Understanding adverse experiences in a stigma reduction project in Cirebon, Indonesia

Some questions:

1. Have you ever implemented a strategy that aims to improve the lives of people affected by leprosy?
Some questions:

1. Have you ever implemented a strategy that aims to improve the lives of people affected by leprosy?
2. Were there participants where such a strategy did not have any effect?
3. Were there participants that had any adverse* experiences?

* Adverse experiences are, short-term or long-term, negative impacts on participants or persons close to them.
Adverse experiences & SARI

• Observed a few adverse experiences (~10 stories)
• Short and long term adverse experiences
• Not directly related to SARIs work, but happening in a social environment with SARI as an actor
• Each case is important to us
Understanding adverse experiences

Aim:

1) To address adverse experiences with the utmost care
2) To prevent the preventable adverse experiences
3) To build capacity to deal with the unpreventable
Supporting theories

• Concept of stigma:
  – Different facets: anticipated, internalised, enacted
  – Role of power: “it takes power to stigmatize”

• Complexity theory:
  – Five contexts: nature cause and effect
  – Complex: many elements, non-linear interactions, dynamic, history, external conditions
  – Understand why things happen in retrospect
Methods and materials

• Study site: Cirebon district, Indonesia
• Period: throughout project and specifically Nov–Dec 2012
• Methods: notes, group interviews, dialogues with the SARIs staff
• Focus on adverse experiences and other cases that help understand the context
Case 1: Secrecy for spouse

- Phase: baseline study
- Man (in treatment) interviewed at health centre
- Very afraid his wife would find out

Yes, your goals are good. We can meet, but you must call me. We can maybe meet somewhere else, maybe the house of my parents. (SARI participant)
Case 2: Spouse taking distance

- Phase: counselling intervention
- Wife found medicine card
- Moved to her parents
- Community members have talked about taking distance
Not knowing diagnosis

• An estimated 5% of the participants (n=650) were not aware of their leprosy history/ status
• Dilemma: should the project team inform them?
• Based on personal judgement
• Mainly positive reactions

Two leprosy officers told me that it is better if we do not tell the leprosy status to the patient, because the patient will be afraid, worried or maybe get a depression. Others said, although it is maybe bitter, we should tell the diagnosis. (research assistant)
Secrecy

- An estimated 5-10% did not tell anybody
- An estimated 10-20% only informed the close family
- In a few cases family members learned about or found out about the leprosy history or status of a participant
- Mainly positive reactions
## Model on extent of knowing

<table>
<thead>
<tr>
<th>Persons who <strong>don’t know</strong> they are affected by leprosy</th>
<th>Persons who <strong>forgot</strong> they are affected by leprosy but who do <strong>not acknowledge</strong> it or deny it</th>
<th>Persons who were told they are affected by leprosy but <strong>didn’t tell their spouse</strong> or close family members</th>
<th>Those who know they are affected by leprosy but whose <strong>neighbours and friends don’t know</strong></th>
<th>Persons who know they are affected by leprosy but whose <strong>think their neighbours and friends don’t know</strong> but who in fact know about it</th>
<th>Persons who where <strong>everybody knows</strong> they are affected by leprosy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*International Leprosy Congress, Brussels, 16-19th September 2013*
4 Key conclusions/recommendations

1. Adverse experiences are common and should be expected in a stigma reduction project (so actively look for them)

2. Projects should aim to prevent adverse experiences but should anticipate that it is impossible to prevent all
4 Key conclusions/recommendations

3. Beforehand decide on principles and practices
   – Thorough understanding of the local context
   – The degree of knowing the leprosy history or status is important

4. Ensure capacity to deal with unexpected adverse experiences (e.g. open/encouraging atmosphere, reflectivity and action)