

Recent evidence and insights into leprosy-related stigma

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Current definition of stigma

“Stigma is a **social process**, experienced or anticipated, characterized by **exclusion, rejection, blame or devaluation**, that results from experience, perception, or reasonable anticipation of **an adverse social judgment** about a person or group.”
(Weiss & Ramakrishna)



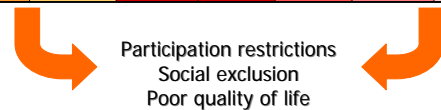
Types of stigma

People who are stigmatised		
Anticipated stigma (perceived)	Internalised stigma (self-stigma)	Experienced stigma (discrimination)

Model modified from Weiss, 2008

Types of stigma

People who are stigmatised			Stigmatisers (e.g. community, health workers)			
Anticipated stigma (perceived)	Internalised stigma (self-stigma)	Experienced stigma (discrimination)	Enacted stigma (discrimination)	Perceived stigma		
				Fear (of the disease)	Symbolic stigma (associations)	Attitudes



Model modified from Weiss, 2008

Impact of stigma on people

	Lep	H/A	TB	MI	Ep	Dis
Stress and anxiety, depression, etc.	x	x	x	x	x	x
Problems in marriage or getting married	x	x		x	x	x
Problems in social relationships	x	x	x	x	x	x
Problems with employment	x	x		x	x	x
Problems with education (own or children)	x	x		x	x	x
Concealment	x	x	x	x	x	
Isolation	x	x		x	x	x
Increased disability / worse prognosis	x	x	x	x		
Increased gender differences	x	x	x	x		x

What people themselves said:

(leprosy-affected persons in South Sulawesi, Indonesia)

- “After I got sick even my own family started to avoid me. They no longer expect me to come to their activities or events; I understand that they feel ashamed of me.”
- “I know people will avoid me, especially when I go to public places.”
- “We are no longer involved in sports; we are also no longer involved during village meetings.”
- “I’m no longer invited to weddings or circumcision ceremonies.”
- “I don’t even go to the mosque for Friday prayer anymore. I am self-conscious; people avoid praying side by side with me in the mosque. [...] Sometimes I go to a wedding ceremony and stay outside the party area, just to listen to the music.”

Impact on public health programmes

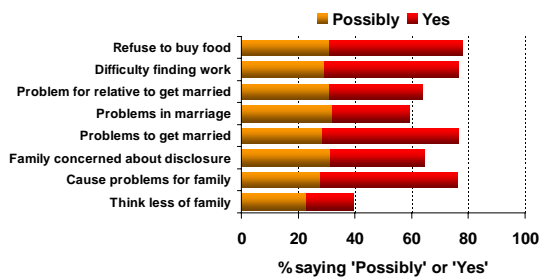
	Lep	H/A	TB	MI	Ep	Dis
Delay in presentation	x	x	x	x		x
Failure of prevention / continued transmission	x	x	x			
More complicated, more expensive treatment	x	x	x	x		x
Poor adherence and default	x	x	x	x		
Risk of drug resistance	x	x	x			
Poor image of the public health services	x	x	x	x		

Measuring stigma

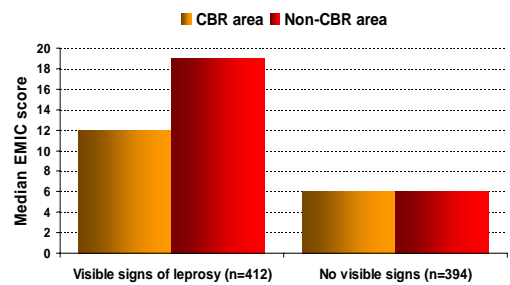
- Direct
 - Attitudes
 - Among rehabilitation staff or health care staff
 - Internalised (or self-)stigma
 - Discrimination (enacted stigma)
 - Media
 - Legislation
 - Structural
- Indirect
 - Participation
 - Psychological well-being
 - Self-esteem
 - Quality of life.



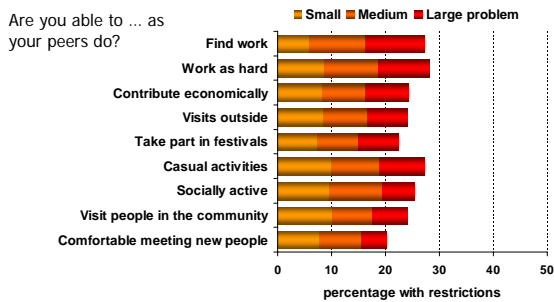
Profile of stigma in the community (5 districts in Indonesia, n=959)



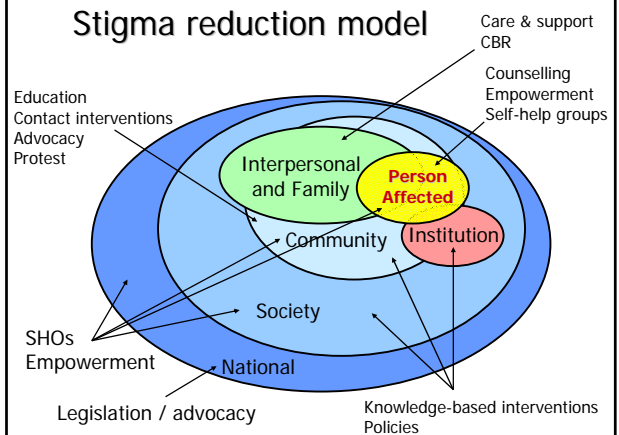
Differences in EMIC score between people in CBR and non-CBR areas



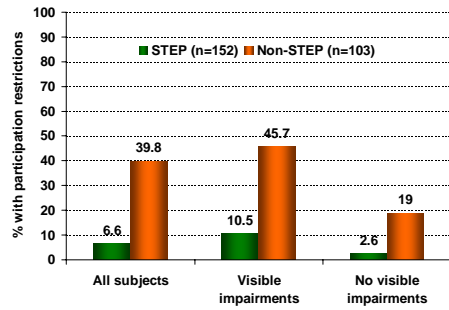
Profile of participation restrictions (n=1,342; 5 districts in Indonesia)



Stigma reduction model



Evaluation of stigma elimination project (STEP) in Nepal (after 3 years)



Recommendations

- Research to use multiple perspectives
- Involve persons affected by leprosy (emancipatory research)
- Conduct systematic reviews of available evidence
- Test and compare instruments to find most optimal and simple way of assessment
- Conduct studies on effectiveness of stigma interventions.

