WHAT THE PARENTS SHOULD KNOW WHILE THEIR CHILD IS ON MDT? : INSIGHTS FROM A QUALITATIVE STUDY IN EASTERN INDIA

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Introduction

• Number of child leprosy cases is an indicator of active & recent transmission of the disease

• India reported 134,752 new leprosy cases (2012-13)
  – Around 10% (13,387) were children
  – Child proportion much higher in high burden states
    (D & N Haveli 26.09%, Bihar 15.88%)
Rationale of Study

• Childhood leprosy has remained neglected
  – Paucity of information on experience of children while on MDT

• Need to provide high-quality leprosy services to children affected by leprosy
  – Envisaged in ‘Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy by 2015’
  – Necessary to actively engage parents in the management of their children
Methods

• Aim of study- To explore the experiences of parents with regard to the diagnosis of leprosy & treatment of their child
• Study type- Qualitative
• Study site- Bankura district of West Bengal, India
  – High endemic district with ANCDR 38.55/100,000 population & Child proportion 9.98% (2012-13)
• Sample size- Purposive sample of 15 parents whose child was on MDT
  – Sample size determined by non-emergence of new themes & data saturation
Methods

• Parents interviewed in their homes
• Informed consent obtained
• Semi-structured interview guide covering five themes:
  – Initial symptoms
  – Care-seeking behaviour
  – Experience with MDT
  – Experience with health system
  – Stigma & discrimination in community
• Framework approach used for analysis of transcribed interviews
Results

• Majority of children was students (age group 9-14 years)

• White patch was the most common initial symptom which prompted the parents to seek care from the health worker

• 10 out of the 15 children had been diagnosed as MB
Results

• MDT was usually self-administered by the child

• Majority of children were reported to be adherent to MDT
  – Few children were observed to be taking them incorrectly

• Some parents complained
  – “My child has been taking treatment properly for a long time, then why has the patch remained white?”
Results

• Black skin discolouration was most common side-effect
  – Children were often made fun of at school due to the discoloration
  – Non-adherence among a few children
  – School absenteeism
Results

• All parents ignorant about symptoms of reactions & importance of reporting them early
  – Two children were found to be suffering from reaction & were not identified
  – Parents expressed anguish & concern that despite being on MDT, the symptoms had flared up
Discussion

• Major success of the National Leprosy Eradication Programme in India has been the integration of leprosy services with the general healthcare system
  – Enabled early case detection

• Current challenges:
  – Ensuring treatment completion
  – Early care-seeking & management of complications in the form of reactions to prevent disabilities
Discussion

• MDT is a cure for the disease & not the patch
  – Patch may persist despite successful treatment

• Clofazimine-induced skin discolouration although reported less frequently as a side-effect, resulted in interruption of treatment among children and led to discrimination
  – Brownish-black discolouration caused by the drug disappears within a few months after stopping treatment
Recommendations

• Training programmes should make health workers aware of side-effects & complications

• Increased emphasis to be laid on interpersonal communication to empower parents whose child is on MDT, to appreciate the side-effects & recognize the complications early

• Innovative school-based activities to focus on mitigating stigma & discrimination