Assessing Social Distance as Stigma Predictor:

Exploring Silent Stigma Towards People Affected By Leprosy From A Community Perspective In Indonesia
Introduction

- Indonesia eliminated leprosy in year 2000
- Ranks 3rd with average 17,000 new leprosy cases per year in the last decade.
- 14 of 33 provinces still reported high figures.
- Stigma can generate socio economic problems, and lessen willingness of patients to have appropriate treatment.
- People have not realized that their social distance towards people affected by leprosy is increased.
Objectives & Method

Objectives
• To explore attitudes towards people affected by leprosy among community members

Method
• Quantitative and qualitative approach
• A baseline study conducted in Cirebon district, Indonesia, in 2011.
• Perceived social distance was measured as proxy for attitude regarding leprosy, using a 7-item scale.
• The scale score ranges from 0-21.
• A vignette was used describing a leprosy-affected man or woman.
Objectives & Method (2)

- We selected randomly 3 Person affected in one sub district (30 sub district)
- We selected 3 community members who lived in the neighbourhood of every person affected by leprosy enrolled in the study.
- In total, the study recruited 250 respondents
Vignette

- **Mr. R** is a 23-year-old. He has been treated for leprosy during the past year. The doctor has declared him cured, even though some of the fingers on his right hand are still bent and his skin is still dark, because of the treatment. Mr. R has a job in the local small business that belongs to his uncle. He earns Rp 1.2 million ($120) per month and is doing well in his job. He is a little bit slower than before, because of the effects of leprosy on his hand, but the employer never complained about that. At his job, Mr. R gets along well with his colleagues. Mr. R would like to get married. He is considering joining a local youth organization, so he can meet people of the same ages. He also hopes to get a better job to be able to earn more than in his present job.

Questions: Would you

- Rent a room to him
- Hire being coworker
- Accept as neighbor
- Care taker your children for hour
- Introduce to friends
- Allow to be married to one of your children
- Recommend to your friend

Response

- Definitely Yes;
- Probably willing;
- Probably not willing, and
- Definitely Not
<table>
<thead>
<tr>
<th></th>
<th>Definitely willing</th>
<th>Probably willing</th>
<th>Probably not willing</th>
<th>Definitely not willing</th>
<th>score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How would you feel about renting a room in your home to someone like R?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>How about being a worker on the same job with someone like R</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>How would you feel having someone like R as a neighbor?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>How about having someone like R as caretaker of your children for a couple of hours?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>How about having one of your children marry someone like R?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>How would you feel about introducing R to a young woman you are friendly with?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>How would you feel about recommending someone like R for a job working for a friend of yours?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Result

“Measuring is knowing”
# Characteristics & mean SDS score

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>Mean SDS Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>42 (18%)</td>
<td>9.05</td>
<td>4.14</td>
</tr>
<tr>
<td>31-45</td>
<td>100 (43%)</td>
<td>8.35</td>
<td>4.06</td>
</tr>
<tr>
<td>46-59</td>
<td>59 (25%)</td>
<td>9.14</td>
<td>4.15</td>
</tr>
<tr>
<td>&gt;60</td>
<td>31 (13%)</td>
<td><strong>10.29</strong></td>
<td>4.37</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>100 (40%)</td>
<td><strong>9.20</strong></td>
<td>4.30</td>
</tr>
<tr>
<td>Male</td>
<td>150 (60%)</td>
<td>8.67</td>
<td>4.00</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No schooling</td>
<td>13 (6%)</td>
<td><strong>11.08</strong></td>
<td>5.60</td>
</tr>
<tr>
<td>Primary school</td>
<td>86 (37%)</td>
<td>9.40</td>
<td>4.13</td>
</tr>
<tr>
<td>secondary school</td>
<td>105 (45%)</td>
<td>8.21</td>
<td>3.98</td>
</tr>
<tr>
<td>University</td>
<td>28 (12%)</td>
<td>9.25</td>
<td>3.80</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>8.94</strong></td>
<td>4.16</td>
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</tbody>
</table>
Figure 1: Comparison Of Mean Scores On The Social Distance Scale By Characteristics In The Community Of The SARI Project Baseline Study In Cirebon District, Indonesia (N=250)
Figure 2: Profile of responses on the social distance scale among community members of the SARI project baseline study in Cirebon district, Indonesia (N=250)

- Recommend affected person to friend for...
- Introduce friend to affected person
- Marry your child to affected person
- Accept affected person as care giver
- Accept affected person as neighbour
- Accept affected person as coworker / colleague
- Rent a room in your house to affected person

- Strongly willing
- Probably willing
- Probably unwilling
- Strongly unwilling

Percentage
SDS score and profile response SDS

• SDS score is relatively high: 8.9 (scale 0-21)
• Proportion profile response of community with lower stigma (strongly willing): 15.7%
• Proportion profile response community who report “uncertainty” (probably willing and not willing) : (75%)

Proportion of community members who has perceived stigma getting higher when it related to personal life area, such as take care children, married to their children's and introduce to a friends.
Figure 3: Profile response community on stigma against leprosy (EMIC)

- 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?

Percentage: Yes, Maybe, No, Don't know.
Result: Confirmation from EMIC scale

- Proportion of community stigma on Person affected by leprosy is higher on
  - Shame (62%)
  - To find works (60%)
  - To get married (53%)
  - Dislike buying food (50%)
  - Disclosure (46%)
Result

• Social distance indicated potential of stigma among community → ‘silent stigma’

• When the stigma is high Social distance prediction will be high
Result: Qualitative observation

- People affected by leprosy keep silent about situation they face, since they are afraid, ashamed and worried about exclusion by neighbours.
- Current people affected by leprosy perceived that nobody in the community knows about their illness, since they never mentioned it to anybody in neighborhood.
- Community tend not to talk about a neighbour’s leprosy status, even though they know the person has leprosy.
- More community members can mention past leprosy cases; few community members are able to point out current leprosy cases in their neighborhood.
Conclusion

- Social distance score reported relatively high among community.
- Community tends to create social distance against persons affected by leprosy on personal relationship.
- Stigma creates social distance that restricts people affected by leprosy in various activities and opportunities.
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