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Interdisciplinary perspectives on 'what matters most' in the cultural shaping of health-related stigma in Indonesia

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ABSTRACT

Health-related stigma plays a significant role in the burden of various health conditions such as neglected tropical diseases and mental illnesses, and undermines successful health outcomes. Stigmatised individuals can face lifelong socioeconomic consequences because of their condition. It is broadly recognised that culturally salient factors interact with the way stigma is expressed in different local contexts. This study aimed to capture cultural capabilities that shape health-related stigma in Indonesia, using the 'what matters most' (WMM) stigma framework. In this qualitative research, 15 in-depth interviews with experts in the field of Indonesian culture and health studies were conducted, followed by a group discussion. Data were collected between April and September 2021, and analysed using thematic content analysis. The analysis shows that cultural values such as communal participation in local networks and the 'shame culture' shapes experiences of stigma in Indonesia. Moreover, the participants explained that achieving full standing in the Indonesian context meant contributing to the collective interest and maintaining the family reputation. Personhood is also related to socially defined gender roles. For example, community participation was often influenced by patriarchal values, which lead to differences in access to life opportunities, while recognition in the family was often connected to complying with gender roles. This study contributes to research on the cultural shaping of health-related stigma involving the WMM framework in the Indonesian context. Future research should focus on the perspectives of those who are affected by stigmatised conditions and on integrating these insights in the assessment and reduction of health-related stigma.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is increasing attention to include moral experience and cultural context to better understand health-related stigma in different cultures.
⇒ Many efforts have been done to reduce stigma related to diseases such as leprosy, neglected tropical diseases and mental illnesses.

WHAT THIS STUDY ADDS

⇒ This research offers comprehensive and context-specific insights into Indonesian culture and health-related stigma, highlighting the importance of community participation and family recognition for social acceptance.
⇒ We found that expectations within the community and the family were different for men and women.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings of this study underscore the need to incorporate these cultural capabilities into the design and assessment of health-related stigma reduction interventions.

INTRODUCTION

Health-related stigma contributes greatly to the burden of disease for affected individuals, driven by various factors, including negative attitudes, fear and a lack of knowledge regarding the condition.[1 2] Health-related stigma undermines access to diagnosis, treatment and successful health outcomes,[3] and can lead to lifelong health and socioeconomic consequences.[4 5]

Yang *et al* posit that health-related stigma is shaped by *moral experience*, denoting the daily interactions and everyday engagements, also referred to as cultural capabilities, that are perceived to 'matter most' and enable recognition of an individual as a 'full or whole person' to members of a local world, signifying 'personhood'.[6] As such, 'what matters most' (WMM) is conceptualised as a cultural mechanism denoting meaningful community participation and locally shaped meanings, outcomes and experiences of stigma.[6–8] Moral experience is thus suggested to intensify or protect against stigma via one's ability or inability to participate meaningfully in what defines personhood in their community.[8] The literature offers various and debated definitions of 'personhood'. In this paper, we define 'personhood' as the condition of being a social, physical and conscious individual

and as a notion required to acknowledge existence in society.[6 8 9] Personhood is constantly shaped and negotiated within specific contexts and periods, influenced by different circumstances and social connections.[10]

Indonesia is a vast and culturally rich country, which is undergoing various socioeconomic and epidemiological transitions. With a population of over 276 million and more than 300 distinct ethnic and linguistic groups, the socioeconomic and epidemiological transitions also pose several challenges.[11 12] For example, patriarchy and gender inequality are deeply rooted in society, influenced by certain social and religious norms.[13] As men are often seen as the head of the family, autonomy and decision-making are perceived as their responsibility, which directly affects decisions regarding family members' health.[1415] Along with the fact that certain stigmatised conditions are still relatively prevalent, Indonesia is a relevant context in which to examine how cultural capabilities shape stigma.

Previous research conducted in Indonesia found that social exclusion and rejection (eg, confinement (*pasung*))[16 17]; separation of personal belongings[18] or forced relocation[19] was associated with neglected tropical diseases (NTDs), HIV or serious mental illness.[18 20–22] Stigmatised individuals in Indonesia are found to be more likely to face long-term social, educational and occupational impairment than those who are not stigmatised, which exacerbates the negative consequences of the condition.[4] Further, several studies have highlighted that culturally defined gender roles affect experiences of stigma.[14 23 24] While several studies have focused on stigma related to NTDs or mental illness in Indonesia,[14 16 21] insights into how culture shapes health-related stigma experiences in Indonesia are lacking. Moreover, the 'WMM' theory has, to the best of our knowledge, not yet been applied in the Indonesian context. Therefore, gathering perspectives from a multidisciplinary group of experts could provide initial insights into which cultural capabilities shape stigma towards those affected. Interdisciplinary experts are well-suited for this inquiry, since they participate in the daily activities that 'matter most' in Indonesia and can reflect on its cultural aspects within their work.

This study aims to increase our understanding of culturally salient capabilities shaping health-related stigma in Indonesia by exploring the perspectives of local experts in the field of culture and health studies on cultural capabilities that intensify or mitigate health-related stigma. This knowledge could be valuable for assessing health-related stigma, developing stigma-reduction interventions and enriching the WMM theoretical framework within the Indonesian context.

METHODS

This qualitative study on 'WMM' and health-related stigma in Indonesia used in-depth interviews and a group discussion to explore the perspectives of scholars who interact with health-related stigma in various Indonesian contexts. This study is part of a larger research project and precedes a study in which the perspectives of persons affected by stigmatised conditions are ascertained (Sopamena *et al*, in preparation).

Context of the study

The collectivist nature of Indonesian culture plays a significant role in individuals' daily lives, relationships and beliefs.[25 26] Collectivism has been strongly influenced by sociocultural beliefs, norms and values towards community members' attitudes and forms of behaviour.[26 27] Social norms are also heavily influenced by religious and local customs (*adat*)[28] and Indonesia's culture is interwoven with various religious aspects.[12] External influences from other cultures, like Hinduism and Buddhism from India, started to pervade Indonesia from the beginning of the first century. Islam gradually spread among the population through Arabic traders, followed by European missionaries who introduced Christianity during the colonial period.[29] Currently, over 87% of Indonesians identify as Muslim.[30] An example of the interconnectedness of culture and religion are the *Walisongo* (the Nine Saints), which adopted a humanist approach to gradually introduce Islamic values to the Javanese population who then held their own traditional values.[29] Globalisation continues to impact culture and religion, for example through human rights, feminism and beliefs in equality.[31] In this study, we understand religion as being a part of culture.[32]

Study population and recruitment

Study participants were recruited using purposive sampling based on predetermined criteria.[33] Women were made up approximately half of the participants, to include male and female gender perspectives, since gender was thought to impact WMM. The inclusion criteria for participants were to be (a) a native Indonesian expert in one of the following disciplines: anthropology, sociology, public health, psychology and/or medicine, who had lived in Indonesia for most of their life; (b) involved in work concerning health-related stigma in Indonesia; and (c) able to participate in an online interview with the researchers. Emails were sent to such experts and snowball sampling was used to find additional participants from information provided by initial participants.[34]

Patient and public involvement

During the development of the proposal for the larger research project, persons affected by leprosy were asked to contribute and their recommendations were incorporated in the study design.

Research methods

An interview guide (presented in online supplemental appendix I) was piloted with an international expert who had recently completed a study on health-related stigma in Indonesia. The interview was structured

around concepts relevant to WMM, including 'cultural dynamics', 'health-related stigma experience', 'moral experience'/'capabilities that signify personhood' and 'personhood in local communities'. Since earlier studies had shown that gender roles are salient in Indonesian culture,[23 35–37] this was investigated for men and women separately. During the course of data collection, the interview guide was adapted to improve the interviews. For example, we added more questions on gender expectations since it seemed to be a significant topic during the first few interviews conducted.

Data were collected until we obtained data saturation.[38] 15 in-depth interviews were conducted in total. Due to the COVID-19 circumstances, the interviews were conducted online via Zoom and Microsoft Teams. Interviews lasted from 45 to 60 min and took place between April to September 2021. Most interviews were conducted in English, but five participants preferred to do the interview in Bahasa Indonesia.

To gain more insight into why certain cultural capabilities were deemed to 'matter most' all participants were invited to join a member check through a small online group discussion. The group discussion consisted of three participants, each covering a different geographical area of Indonesia (West, Central and East).

Data analysis

The in-depth interviews and group discussion were audio-recorded, transcribed verbatim and if necessary, translated into English. The data were arranged and coded with the support of Atlas.ti 9 and analysed using thematic content analysis. This consisted of both inductive and deductive approaches, described in the next section.[33 39] To enhance the credibility of the data analysis, researcher triangulation ensured that the process was collaborative.

The final code list (27 codes) was determined after eight interviews when no new codes emerged. At the end of this open-coding process, all transcripts were revisited using the final coding list, to ensure that all potential codes had been applied to all transcripts. Codes were analysed using thematic content analysis and codes were grouped under three main categories: (a) 'cultural capabilities that matter most'; (b) 'how WMM can shape and intensify stigma' and (c) 'how WMM can act to preserve personhood'. These categories were taken deductively from previous work of Yang and colleagues.[6 8 40] A more detailed description of the categories can be found in online supplemental appendix II.

RESULTS

Research population

The sociodemographic characteristics of the participants are presented in table 1. A total of 15 participants were interviewed, of whom 7 were public health experts, 3 were psychologists, 2 were sociologists, 2 were anthropologists and 1 was a medical doctor. All participants lived in urban areas, like Jakarta, Surabaya and Makassar. Most participants were Javanese, followed by other minority ethnic groups like Malay, Aceh, Bali and Betawi. The stigmatised diseases they studied included, among others, leprosy, mental illness and HIV. Participants have conducted most of their research on Java, in provinces like Jakarta, Yogyakarta and East Java.

Table 1 Overview of the research population

	Gender	Field of work	Provinces*
1	Male	Public health	West Papua
2	Male	Psychology	East Java
3	Female	Medicine	Aceh
4	Male	Anthropology	East Java
5	Female	Anthropology	East Java
6	Male	Public health	Bali
7	Female	Public health	East Java
8	Female	Psychology	Jambi
9	Male	Public health	Jakarta
10	Female	Psychology	Aceh
11	Female	Public health	Yogyakarta
12	Male	Public health	Jakarta
13	Female	Sociology	Jakarta
14	Male	Public health	South Sulawesi
15	Female	Sociology	Jakarta

*Provinces in which the experts conducted (most of) their research.

What matters most

In this study, personhood is the condition of being a social, physical and conscious individual which is constantly shaped within 'local worlds'. Two domains of everyday engagements that 'matter most' in low-resource rural and urban settings in Indonesia could be identified that would reflect 'personhood'. These domains include (a) achieving community participation and (b) family recognition, which are mutually constitutive and interact with other cultural values.

Community participation

Experts emphasised the importance of maintaining a good community reputation, influenced by collectivism. The first salient cultural aspect was '*gotong royong*', described as Indonesian philosophy emphasising 'mutual assistance' and voluntary work. This cultural value implies that people living in a community are expected to help each other, undertake voluntary work (*kerja bakti*), and to put group needs before their own needs. The following quotes illustrate the importance of communal activities and its impact on social standing:

> So, the functioning of a person is also highly viewed from his ability to join the community. (P2)

> You just need something to fall back on. So when I built my certain group of people, it is more like I just need to create my circle of people who care, whom I can trust (P11)

This relates to the second salient aspect, 'propriety'. Several participants, mostly experts in HIV-related stigma, noted Indonesia's emphasis on proper conduct in everyday behaviour. Conformity to social and religious values is expected, and deviating from these norms can result in shame and have a negative influence on one's reputation, affecting not only the individual but also their immediate and extended family within the community.

> If we do something wrong and it is proven that way, then this is embarrassing … not only for ourselves but also for our family and even the extended family. (P1)

> Men and women must try to maintain a good [family] name. If someone disrupts that good name, they will also, whether male or female, feel hurt and humiliated. (P1)

A good reputation could be achieved by being acknowledged within a larger entity, like the community or the family. For instance, one is expected to socialise and make themselves useful by participating in communal activities, such as funerals, weddings, birth or circumcision ceremonies. These are also called *selamatan:* communal celebrations often accompanied with religious activities. Participants noted that a favourable reputation and involvement in social network could provide individuals with an increased access to opportunities, also termed 'social capital' by one participant. These essential social connections offer benefits like moral support or work opportunities, underscoring the importance of socialising, as described in the following quotes:

> … because we live side by side, so it is very important to respect each other and to be able to socialize with the other people who live around us. (P8)

> People here think that they cannot live or die alone. So, they need support, need society to socialize and to build a support system for themselves. And when they lose it [the community], they feel like they lost everything. (P1)

Some participants explained that the collective culture can also have negative consequences by providing limited space for individual independence or self-expression that are contrary to cultural norms. The following quotes underscore this notion and illustrate possible repercussions:

> In this communal culture there is almost no space for individual freedom. Individuals cannot actualize themselves and express themselves according to their will, even though they do not violate certain values or norms. (P15)

> People will be very scared to deviate from the expectations or the norms, because it is very frowned upon; something that is unacceptable. You will be more isolated from the community, and then you'll lose it. (P11)

Family recognition

Participants highlighted the significance of contributing to the family for achieving personhood in Indonesia. Individuals must meet family expectations and families must maintain their reputation in the community.

Underlying aspects of family recognition vary by region; for instance, one participant connected family reputation to a caste system, emphasising its importance in upholding honour in society:

> The cultural structure in Bali is based on the caste system … For example, if a man [from a higher caste] falls in love with a lower caste woman, he will not dare to tell his family … Higher caste means they are descendants of the ancient royal families. If he told his family, then he would be stigmatized by his extended family. (P6)

The participants also described situations in which the family reputation could be tarnished or lost. Examples were having a family member with a stigmatised health-related condition, occupational or educational failure, or any other type of behaviour that goes against cultural norms and religious values, like promiscuity or being identified as a sexual minority. The subsequent quote illustrates this:

> One of the reasons why people are not telling their HIV status to their families is because they are afraid that their extended family will stigmatize my their immediate family' … They keep their status hidden to protect the reputation of their [immediate] family. (P9)

On the other hand, factors which could earn respect for a family were employment, a good education and sometimes material possessions (eg, owning a large home). Moreover, the notion of 'shame' was frequently linked to family recognition, impacting both individual and their family members, often tied to propriety. Consequently, stigmatised conditions are often concealed within the family, or people with stigmatised conditions may be confined or secluded at home. Secrecy serves as a coping mechanism, although potentially leading to stress, to maintain one's daily activities. Moreover, in cases that the family reputation was tarnished, family members were observed to limit participation in communal activities. This is aggravated by gossip, which appeared as the main cultural mechanism that could mark 'loss of personhood', illustrated in the following quotes:

> In our culture, we love to talk about bad things from others, like 'oh this is a bad family'. It is very important to maintain the good name of the family, so that we can be accepted in society, and able to participate in all community activities around us. (P8)

> I remember there is a food seller near my house, and she had a lot of customers, until there was a rumour saying that she got leprosy. People stopped visiting her restaurant, and then she moved away to somewhere else … That's how leprosy is used to spoil people and also businesses. (P4)

Another participant also stated that individual achievements and successes are not enough to gain a good

reputation and that family name still plays a big role in Indonesian culture:

> So, who is your father, your grandfather … I guess reputation can come from any of those. Having a good job or a high education are main [big] things, but I guess family name is a big factor in Indonesia [significantly contributes] to gain reputation. (P11)

Intersection with gender (equality) and patriarchal norms and values

Community participation

According to many participants, the opportunities in life differ for men and women due to a patriarchal culture in Indonesia. It was often stated that men generally have more opportunities in life than women. One participant described this:

> Indeed, men have more … get more appreciation than women in a society with a communal culture and very high patriarchal ideology. And not only differences in appreciation, but also consequently differences in opportunities and access. (P15)

Engaging in communal activities boosts community standing and foster socialisation, important for both male and female genders. However, the type of communal activities is gendered and different for men and women. Examples of activities for men involve community meetings, village fund (*dana desa*) allocation and guarding of the village to maintain security (*ronda malam*). Tasks for women included work in an integrated health centre (*posyandu*) and participation in certain community gatherings (*dasa wisma*) supporting family, health and well-being programmes. These duties deemed significant and were entrusted only to those seen as responsible. Other reported communal activities revolve around religious events, like funerals and circumcision ceremonies.

Family recognition

Achieving personhood differed between men and women due to differences in social expectations relating to family matters. All participants acknowledged gender-specific norms in maintaining family roles. Men are seen as the head of the family and are therefore expected to take decisions and financially provide for the family. As per result, one way for men to increase their family's community standing is through their occupation. According to many ethnic traditions and customs (*adat*), men also have the responsibility to pass on their family names and cultural traditions to their children. Women are often perceived as responsible for their children's upbringing. Thus, finding an appropriate spouse, getting married and having children is seen as a prerequisite for achieving personhood for both men and women to continue the family line and pass on customs. Further, having children outside marriage is often perceived as unacceptable. Some participants explained that having a stigmatised condition could diminish marriage prospects (for women) or hinder employment opportunities (for men) in low-resource areas and in turn, affect personhood:

> In Java for example … It is hard for them [women] to get married. Especially if they are descendants of leprosy patients, that's what I have heard. (P1)

> In our very patriarchal society, the burden of unemployment can evenly affect … is a gendered phenomenon. If you are a man and you are not working, most likely not just your family but also your neighbours will have a negative view about you. (P14)

Both men and women can tarnish a family's social standing by committing acts which are contrary to the cultural norms and gender expectations. The participants indicated that the consequences would affect their immediate family which are usually exacerbated by gossip.

WMM can intensify stigma

All participants agreed that stigmatised conditions have a big impact on the daily lives, activities and social engagements of affected persons. The stigmatising dynamics did not seem to differ across the different stigmatised conditions. Further, individuals with visible symptoms such as extreme weight loss (HIV), skin ulcers (leprosy) or episodes of delusions (schizophrenia) are more likely to be excluded from communal activities. Members of the extended family who live close to the affected stigmatised person, will most probably be stigmatised as well. The individual's behaviour will be labelled as wrong (*dicap buruk*) by the community and affects women and men similarly. In almost every interview, it was said that people with a stigmatised condition could participate to a limited extent in social gatherings and fulfil their daily duties compared with non-affected persons:

> If the celebratory feast comes from a family with leprosy, others will not accept it. Sometimes people accept food, but then they throw it away once they get home. So that is actually proof that they are shunned. They live together, as neighbours, but they are shunned. (P5)

> Sometimes people with mental illness do not get invited [to attend gatherings] … So, people do have that prejudice and it does limit their network, or their friends, or their access to even have friends, or to attend meetings. (P10)

> One of the causes of people who are infected with HIV may be exposure to behaviours that are not in accordance [deviate] with the norms and culture of Indonesia. … Someone with the disease, often face stigma and discrimination from society. (P8)

Some participants mentioned the feeling of 'being a burden to the family' and feeling useless, which denotes a 'social death'. Stigma can be exacerbated by community gossip surrounding an individual and their family. Women's behaviour tends to be more frequently gossiped about due to the patriarchal norms, hampering reintegration and acceptance into the community, as illustrated in the following quotes:

> But when we talk about stigma or why stigma happens when a certain health condition occurs to people, … I think it is more related to that they don't want to lose their social standing. And such disease is being labelled as something related to moral values or things like that. (P11)

> Maybe men are more indifferent [cuek] if they make mistakes. Due to his coping, he may be faster to return to normal. But for women, it usually takes time to go back to their own self or to the community again, it will take longer than for men. (P8)

Importantly, social cohesion and gossip seemed to be more prominent in rural than in urban areas, which one participant perceived as more individualistic with less social cohesion:

> … In urban areas, more people get better education, read the news, starting to filter the news they read or heard. People do not engage as much socially, they work so they don't have time to gossip with their neighbours. (P3)

WMM can act to preserve 'personhood'

Interestingly, participants noted that stigma could decrease when individuals fulfilled societal expectations, despite facing stigmatisation. For example, adhering to traditional gender roles could improve one's community status even when affected with a stigmatised condition. While urbanisation brings Western influence, many still uphold traditional gender norms although some recognise the increasing significant roles of women's roles:

> … when he can do his job, earn money for himself, at least the family members will still respect him. (P8)

> … they manage to reduce the stigma because she can demonstrate to the people around her that she is healthier than before. She can get to be a better mother for her children and contribute to the social gatherings and the communities, things like that. (P14)

DISCUSSION

This study offers interdisciplinary perspectives on cultural capabilities enabling people to achieve personhood in the context of health-related stigma in Indonesian culture. Guided by the 'WMM' theory by Yang *et al*,[6] expert perspectives were examined regarding how a stigmatised condition impacts personhood and how personhood can mitigate stigma in case one is still capable of achieving it. Our study revealed that Indonesian personhood entail community recognition and participation, alongside preserving family recognition and status. For example, these include participating in social gatherings and communal events or supporting the family's needs by means of financial aid. By doing so, people were perceived as 'capable' and 'responsible', resulting in a person's good reputation in the community. These community and family capabilities and maintaining family reputation were reported to interact with stigma experiences, potentially providing protection in certain situations.

Reflection on the findings

Our findings revealed that '*gotong royong*', or mutual assistance, which denotes reciprocal support, serves as a key cultural capability in moderating health-related stigma. This finding is in line with Slikkerveer who found that '*gotong royong*' is essential in Indonesian village culture and promoting indigenous 'knowledge, practices and beliefs'.[41] In turn, this could foster local community involvement in sustainable development interventions.[38 41] A similar concept of mutual assistance is observed in other collectivist cultures, such as Japan and Eswatini (formerly Swaziland). For example, Murayama *et al* found that mutual assistance is effective in Japan, improving mental health and reducing fear among elderly individuals living alone.[42] Fonner *et al* found mutual assistance to support disadvantaged groups in Eswatini to gain access to social capital and material assistance, consequently promoting protective HIV-related behaviours.[43] Further, our study revealed that having a stigmatised health condition may undermine an individuals's contribution to collective interests, as they are often perceived as weak and incapable; a perception that is potentially intensified by community gossip. This threatens personhood and hampers full community participation. These findings are consistent with research in other cultures, like Botswana and India.[44 45]

Another cultural value moderating health-related stigma is propriety, which was strongly related to feelings of shame. Deviating from cultural standards was reported to result in shame, felt by the affected person and their family. Stigmatised conditions and their symptoms were perceived as abnormal, and the resulting sense of shame could lead to a delay in health-seeking behaviour or in potentially harmful coping strategies, such as secrecy. Although secrecy can be experienced as very stressful, it is still common among affected individuals in Indonesia.[24 46–48] These findings are in line with Subandi and Good who studied shame in the Javanese culture within the context of psychotic illness. They found that shame plays a major role in social relations, prompting families to conceal the illness of an affected family member.[49–51]

Further, family recognition and participation were found to moderate health-related stigma. The family name could enhance life opportunities but could also be tarnished by a stigmatised health condition. In turn, not achieving these capabilities due to a health condition could further intensify stigma. For instance, marriage is viewed as essential for attaining personhood, as it is culturally preferred to be married before starting a family and it allows individuals to contribute to their immediate family. These findings are supported by previous research showing that a stigmatised condition can jeopardise marriage prospects disrupt existing marriages.[37 50 52 53] Since family ties hold significance in Indonesian culture, health-related stigma often extends to other family members, termed 'courtesy stigma' by Goffman.[54] This means that stigma affects not only the affected person but also their close relatives.[9 53 55 56] Tekola *et al* argued

that in Ethiopia, a family's honour could be compromised by a member with developmental disorders.[57] Yang and Kleinman, similarly found that stigma surrounding schizophrenia impact entire families and social networks, limiting access to resources and opportunities. To counter stigma, families often conceal or deny mental illness.[9]

Finally, our study suggests that the relationship between cultural capabilities and health-related stigma is gendered. This results from the reinforcement of specific gender roles, which are largely based on patriarchal systems and structures which are enforced via socialisation at home and in society.[58 59] The traditional role division in Indonesia, particularly on Java, is influenced by the norms of conventional Javanese culture and the values of Islam.[60] Men mostly fulfil the role of breadwinners, while women bear and take care of children.[61 62] The existence of patriarchal values and norms in society can give rise to inequality. This has been previously raised by Supraptiningsih and Jubba in a study conducted in Madura.[63] Societal expectations for women can hinder abilities, autonomy, opportunities and access to resources. Moreover, Rai *et al* found that intersectionality and health-related stigma towards people affected by several stigmatised conditions in Indonesia supports findings on how multiple dimensions such as gender and socioeconomic status can intersect to shape experiences of health-related stigma such as social exclusion, discrimination or prejudice.[23]

Strengths and limitations

Interviewing scholars offered valuable and in-depth insights. However, our study population did not include participants from all provinces of Indonesia, which means that certain cultural nuances from other areas may have been overlooked. Further, their perspectives may not fully reflect all aspects of moral experience and experiences of stigma in 'local worlds', given their socioeconomic status and level of education, which could also be potentially influenced by globalisation. Nevertheless, the study included diverse participants, including academics from various disciplines, each with expertise of various health conditions. This variety enabled us to gather rich insights into the underpinnings of health-related stigma in Indonesian society.

Implications

Our findings based on perspectives from scholars revealed that community engagement and family recognition impact stigmatisation of individuals and their close family. Therefore, incorporating these factors into stigma reduction approaches such as peer support groups and family counselling is important.[64 65] These programmes should uphold the concept of personhood while fostering meaningful participation to restore self-esteem and productivity.[57 59 60] Future qualitative research should include individuals from various socioeconomic background to explore a wide range of experiences, particularly about the effects of exclusion and potential strategies to pre-empt these. Further research is needed to develop and evaluate interventions based on promoting personhood and informed by 'WMM'.[66 67] Efforts to assess and reduce stigma should take into account the intricate nuances of communal sense in the daily lives of those affected, and incorporate considerations of social standing, acceptance and empowerment into their design.

Conclusion

This study explores interdisciplinary perspectives on cultural capabilities that 'matter most' to achieve personhood and their interactions with health-related stigma in Indonesia. A collectivist society and shame culture shape experiences of stigma and personhood can be achieved by being recognised as part of the community and family. These findings show that cultural capabilities in the community potentially intensify stigma as well as may protect or against stigma. This study contributes to research on the cultural shaping of health-related stigma using 'WMM' in Indonesia. Future research should prioritise insights from individuals affected by health conditions and develop stigma-reduction interventions incorporating these cultural capabilities.

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Contributors AS and YS contributed equally to this paper. AS, YS, MV, DD, LY and RP conceptualised the study and the study design. YS serve as guarantor. Data were curated and analysed by AS and YS. AS and YS were responsible for drafting the manuscript and supervised by MV and RP. Review and editing were performed by all authors. All authors have read and agreed to the published version of the manuscript. The manuscript used ChatGPT technology, primarily in the later stages, to condense text and reduce word count. It is important to note that AI was not involved in the initial writing of the manuscript, during the course of data collection, nor the data analysis phases of the manuscript.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and ethical approval from the ethics committee of Atma Jaya University in Jakarta was obtained for the overall project (1010A /III/LPPM.PM.10.05/09/2020). For this study, the Research Ethics Review Committee of the VU Amsterdam (BETHCIE) concluded that further review was not required. The recommended ethical standards for conducting research according to the principles of the Declaration of Helsinki were followed. Informed consent was obtained from all participants before data collection. All data were stored confidentially.

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REFERENCES

1 van Brakel WH, Cataldo J, Grover S, *et al*. Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention. *BMC Med* 2019;17:13.
2 Nyblade LC. Measuring HIV stigma: Existing knowledge and gaps. *Psychol Health Med* 2006;11:335–45.
3 Stangl AL, Earnshaw VA, Logie CH, *et al*. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med* 2019;17:31.
4 Dadun D, Peters R, Lusli M, *et al*. Exploring the Complexities of Leprosy-related Stigma and the Potential of a Socio-economic Intervention in a Public Health Context in Indonesia. *DCID* 2016;27:5.
5 Van Brakel WH. Measuring health-related stigma—A literature review. *Psychol Health Med* 2006;11:307–34.
6 Yang LH, Kleinman A, Link BG, *et al*. Culture and stigma: Adding moral experience to stigma theory. *Soc Sci Med* 2007;64:1524–35.
7 Murthy RS. Stigma is universal but experiences are local. *World Psychiatry* 2002;1:28.
8 Yang LH, Chen F-P, Sia KJ, *et al*. 'What matters most:' a cultural mechanism moderating structural vulnerability and moral experience of mental illness stigma. *Soc Sci Med* 2014;103:84–93.
9 Yang LH, Kleinman A. 'Face' and the embodiment of stigma in China: the cases of schizophrenia and AIDS. *Soc Sci Med* 2008;67:398–408.
10 Shir-VerteshD. Personhood. 2017. Available: https://www.oxfordbibliographies.com/display/document/obo-9780199766567/obo-9780199766567-0169.xml
11 The World Bank. Population, total - indonesia: the world bank. 2021. Available: https://data.worldbank.org/indicator/SP.POP.TOTL?locations=ID
12 Ananta GCZ, Hasbullah MS, Handayani NB, *et al*. *Demography of Indonesia's ethnicity*. Taylor & Francis, 2017.
13 UNDP. *Human development report 2019: inequalities in human development in the 21st century*. New York: NY UNDP, 2019.
14 Krentel A, Wellings K. The role of gender relations in uptake of mass drug administration for lymphatic filariasis in Alor District, Indonesia. *Parasit Vectors* 2018;11:179.
15 WHO. Gender and health. 2021. Available: https://www.who.int/news-room/questions-and-answers/item/gender-and-health
16 Hartini N, Fardana NA, Ariana AD. PRBM. 2018;11:535–41.
17 Laila NH, Mahkota R, Shivalli S, *et al*. Factors associated with pasung (physical restraint and confinement) of schizophrenia patients in Bogor regency, West Java Province, Indonesia 2017. *BMC Psychiatry* 2019;19:162.
18 Fauk NK, Hawke K, Mwanri L, *et al*. Stigma and Discrimination towards People Living with HIV in the Context of Families, Communities, and Healthcare Settings: A Qualitative Study in Indonesia. *IJERPH* 2021;18:5424.
19 Paxton S, Gonzales G, Uppakaew K, *et al*. AIDS-related discrimination in Asia. *AIDS Care* 2005;17:413–24.
20 Lusli M, Zweekhorst MBM, Miranda-Galarza B, *et al*. Dealing with stigma: experiences of persons affected by disabilities and leprosy. *Biomed Res Int* 2015;2015:261329.
21 Peters RMH, Lusli M, *et al*. The meaning of leprosy and everyday experiences: an exploration in cirebon, indonesia. *J Trop Med* 2013;2013:507034.
22 Rai SS, Irwanto I, Peters RMH, *et al*. Qualitative Exploration of Experiences and Consequences of Health-related Stigma among Indonesians with HIV, Leprosy, Schizophrenia and Diabetes. *Kesmas Natl Public Health J* 2020;15:7.
23 Rai SS, Peters RMH, Syurina EV, *et al*. Intersectionality and health-related stigma: insights from experiences of people living with stigmatized health conditions in Indonesia. *Int J Equity Health* 2020;19:206.
24 Peters RMH, Hofker ME, Van Brakel WH, *et al*. Narratives Around Concealment and Agency for Stigma-reduction: A study of Women affected by Leprosy in Cirebon District, Indonesia. *DCID* 2014;25:5.
25 Fauk NK, Ward PR, Hawke K, *et al*. Cultural and religious determinants of HIV transmission: A qualitative study with people living with HIV in Belu and Yogyakarta, Indonesia. *PLoS One* 2021;16:e0257906.
26 KroefJM. Collectivism in Indonesian society. *Soc Res (NY)* 1953;193–209.
27 Schwartz SH. Individualism-collectivism: Critique and proposed refinements. *J Cross Cult Psychol* 1990;21:139–57.
28 Ananta A, Nurvidya Arifin E, Sairi Hasbullah M. Demography of indonesia's ethnicity: institute of southeast asian studies. 2015.
29 Haryanto S. The sociological context of religion in indonesia. In: *Research in the social scientific study of religion*. . Brill, 2019: Volume 30. 67–102.
30 Statista. Share of indonesian population in 2010, by religion: statista. 2022. Available: https://www.statista.com/statistics/1113891/indonesia-share-of-population-by-religion/
31 Visalo PP. 25. The dynamics of religion in the age of globalization: lessons from indonesia, philippines, and japan. The Asian Face of Globalisation: Reconstructing Identities, Institutions, and Resources; 2003.
32 Edara IR. Religion: A Subset of Culture and an Expression of Spirituality. *Archit Aujourdhui* 2017;07:273–88.
33 Gray DE. *Doing research in the real world*. Sage, 2013.
34 Acharya AS, Prakash A, Saxena P, *et al*. Sampling: why and how of it? *Indian J Med Spec* 2013;4:330–3.
35 Loganathan S, Murthy RS. Living with schizophrenia in India: gender perspectives. *Transcult Psychiatry* 2011;48:569–84.
36 Turan JM, Elafros MA, Logie CH, *et al*. Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Med* 2019;17:7.
37 Asiedu GB, Myers-Bowman KS. Gender differences in the experiences of HIV/AIDS-related stigma: a qualitative study in Ghana. *Health Care Women Int* 2014;35:703–27.
38 Saunders B, Sim J, Kingstone T, *et al*. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.
39 Green J, Thorogood N. *Qualitative methods for health research*. Sage, 2018.
40 Yang LH, Valencia E, Alvarado R, *et al*. A theoretical and empirical framework for constructing culture-specific stigma instruments for Chile. *Cad Saude Colet* 2013;21:71–9.
41 Slikkerveer LJ. Gotong royong: an indigenous institution of communality and mutual assistance in indonesia. In: *Integrated community-managed development*. Springer, 2019: 307–20.
42 Murayama Y, Hasebe M, Nishi M, *et al*. The impact of mutual aid on mental health and perceived isolation among the single elderly: An examination of economic status. *Geriatrics Gerontology Int* 2021;21:555–60.
43 Fonner VA, Kerrigan D, Mnisi Z, *et al*. Social cohesion, social participation, and HIV related risk among female sex workers in Swaziland. *PLoS One* 2014;9:e87527.
44 Yang LH, Poku OB, Misra S, *et al*. n.d. Stigma, Structural Vulnerability, and 'What Matters Most Among Women Living With HIV in Botswana. *Am J Public Health (N Y)*2021:e1–9.
45 Koschorke M, Padmavati R, Kumar S, *et al*. Experiences of stigma and discrimination of people with schizophrenia in India. *Social Science & Medicine* 2014;123:149–59.
46 Raya NAJ, Nilmanat K. Experience and management of stigma among persons living with HIV in Bali, Indonesia: A descriptive study. *Jpn J Nurs Sci* 2021;18:e12391.
47 Peters R, Mieras L, Subedi M, *et al*. A single dose of rifampicin to prevent leprosy: qualitative analysis of perceptions of persons affected, contacts, community members and health professionals towards chemoprophylaxis and the impact on their attitudes in India, Nepal and Indonesia. *LEPROSY* 2018;89:335–52.
48 Pribadi T, Lin ECL, Chen PS, *et al*. Factors associated with internalized stigma for Indonesian individuals diagnosed with schizophrenia in a community setting. *J Psychiatr Ment Health Nurs* 2020;27:584–94.
49 Subandi MA, Good BJ. Shame as a cultural index of illness and recovery from psychotic illness in Java. *Asian J Psychiatr* 2018;34:33–7.
50 Subandi MA, Praptomojati A, Marchira CR, *et al*. Cultural explanations of psychotic illness and care-seeking of family caregivers in Java, Indonesia. *Transcult Psychiatry* 2021;58:3–13.
51 Rai SS, Syurina EV, Peters RMH, *et al*. Assessing the prospect of a common health-related stigma reduction response: Cross-

perspectives of people living with stigmatised health conditions in Indonesia. *Glob Public Health* 2021;16:1856–69.
52 Try L. Gendered experiences: marriage and the stigma of leprosy. *Asia Pac Disabil Rehabil J* 2006;17:45–6.
53 Thara R, Kamath S, Kumar S. Women with Schizophrenia and Broken Marriages - Doubly Disadvantaged? Part I: Patient Perspective. *Int J Soc Psychiatry* 2003;49:225–32.
54 Goffman E. Stigma and social identity. In: *Understanding deviance: connecting classical and contemporary perspectives*. 1963: 256. 265.
55 Barrett R. Self-mortification and the stigma of leprosy in northern India. *Med Anthropol Q* 2005;19:216–30.
56 Koschorke M, Padmavati R, Kumar S, *et al*. Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India. *Soc Sci Med* 2017;178:66–77.
57 Tekola B, Kinfe M, Girma F, *et al*. Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Soc Sci Med* 2020;256:113034.
58 Islam KMM, Asadullah MN. Gender stereotypes and education: A comparative content analysis of Malaysian, Indonesian, Pakistani and Bangladeshi school textbooks. *PLoS One* 2018;13:e0190807.
59 Ernanda E. Challenging the patriarchal culture; Feminist critical discourse analysis of the Indonesian environmental heroines. *Wacana* 2023;24:4.
60 Ida R. The construction of gender identity in Indonesia: Between cultural norms, economic implications, and state formation. *Mas Keb dan Pol* 2001;14:21–34.
61 Sakina AI, Siti D. Highlighting patriarchal culture in Indonesia. *Soc Work J* 2013;7:71–80.
62 Indraswari R, Suryoputro A, Widjanarko B, *et al*. Characteristics of Indonesian Adolescents who had Experienced Pregnancy Under the Age of 20 Years: Basic Health Research 2018. *JPK* 2021;9:159.
63 Supraptiningsih U, Jubba H, Hariyanto E, *et al*. Inequality as a cultural construction: Women's access to land rights in Madurese society. *Cog Soc Sci* 2023;9:2194733.
64 Derose KP, Bogart LM, Kanouse DE, *et al*. An intervention to reduce HIV-related stigma in partnership with African American and Latino churches. *AIDS Educ Prev* 2014;26:28–42.
65 Shrestha D, Napit IB, Ansari S, *et al*. Evaluation of a self-help intervention to promote the health and wellbeing of marginalised people including those living with leprosy in Nepal: a prospective, observational, cluster-based, cohort study with controls. *BMC Public Health* 2021;21:873.
66 Lusli M, Peters R, van Brakel W, *et al*. The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia. *PLoS Negl Trop Dis* 2016;10:e0005088.
67 Lusli M, Peters R, Bunders J, *et al*. Development of a rights-based counselling practice and module to reduce leprosy-related stigma and empower people affected by leprosy in Cirebon District, Indonesia. *LEPROSY* 2017;88:318–33.

Appendix I: Interview guide

Questions in-depth interviews

THEME 1: CULTURE	
Culture	Do you believe that culture and health-related stigma interact with one another? ● If yes, in what way and could you specify your answer to the [Indian/Nigerian/Indonesian] context?

THEME 2: FULL STATUS AND WHAT MATTERS MOST / MORAL ASPECTS	
Full status and What matters most	One way to look at the relation between culture and stigma is to see how stigma is embedded in people's everyday engagements in their community and how this stigma can threaten to diminish a person's ability to participate in fundamental everyday activities. This could be for example social status, wealth, being healthy or life chances. The next questions will be about this topic. What does it mean to be a "complete" person or person with "full status" in the culture of [country Y]? (If too broad, ask respondent to focus on a specific area in [country Y]) ● What are components or values that give a person "full status" or "complete personhood" in [country Y]? ● What would you describe as important or the most important components or values for attaining this "full status"? ● What can people do to fully participate in the community? ● How does having a stigmatiz ed health condition or [condition X] affect a person's ability to attain "full status"? ● What components or values that matter most to [Indian/Nigerian/Indonesian] people for attaining "full status" are threatened in people with a stigmatiz ed condition or [condition X]? ● What are the consequences to their health status when they can not perform their obligations within the community? Are there manners in which a stigmatised person or person with [condition X] can do to achieve these values despite having their condition? (Ways to go around stigma/coping strategies that can be applied) ● If the community knows that someone has [condition X], can he or she still be seen as a full member of the community?
Concept of face	An example of what matters most could be 'face' or 'loss of face', which for instance can be determined by a person's reputation.

	According to you, is the concept of 'face', or something similar to the concept of face, also embedded in the [Indian/Nigerian/Indonesian] culture? ● Could you explain? (How can this affect a person's daily life in [Indian/Nigerian/Indonesian] culture?) ● Can a person with a stigmatised condition or with [condition X] experience a loss of face in their local community? In what way? Can you give examples?

THEME 3: INTERSECTIONALITY	
Intersectionality	According to you, what other forms of identity are stigmatiz ed are present in the culture of [country X]? ● Which of them do you think interacts with health-related stigma? ● How do these forms of stigma influence health? ● Do you think these other forms of stigma have a positive or negative effect on health-related stigma? Could you explain? Do you think the aspects that make up "full status" differ for men and women? What obligations do men have in their community? ● What does it mean to be a man in Indonesian culture? (What components make up a man?) What obligations do/women have in their community? ● What does it mean to be a woman in Indonesian culture? (What components make up a woman?) How do you think stigma (for condition X) affects men and women differently in the Indonesian context? ● In what way would stigma affect younger and older men differently? ● Are the components of values that make up "full status" different for younger and older men? ● In what way would stigma affect younger and older women differently? ● Are the components of values that make up "full status" different for younger and older women?

THEME 4: INTERPERSONAL ASPECTS	
Stigma between members of the community	How do community members stigmatize individuals with [condition X] in [country Y]? ● How does culture influence this stigmatization? ● In what way do community members treat the affected individual differently than other non-affected community members?
Stigma between family members	Do family members stigmatise the affected individual? ● If yes, in what way? ● What are the underlying cultural influences for why family members stigmatize affected individuals?

	Are family members also affected by stigma due to association with the stigmatized family member? ● If yes, in what way? ● To what extent is the family stigmatized in comparison to the stigma experienced by the affected individual?
Health professional stigma	Do you think that health professionals stigmatize affected individuals? ● If yes, in what way? ● What are the underlying cultural influences for why health professionals stigmatize affected individuals? Are health professionals stigmatized due to their association with stigmatized patients? ● If yes, in what way?

THEME 5: SOCIETAL FACTORS	
Public conceptions	What stereotypes or prejudices are there in [country Y's] culture towards people suffering from a stigmatized condition? How do you think these stereotypes and prejudices affect these people? ● Which aspects in life do you think are influenced negatively/positively by these stereotypes and prejudices? What cultural aspects do you think have an influence on these stereotypes and prejudices? ● Do these public conceptions differ between various ethnicities/geographical areas within [country X]?
Institutional forms of stigma	Do you recognise the issue of institutional forms of stigma in your field of practice? Could you give examples of certain institutions or policies that are disadvantageous for people with a stigmatized condition in [country Y]? How do you think institutional forms of stigma impacts the lives of those affected? According to you, how do institutional forms of stigma influence health-seeking behaviour?

THEME 6: INDIVIDUAL ASPECTS	
Social experiences and emotional/somatic consequences	According to you, what role do you think social communities have on health-related stigma for a stigmatized person? ● What role does the social community have on the coping experience of a person with a stigmatized condition? ● What impact (positive/negative) has the social community of a patient on the experience of health-related stigma? What consequences on a person's mental health do you think are linked to these stigma experiences?

	What consequences on a person's physical health do you think are linked to these stigma experiences?

Questions GD		
	Group discussion questions	1) Why is it important to be recognized as part of the community or family? *Is there a difference between them? Which one is more important (community or family) and why?* 2) Why is it important to maintain family name? *How can you maintain family name? How can you lose your family name?* 3) Are there differences between men and women? *Is it equally important to be part of the community or family for men and women? Is it equally important to maintain the family name?* 4) Is there something else we missed regarding full status? *How can you lose full status in the community? Can you elaborate?*

Appendix II: Coding process

Methods

Data analysis

The first three transcripts were coded independently by two Indonesian researchers (YS and AAS) using open coding to highlight cultural activities and engagements that appear to "define personhood" according to the participants. The topics that came up frequently during the interviews or similarities and differences in the perspectives and experiences of the interviewees were also distinguished in this step to allow for inductive coding of topics. The participants' perspectives and experiences were also structured by geographical area, namely rural and urban. The two researchers then discussed the codes with the wider team (including expert in this approach, LHY) to develop a preliminary coding list, which was used to code the remaining 12 transcripts together and was further modified inductively as new topics arose during interviews. Any discrepancies between the researchers were resolved by discussion until consensus was reached.

The final code list (27 codes) was determined after eight interviews when no new codes emerged. At the end of this open-coding process, all transcripts were revisited using the final coding list, to ensure that all potential codes had been applied to all transcripts. Codes were analyzed using thematic content analysis and codes were grouped under three main categories: i) "cultural capabilities that matter most"; ii) "how WMM can shape and intensify stigma" and iii) "how WMM can act to preserve personhood". These categories were taken deductively from previous work of Yang and colleagues (6, 8, 42).

The first category included the sub-categories "cultural dynamics", "family recognition" and "community participation". These sub-categories were further explored for men and women separately. The second category contained the sub-categories "moral experience", "societal factors" and "intersectionality". The last category consisted of sub-categories that portrayed how significant cultural aspects could protect against stigma. This category was also further divided by gender.

MAIN CATEGORIES	SUB-CATEGORIES
Cultural capabilities that matter most	Cultural dynamics (men / women)
	Family recognition (men / women)
	Community participation (men / women)
How WMM can shape and intensify stigma	Moral experience
	Societal factors
	Intersectionality
How WMM can act to preserve personhood	Men
	Women