SARI Project
Methods and Baseline Studies

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Aims

- To measure and compare the effectiveness of three stigma reduction interventions tested in pairs
  - Counselling and empowerment
  - Contact with affected people
  - Socio-economic development
- To assess and study changes in communities and clients and work with them to optimise positive effects.
Desired outcomes

- Community-based participatory interventions: tested and approved
- Training manual on stigma reduction
- Scientific publications on methods, process and results
- Toolkit of quantitative and qualitative research methods for stigma.
Cirebon District, West Java
Cluster-randomised trial of pairs of interventions
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
Mixed methods to assess stigma and changes among persons affected by leprosy

- SARI Stigma scale (based on Berger scale)
- Participation Scale (P-Scale)
- WHOQOL-BREF
- Qualitative methods
  - In-depth interviews
  - Observation
  - Focus groups
  - Mapping
Mixed methods to assess attitudes and changes in the community

- Social Distance Scale
- EMIC Community Stigma Scale
- Short leprosy knowledge questionnaire
- Qualitative methods
  - In-depth interviews
  - Key informant interviews
  - Focus groups
  - Mapping.
Mixed methods in action
Assessment plan

- Exploratory study
- Cultural validation + piloting
- Psychometric validation study
- Baseline survey
- On-going monitoring
- Quantitative assessments after two years.
Results community stigma (n=245)

Dislike buying food from affected person?
Cause problems for affected to find work?
Problems for relative to get married?
Cause problems in ongoing marriage?
Problem for affected to get married?
Family concerned about disclosure?
Would it cause problems for family?
People think less of the family?
Others refuse to visit?
People avoid someone with leprosy?
Would it have an adverse effect?
Others think less of affected person?
Does leprosy cause shame?
Would you think less of yourself?
Keep people from knowing?
Results social distance community (n=250)
“[I am] feeling weak, [have] less interaction, fear of people being hostile and fear of being excluded”

“No. Nobody knows, I am afraid my friends won’t make friend with me any longer, I fear they will avoid me”
Impairment in SARI sample (n=522)

![Bar chart showing impairment distribution by site and grade]
Internalised and anticipated stigma of affected persons (n=504/520)
Experienced stigma and disclosure concerns of affected persons (n=522)
Results social participation ($n=513$)
Results quality of life \( (n=430) \)
Take home messages

- Toolkit of stigma assessment methods available
- Stigma very prominent in community perception
- Many patients do not disclose, but anticipated stigma and disclosure concerns high
- People with impairment, esp. when visible, report more stigma, less participation and reduced QoL compared to those without
- Mixed methods approach preferred.
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