

Capturing culture-specific health-related stigma dynamics by understanding ‘What matters most’ (WMM). Results from Cirebon, Indonesia and Enugu, Nigeria.

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BACKGROUND

- Stigma is a complex social phenomenon, playing a role in a range of health conditions.
- Stigma can vary between cultural settings** regarding how it impacts individuals.
- Yang et al.¹ suggest to examine stigma through the key interactions and roles that hold significance within a particular cultural group or local context. When one cannot engage in these key cultural dynamics (‘What Matters Most’), it can damage one’s sense of self and increase stigma.

Aim. This study aims to capture culture-specific stigma dynamics related to leprosy, lymphatic filariases (LF) and depressive disorder by understanding ‘what matter most’ in Indonesia and Nigeria to inform approaches to assess and reduce stigma.

METHODS

- Semi-structured in-depth interviews and focus group discussions (FGDs)** on ‘What matters most?’ and ‘What defines full-status?’ and the influence of health conditions (Leprosy, LF, Depression Disorder) on these themes.
- Thematic content analysis** set out to explore key themes that ‘mattered most’ for men vs. women, leprosy vs. other health conditions, health providers vs. people affected vs. family member of people affected.

RESULTS

People affected by stigmatized conditions, their family and health providers were included and purposively selected.

- 23 interviews** (16 in Cirebon and 7 in Enugu) with experts in different contexts and fields
- 50 interviews** and **14 FGDs** in Cirebon District, Indonesia = 101 respondent
- 42 interviews** and **14 FGDs** in Enugu State, Nigeria = 112 respondents.

Key Result A: Key thematic areas to matter most were identified across contexts;

- Individual character (incl. mutual respect, honor and integrity)
- Family (incl. marriage, children and household)
- Community (incl. participation and status)
- Religion (incl. being religious, practicing religion/faith)

“A decent guy frequently goes to the mosque to pray...”
(Man affected by depression, Cirebon)

“A good woman is a woman that listens to her husband, takes care of her children, and does domestic work efficiently and effectively without grudges or frowning”
(Health professional, Enugu)

Key Result B: Stigma continued to impact individuals’ daily lives in both Cirebon and Enugu.

- In some cases, high levels of stigma were expressed, especially related to leprosy.
- Leprosy, depressive disorder or LF could lead to social exclusion, lower community status and difficulty to find work or a partner.

Key Result C: Interactions that ‘mattered most’ (see result A) were identified to have the ability to intensify and/or protect against health-related stigma (see Table 1).

“The people around me are kind to me and my family. This is because I often help with business in the surrounding area”
(Male family member, Cirebon)

“It depends on how people present themselves.... [Leprosy] encourages cleanliness. You cannot have this illness and be dirty, like some that are affected and not have their bath for up to one month. The bandages will definitely be dirty”
(Female family member, Enugu)

Table 1. Cultural dynamics with a potential to resist stigma per context.

Context	Local cultural dynamics with potential to resist stigma
Cirebon, Indonesia	<ul style="list-style-type: none">Maintaining mutual respect and community contribution (‘gotong royong’)Seeking health/ health-oriented attitudes
Enugu, Nigeria	<ul style="list-style-type: none">Having a family and bearing childrenAppearance and cleanliness

CONCLUSION

There is an untapped potential to promote interactions between (culturally salient) family, religious and community life and stigmatized health conditions to assess, prevent and reduce (impacts of) health-related stigma, which are fundamental to health and wellbeing.

References:

1. Yang L.H., Kleinman A., Link B.G., Phelan J.C., Lee S., Good B. Culture and stigma: adding moral experience to stigma theory. (2007) Soc Sci Med. 2007; 64(7):1524–35.