SARI Project
Measuring Stigma and Social Participation

Wim van Brakel, Dadun, Mimi Lusli, Ruth Peters,
Beatrice Miranda, Sorana Iancu, Rita Damayanti,
Ery Seda, Marjolein Zweekhorst, Joske Bunders, Irwanto
Athena Institute, VU University Amsterdam
Disability Studies Centres, Universitas Indonesia
Assessment framework for stigma

Condition
- Leprosy

Community
- Perceived stigma
- Enacted stigma

Affected person
- Anticipated stigma
- Internalised stigma
- Experienced stigma

Impact
- Participation
- Well-being (QoL)
- Self-esteem
- Self-efficacy

Rensen et al, 2010
Cross-cultural equivalence

Herdman et al. 1998
Cross-cultural validity P-scale and SARI stigma scale

- P-scale had been previously evaluated => only measurement equivalence tested
  - Concept of ‘Peer’ still difficult
- Berger Stigma Scale: major changes => new name: SARI Stigma Scale
  - Wording of items
  - Response options
  - Statement format.
Key measurement properties

- Acceptability (missing values)
- Internal consistency
- Factor structure
- No floor or ceiling effects
- Reproducibility
  - Reliability (ability to distinguish people)
  - Agreement (SEM, Smallest Detectable Change)
# Measurement equivalence

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Missing values</th>
<th>Alpha</th>
<th>Factor struct.</th>
<th>Floor effect (%)</th>
<th>Ceiling effect (%)</th>
<th>SEM</th>
<th>SDC</th>
<th>Reliability coefficient (ICC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SARI stigma scale</td>
<td>0.03%</td>
<td>0.89</td>
<td>4 factors (n=590)</td>
<td>3.8</td>
<td>0.5</td>
<td>6.4</td>
<td>18/1.5</td>
<td>0.72 (n=140)</td>
</tr>
<tr>
<td>Participation Scale</td>
<td>0.4%</td>
<td>0.87</td>
<td>2 factors (n=586)</td>
<td>1.7</td>
<td>0.35</td>
<td>5.1</td>
<td>14/1.4</td>
<td>0.85 (n=96)</td>
</tr>
</tbody>
</table>

**Criteria**
- Missing values <3%
- Alpha ≥0.80
- Floor and ceiling effects <15%
- Reliability coefficient ≥0.80

SEM = standard error of measurement
SDC = smallest detectable change
ICC = intra-class correlation coefficient
Reliability of the SARI stigma scale to distinguish people with various degrees of impairment (n=510)
Reliability of the Participation scale to distinguish people with various degrees of impairment (n=513)
Perceived and experienced stigma (SARI scale) (n=590)

- Person affected is disgusting
- Do people feel uncomfortable
- Do people loose their jobs
- People backed away from you
- Do people seem afraid of you
- Did you loose friends
- Do people keep distance

![Bar Chart]

- Seldom/once
- Sometimes
- Often/always

Percentage
Disclosure concerns (SARI scale) (n=590)

- Do you regret having told...
- Worry that people would...
- Careful who to tell
- Feel need to hide status
- Telling people is risky

<table>
<thead>
<tr>
<th></th>
<th>Seldom/once</th>
<th>Sometimes</th>
<th>Often/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you regret having told...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worry that people would...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Careful who to tell</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel need to hide status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telling people is risky</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentage
Expressions of internalised stigma (SARI scale) (n=590)

- Feel a bad person
- Feel apart and isolated
- Does leprosy make your feel...
- Embarrassed to have (had)...
- Feel not as good a person
- Do you feel guilty

**Percentage**

- Seldom/once
- Sometimes
- Often/always
Participation restrictions (P-scale) (n=592)

- Find work
- Contribute economically
- Casual activities
- Socially active
- Move around...
- Visit other people
- Help other people

Percentage

Small problem
Medium problem
Big problem
Take home messages

- Cultural validation important
  - Testing led to major changes in Berger Stigma Scale => evolved into new instrument
- SARI stigma scale and P-scale show good validity
- Important to consider different aspects of stigma, since they should different results.
Acknowledgements

- SARI field team
- Provincial and district health services
- Many persons affected by leprosy in Cirebon
- Financial support by NLR, ALM, SMHF and TLMC