UNEXPECTED FINDINGS IN A STUDY OF PARTICIPATION AND STIGMA: COMPARING PERSPECTIVES OF PEOPLE WITH LEPROSY AND OTHER DISABILITIES WITH PERSPECTIVES OF COMMUNITY MEMBERS
• Intro to NW Bangladesh
• Overview of research
• Assessment tools
• Findings
Bangladesh

- small, flat
- 160 Million
- 1000 per square km
- poor
North-West Bangladesh
Research Design

Intervention Groups
- Cohort 1: New area, n = 500
- Cohort 3: Old area, n = 500

Control Groups
- Cohort 2: New area, n = 500
- Cohort 4: Old area, n = 500

n = 1000
Intervention Groups
- Cohort 1: New area
- Cohort 2: New area

Control Groups
- Cohort 3: Old area
- Cohort 4: Old area

2 years

Pre-Assessment

CBR Intervention

Post-Assessment

No CBR Intervention

Community

Hidden challenges
Research Design: Assessments

Routine demographic data:

- economic status
- education level
- access to clean water and sanitation
- disability status
- children's education
- access to government stipends
Screening of Activity Limitation and Safety (SALSA) Scale

- Assesses activity limitations due to peripheral neuropathy (including leprosy)
- Standardized
- Cross cultural
Research Design: Assessments

Participation Scale (P-scale)
• Assesses participation restriction
• Standardized for use in low income countries
• Culture free
Research Design: Assessments

World Health Organization Abbreviated Quality of Life Assessment (WHOQOL-BREF)

- Assesses four domains of quality of life
- Standardized
- Cross cultural
Research Design: Assessments

HIV/AIDS-related stigma and discrimination scale (Genberg, 2009)
- quickly assess stigma
- developed in Tanzania, Zimbabwe, South Africa and Thailand

Assesses
- negative attitudes
- perceived discrimination
- equity
Geographical midpoint used to find the location of the control groups
Random point generator used to find a location within 1km radius of geographic midpoint
## Community Attitude survey sub-scales

<table>
<thead>
<tr>
<th>Negative Attitudes</th>
<th>Perceived Discrimination</th>
<th>Equity</th>
</tr>
</thead>
<tbody>
<tr>
<td>• People with leprosy should be ashamed</td>
<td>• People living with leprosy in this community face verbal abuse and teasing</td>
<td>• A person with leprosy should be allowed to work with other people</td>
</tr>
<tr>
<td>• People who have leprosy are cursed</td>
<td>• People living with leprosy in this community face rejection from their peers.</td>
<td>• People with leprosy should be treated the same as everyone else.</td>
</tr>
</tbody>
</table>
Preliminary Findings

Average Sub-Scale Scores

Transformed score

Sub-Scale

Negative Attitudes
Perceived Discrimination
Equity
Preliminary Findings: Religion

Kendall’s Tau

<table>
<thead>
<tr>
<th></th>
<th>Negative</th>
<th>Attitudes</th>
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<th>Equity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cor.</td>
<td>0.071</td>
<td>-0.083</td>
<td>0.141</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>561</td>
<td>561</td>
<td>561</td>
<td></td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.05</td>
<td>&lt;.05</td>
<td>&lt;.001</td>
<td></td>
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</table>
Preliminary Findings: Education

<table>
<thead>
<tr>
<th>Kendall’s Tau</th>
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<th>Equity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cor.</td>
<td>-0.353</td>
<td>-0.105</td>
<td>-0.18</td>
</tr>
<tr>
<td>N</td>
<td>602</td>
<td>602</td>
<td>602</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
<td>&lt;.001</td>
</tr>
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</table>
Preliminary Findings: Age

Correlation Array

Negative Attitudes

Equity

Correlation Array

Kendall’s Tau

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</tr>
</thead>
<tbody>
<tr>
<td>Cor.</td>
<td>0.212</td>
<td></td>
<td>0.153</td>
</tr>
<tr>
<td>N</td>
<td>602</td>
<td></td>
<td>602</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.001</td>
<td></td>
<td>&lt;.001</td>
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</tbody>
</table>
## Preliminary Findings: Linear Model

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<tr>
<td>• signif &lt; .001</td>
<td>• signif &lt; .001</td>
<td>• signif &lt; .001</td>
</tr>
<tr>
<td>– Education</td>
<td>– Education</td>
<td>– Education</td>
</tr>
<tr>
<td>– Age</td>
<td>– Age</td>
<td>– Age</td>
</tr>
<tr>
<td>• No significant Effect</td>
<td>• No significant Effect</td>
<td>• Small effect</td>
</tr>
<tr>
<td>– Gender</td>
<td>– Gender</td>
<td>– Gender</td>
</tr>
</tbody>
</table>

- **Significance:** signif < .001
- **Effect:** Small effect
Preliminary Findings

Percent distribution of paired SALSA & PSCALE ranks

SALSA vs P-Scale

N=891
Preliminary Findings: P-Scale

Kendall’s Tau Rank Correlation (for rank data, so few assumptions)

Strong correlation:
- SALSA (0.535, p-value <.001, N 891)

Weak correlations:
- Personal income (-0.223, p-value <.001, N 1482)
- Age (0.167, p-value < .001, N 1440)
- Per Capita Income (-0.156, p-value < .001, N 1451)
- Education (-0.136, p-value < .001, N 1441)
Preliminary Findings: District Differences?

Districts: Rangpur, Nilphamari, Dinajpur, Thakurgaon, Panchagarh

P-Scale Scores

Equity
Preliminary Findings: District Differences?

Negative Attitudes

Perceived Discrimination
Conclusions/learning

• SALSA and P-Scale don’t provide “normal” data which limits the analysis
• Religion did not seem to play the role in stigma that was predicted
• Education was the leading predictor of community stigma
• Increased personal income was associated with lower participation restrictions
• An overlap between P-scale scores and the community attitude scores did not yield the expected results
The END

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