



WHAT MATTERS MOST

Capturing culture-specific stigma dynamics by understanding **'What matters most'** to inform (generic) measures to assess and approaches to reduce stigma: a three-country study

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Overview

- Background and aim of study
- Study design
- Study progress
- (Preliminary) Results from Indonesia
 - *Expert perspectives on WMM*
 - *WMM in Cirebon District*
- (Planned) Outputs
- Actions next year



Aim of the study

- Call for more **generic approaches** to assess and reduce stigma
- Promising
- But, currently there is a lack of understanding on how **culture** can be taken on board in these approaches...

...as culture can shape the way stigma is experienced

Main objective is to increase insights in (generic) approaches that are culturally sensitive to assess and reduce stigma-related to leprosy, lymphatic filariasis and depressive disorders in Indonesia, Nepal and Nigeria.

‘What matters most’

Yang et al. (2014)

- Effect of culture on stigma can be understood by capturing ‘**what matter most**’ and what defines ‘**full status**’ within a cultural group.
 - *Shapes stigma*
 - *Protects against stigma*
- Allows for understanding the behaviors and experiences of ‘the stigmatized’ and of the potential ‘stigmatizers’, by observing what is ‘at stake’ for both.
- Framework has been applied in different settings, but
 - *relatively new in the field of leprosy and lymphatic filariasis*
 - *never applied before in Indonesia*

Study design

- Collaboration with partners in Indonesia, Nigeria, Nepal and the United States
- Largely qualitative study
- Semi-structured in-depth interviews and focus group discussions on ‘What matters most?’ and ‘What defines full-status?’
- Study population →
- Thematic analysis, we aim to also draw comparisons between groups (e.g. men vs women, leprosy vs. LF, leprosy vs. depressive disorder)



Table 1: Sample size per study area

		Total # participants	# FGD	# interviews
People with a stigmatized condition	Leprosy	20 men, 20 women	6	10
	LF	10 men, 10 women	2	10
	Mental illness	10 men, 10 women	2	10
Stigmatizers or those who observe or take care	Health professionals	10 men, 10 women	2	10
	Family members	10 men, 10 women	2	10

Study progress

Indonesia

- Data collected, transcribed and translated (pending persons affected with LF)
- Data analysis process started
- Two articles on WMM to men and to women in development
- First draft on expert perspectives on 'WMM' study finalized

Nigeria

- Local research team recruited and trained
- Collaboration with GRLA initiated
- Data collection process started (piloting interviews and FGDs)

Nepal

- Contracts signed
- Pending ethical approval

Results: Expert perspectives on WMM in Indonesia

- Interviews with 16 experts in the field of culture and health studies
- Two domains identified of everyday engagements that appear particularly salient in Indonesian communities:

1. Achieving full status in the community

- *'Gotong royong'*: mutual assistance, helping each other and volunteer work
- *Propriety*: conforming to social values, behaviours and standards

"So who's your father? Your grandfather? Yes, I guess reputation can come from any of those. And even when people have a good job... Like to have a good job or to have a high education is one thing, but I guess family name is a big factor in Indonesia to gain reputation."

(Female, Aceh)

2. Achieving full status through family recognition and status

- Upholding/protecting family name/status by living up to expectations and social values as to prevent shame

"... because we live side by side [hidup berdampingan], so it is very important to respect each other and to be able to socialize with the other people who live around us."

(Female, Jambi)

Preliminary results: WMM to men and women in Cirebon district

- Total of 30 interviews and 10 FGDs with people living with a stigmatized condition
- Total of 20 interviews and 4 FGDs with health professionals and family

~ 120 study participants

Groups Characteristics	Stigmatized (n=59)	Stigmatizer	
		Family (n=22)	Health Professional (n=20)
Gender			
Female	31 (52.5%)	10 (45.5%)	10 (50.0%)
Male	28 (47.5%)	10 (45.5%)	10 (50.0%)
Age Group			
>60 Years	3 (5.1%)	3 (13.6%)	-
41-60 Years	24 (40.7%)	13 (59.1%)	10 (50.0%)
26-40 Years	20 (33.9%)	4 (18.2%)	10 (50.0%)
18-25 Years	12 (20.3%)	2 (9.1%)	-
Marital Status			
Single	17 (28.8%)	1 (4.5%)	3 (15.0%)
Married	38 (64.4%)	20 (91.0%)	17 (85.0%)
Widowed/divorced	3 (5.1%)	1 (4.5%)	-
Not Answered	1 (1.7%)	-	-
Formal Educational Attainment			
Not completed primary school	19 (32.2%)	9 (40.9%)	-
Primary school	23 (39.0%)	9 (40.9%)	-
Junior high school	10 (16.9%)	2 (9.1%)	-
Senior high school	7 (11.9%)	2 (9.1%)	1 (5.0%)
Diploma	-	-	9 (45.0%)
Bachelor or higher	-	-	9 (45.0%)
Not Answered	-	-	1 (5.0%)
Ethnicity			
Sundanese	38 (64.4%)	17 (77.3%)	17 (77.3%)
Javanese	19 (32.2%)	3 (13.6%)	3 (13.6%)
Cirebonese	2 (3.4%)	2 (9.1%)	2 (9.1%)
Employment			
Agricultural	4 (6.8%)	6 (27.3%)	
Laborer	9 (15.3%)	2 (9.1%)	
Teacher	2 (3.4%)	1 (4.5%)	
Own a business/trade	9 (15.3%)	5 (22.7%)	
Housekeeping (own house)	19 (32.2%)	6 (27.3%)	
Unemployed/searching job	3 (5.1%)	-	
Student	1 (1.7%)	-	
Other	3 (5.1%)	1 (4.5%)	
Not Answered	6 (10.2%)	1 (4.5%)	
Have Social Groups			
Cultural	-	-	
Religious	17 (28.8%)	8 (36.5%)	
Neighborhood	2 (3.4%)	1 (4.5%)	
Peer	3 (5.1%)	1 (4.5%)	
Do not have any	37 (62.7%)	12 (54.5%)	

Preliminary results: WMM to men and women in Cirebon district

- Cultural engagements and activities that can exacerbate or protect against health-related stigma in Cirebon:

WMM to Men

- Family: Work and provide for family, lead the family, set an example for and support children
- Socializing in community: Engaging with others, '*gotong royong*' and joining activities
- Good manners: Friendly, polite, generous, forgiving, not being 'loud' and being responsible
- Religious: committed to worship

WMM to Women:

- Family: Supporting children, staying at home/not wandering, advising the family, managing the household and obeying husband
- Socializing in community: Engaging with others, '*gotong royong*' and joining activities
- Good manners: Friendly, polite, generous, forgiving, not being 'loud' and no gossip
- Religious: committed to worship
- Appearance: physical beauty and wearing hijab

Preliminary results: WMM to men and women in Cirebon district



"I think it's always decent people who help. When I was in trouble, for example, she was always willing to help"
(Woman, living with leprosy)

"If you go to school, you get a job, if you recite Quran you will get a gentle heart"
(Woman, living with leprosy)

"Men who don't work will be talked about by other people, 'A's daily habit is just playing, don't marry A because he doesn't work, marry B who works, so that life is guaranteed', the majority of people are like that"
(Woman, health provider)

"We absolutely need other people since we can't live alone. If we can respect one another, neighbors will undoubtedly assist us when we are in need. The reverse is also true."
(Man, living with DD)

"...because socializing is part of faith. Respecting neighbours, respecting friends, respecting our surroundings... has a sense of socializing, helping each other. For instance, if there is a problem or he is in trouble, like our neighbours, the easy example is that we care about everything, working together with them"
(Man, family of person living with DD)

"a decent guy frequently goes to the mosque to pray, engages in organized activities, and gets along well with his neighbors by living in mutual respect and admiration"
(Man, living with DD)

"Politeness and gentleness are also important because educated women will certainly provide good upbringing for their children. So you have to be polite, gentle, so you can set an example for your children".
(Woman, living with DD)

Relevancy of findings

- These findings are relevant to the research objectives
 - *The finding describes what matter most among people*
 - *It describes how the culture affect the perspectives people on WMM*
 - *it informing about what shaping stigma and protect against stigma*

Output in process

- 5 Journal articles [working titles]:
 - *Expert perspectives on 'What Matters Most' and stigma in Indonesia*
 - *Realist review on stigma reduction interventions for leprosy*
 - *Systematic review of reviews on health-related stigma measurement*
 - *'What Matters Most' and health-related stigma among men in Cirebon district, Indonesia*
 - *'What Matters Most' and health-related stigma among women in Cirebon district, Indonesia*

Actions this year

Indonesia

- Finalise collection of LF data in neighbouring districts
- Finalise drafts 'WMM' to men and women
- Workshop implication findings for stigma scales and interventions

Nigeria

- Data collection, transcription and translation in collaboration with GLRA
- Data analysis
- Drafting article(s) WMM to men and women in Nigeria

Nepal

- Identification of research site
- Recruitment local research team and training
- Data collection, transcription and translation
- Data analysis



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