PERCEPTIONS & ATTITUDES INFLUENCING THE PRACTICE OF SELF CARE IN LEPROSY

Shyamala Anand, TLMTI POID Audit Team
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Practice of regular self care the cornerstone of POID

Consequences of neglecting self care

- Loss of productivity
- Deformities and ulcers
- Stigma
- Enormous physical and mental suffering
BACKGROUND-2

**TLMTI 2012 (14 hospitals & 6 Vocational Training Centres in 8 states)**

- 5391 new cases
- 456 children (8.45%)
- 2209 Grade I+II (41 %) - (17% Gr I ; 24% Gr II)
- 3195 reaction & neuritis (outpatients diagnosed)
- 4399 admissions- 995 reaction & neuritis ; 3404 ulcer
- 145 young people affected by leprosy - VTCs
AIM

• Perceptions & attitudes influencing practice of self care (people affected by leprosy & healthcare givers)

• Effective home based / community based POID interventions - lifelong POID for persons at risk
METHODS-1

POID Audit April- June 2012 (Design & Field test)

9 Audit Teams - Physiotherapist, Occupational therapist & Doctor

SELF CARE aspects

- Awareness & IEC
- Practice of self care & lifestyle modifications
- Use of protective footwear, aids & appliances
METHODS-2

6 Hospitals & 3 VT Centres in 7 states

Data Collection
- Patient records audit- Random sampling Mar 2011- 12
- Key Informants- Purposive sampling
  ✓ people with reactions/neuritis, ulcers, insensitive extremities & their families
  ✓ health care staff in POID

Tools
- Observations
- SSIs & FGDs
- Matrix scoring participatory tool (Attitude towards Self care)
FINDINGS-1

- Despite efforts to teach self care, majority not practicing self care at home
- Could tell what should be done rather than *why it should be done*
- No concept of lifestyle modifications; not possible/practical; stigmatizing
- Ulcers inevitable; impossible to prevent; medicines only
- Self care = soaking, scraping and oiling (practiced sporadically)
FINDINGS-2

- Barriers to protecting anaesthetic feet from injury through the regular use of protective footwear*
- Stigma attached to using aids & appliances*
- Did not know how to do ulcer dressings at home
- Elderly - associated geriatric problems; dependent on someone in the family for self care
- Group support & home visits

(*Acceptability of footwear & aids/appliances has not been measured yet)
FINDINGS - 3

- IEC inadequate
- Non participatory
- Demonstrated in Institution (SSO)
- Counselling - Not target specific (reaction/ neuritis, deformities, insensitive hands & feet)
- Lack of home visits limiting self care teaching & preventing customization
FINDINGS-4

Participatory Matrix Scoring Tool Analysis

Reasons for not practicing self care & lifestyle modifications (in order of scoring)

1. Lack of time
2. Lack of awareness
3. Lack of necessary things to practice self care*
4. Limited by physical disability
5. Self stigma and fear of enacted stigma

* students scored 3 highest
FINDINGS-5

Minority practicing self care

Factors contributing

• Supportive family involved in the self care
• Respect and status in the family
• Good understanding of self care & lifestyle modifications
CONCLUSIONS

- Disconnect between self care taught and self care practiced
- Level of self stigma
- Concept of lifestyle modifications
- Behaviour change

Institution based self-care teaching & methodology will not impact as much as self-care teaching & methodology developed in and for the person’s own environment and inclusive of the family and community (‘whose reality?’)
RECOMMENDATIONS

POID programmes for self care

- Institution → community for effective prevention of impairments/deformities
- Self care that community accepts & does not stigmatise
- Address behaviour change
- Inclusive (other disabilities, chronic ulcerating conditions) - minimise stigma

In depth research

- Factors that prevent/enable practice of self care & lifestyle modifications
- Interventions targeted towards advocacy, reinforcing behaviour change & empowerment
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