for delay

<table>
<thead>
<tr>
<th>Reasons for delay</th>
<th>Percentage of pts with delay (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Misdiagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indigenous medications</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>PHC</td>
<td>10%</td>
<td>43%</td>
</tr>
<tr>
<td>Private practitioners</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Ignorance</td>
<td>28%</td>
<td>28%</td>
</tr>
<tr>
<td>Financial constraints</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>Stigma</td>
<td>9%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Conclusion

• These rates of disability in young children are worrying as they point to considerable delay in diagnosis of leprosy.
• Lack of family/household contact could mislead the parents/health practitioners in misdiagnosis leading to delay in seeking the right treatment.
• Lack of association of disabilities with number of skin lesions is significant as only skin patches are counted for classification in the field which can lead to misdiagnosing/wrong classification.
Recommendation for parents / guardians

• Families need to be motivated for early reporting as children cannot be expected to go on their own to a health facility

• It is important for them to know tell tale signs of leprosy, reaction and neuritis
Recommendation for teachers

• Educating teachers not only about early signs of leprosy but also early signs of neuritis, and prompt reporting in suspected cases
Recommendations for health service providers and health professionals

• Further studies need to be carried out to determine the reasons for delay in seeking correct treatment through detailed interviews and questionnaire.
• It would help in developing practical strategies to prevent the complications.
• Supplementing the voluntary reporting through special school surveys as dependence only on it alone at integrated centres is inadequate to detect early cases of leprosy, especially among children.
Any amount of medical care is futile when the children are not brought to the treatment centre early enough before irreversible damage occurs.
References

- Singal A, Sonthalia S, Pandhi D. Childhood leprosy in a tertiary-care hospital in Delhi, India: a reappraisal in the post-elimination era. Lepr Rev. 2011 Sep;82(3):259-69
Acknowledgements

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