

# Qualitative Exploration of Experiences and Consequences of Health-related Stigma among Indonesians with HIV, Leprosy, Schizophrenia and Diabetes

Sarju Sing Rai<sup>1,2</sup>, Irwanto<sup>3\*</sup>, Ruth M H Peters<sup>1,...</sup><sup>1</sup>Athena Institute, Faculty of Science, Vrije University Amsterdam, Amsterdam, The Netherlands<sup>2</sup>Barcelona Institute for Global Health (ISGlobal), University of Barcelona, Barcelona, Spain<sup>3</sup>Department of Psychology, Atma Jaya Catholic University, Jakarta, Indonesia

## Abstract

Health-related stigma causes a negative impact on the lives of affected people and undermines the effectiveness of public health programs. This study aimed to explore experiences and consequences of stigma among people affected by four health conditions relevant in Indonesia— HIV (Human Immunodeficiency Virus), leprosy, schizophrenia and diabetes. In this qualitative study 40 people affected by the four health conditions in Jakarta and West Java, Indonesia—, were interviewed between March and June 2018. Data were analyzed thematically by following an integrative inductive-deductive approach. The experiences and consequences of people with stigma were similar, but such experience were more severe among people affected by HIV, leprosy, and schizophrenia. Those with diabetes either experienced no or less severe stigma. The participants revealed that they experienced enacted stigma in healthcare, employment, and social interactions in the structural and interpersonal levels. They also experience the stigma in the form of internalized and anticipated stigma at an individual level. Incidences of human rights violations were evident. Social, behavioral, psychological, and medical consequences were also reported.

**Keywords:** diabetes, Human Immunodeficiency Virus, leprosy, schizophrenia, stigma Indonesia

## Introduction

Health-related stigma is a global health issue that undermines the effectiveness of public health programs and negatively impact on the lives of affected people.<sup>1</sup> It affects people living with infectious diseases, such as HIV (Human Immunodeficiency Virus),<sup>2</sup> and leprosy,<sup>3,4</sup> and mental health conditions, such as schizophrenia.<sup>5</sup> It also affects people with noncommunicable diseases, including diabetes,<sup>6,7</sup> and cancers.<sup>8,9</sup> As a social phenomenon, stigma occurs within the society and usually depends on the nature of a disease.<sup>10</sup> People with communicable diseases, such as HIV or leprosy, experience stigma because of the infectious nature of diseases.<sup>11,12</sup> They are often blamed for having a transmissible disease and are avoided by others, especially when consequences of the condition are visible, as in leprosy.<sup>4,11,13</sup> People living with noncommunicable diseases, such as diabetes, are known to be blamed and shamed for their lifestyles and for inflicting the condition on themselves.<sup>6,7</sup> People living with chronic mental health conditions, such as schizophrenia are perceived to be aggressive and dangerous, so they are socially avoided and rejected.<sup>5,14</sup>

People with different health conditions experience

stigma that negatively affects their social, physical, psychological, and spiritual well-being.<sup>2,12,15</sup> It reduces the degree of access and uptake of health care services, causing the underdiagnosis of conditions, failing to detect mental health issues, and delaying and disrupting treatment.<sup>16-18</sup> Such consequences of stigma affect preventive and treatment measures for eliminating these diseases, ultimately hampering advancements in decreasing the burden of diseases.<sup>19,20</sup>

Low-and middle-income countries (LMICs) are known to be disproportionately affected by health-related stigma because of the existence of subjugating social norms, lack of health awareness, and inequitable access to health services that contribute to stigma and its negative effects.<sup>21,22</sup> However, much of the burden of health-related stigma in LMICs still remains hidden and unaddressed because of the lack of wider recognition in health policies and practices.<sup>21</sup>

As the world's fourth-most populous developing nation currently in epidemiological transition with relatively high prevalence and distribution of noncommunicable and communicable diseases, Indonesia is particularly vulnerable to the burden of

**Correspondence\*:** Irwanto, Department of Psychology, Atma Jaya Catholic University Jakarta, Jend Sudirman Street, Karet Semanggi, South Jakarta, Jakarta, Indonesia, E-mail: [irwanto\\_i@yahoo.com](mailto:irwanto_i@yahoo.com), Phone: +62-815-940-6896

Received : September 8, 2019

Revised : October 21, 2019

Accepted : December 11, 2019

stigma compared with other Southeast Asian countries.<sup>23,24</sup> It has the highest prevalence of HIV in the Southeast Asian region,<sup>25</sup> and leprosy has the third-highest prevalence in the world.<sup>26</sup> The prevalence of noncommunicable diseases, such as diabetes mellitus (6.7% in adults) and schizophrenia (around 1%), is high.<sup>27,28</sup> With a high burden and growing prevalence of these four diseases in the Indonesian society, these diseases have a social effect, that is, stigma and its experiences in the daily life of affected people.<sup>20</sup> In this regard, the stigma related to these four different diseases, which are relevant to the health of the Indonesian population, should be further explored and understood.

Few studies have reported the negative experiences of stigma among people with HIV,<sup>29-34</sup> and leprosy.<sup>3,4, 11,35-37</sup> in Indonesia. Subu, *et al.*,<sup>38</sup> reported the stigma associated with mental illnesses, including schizophrenia in Indonesia. The Human Rights Watch,<sup>39</sup> published a report on the rampant human rights violations among people with schizophrenia and other mental illnesses in Indonesia. Two studies,<sup>40,41</sup> have reported the community perceptions of people with diabetes and the general experiences of persons living with diabetes in Indonesia. However, studies have focused on the stigma experiences of people with schizophrenia and diabetes. Furthermore, the experiences of the stigma across different health conditions with different kinds of nature, etiology, and attribution, should be compared with record the differences and similarities among those experiences, particularly in the context of the Indonesian culture. Such insights not only help further understand the processes and experiences of stigma across different health conditions and within the specific Indonesian cultural context, but also have strong implications for public health programs in effectively responding to stigma in a variety of health conditions. Therefore, this study aimed to explore aimed to not only explore but also compare the experiences and consequences of stigma among people with HIV, leprosy, schizophrenia, and diabetes. The comparison was done among the four disease groups in order to see if there were any differences, however, the experiences and consequences were very similar across the groups.

## Method

This study was a part of an exploratory community-based study on health-related stigma conducted in Jakarta and West Java in Indonesia between March and June 2018 among people living with/affected by four stigmatized health conditions, namely, HIV, leprosy, schizophrenia, and diabetes. The study locations were selected on the basis of the higher proportion of individuals with different health conditions in these

regions. The participants with HIV and diabetes were recruited in Jakarta, those with leprosy were recruited in Cirebon, West Java, and those with schizophrenia were recruited in Jakarta and Cianjur, West Java. Purposive convenience sampling was used to recruit participants from the community through referrals and recruitment by community-based organizations and peer-support groups related to the four different conditions. Those who were over the age of 16 years (age of consent) and who were willing and consented to participate were included in the study. Therefore, 40 participants (10 from each of the four health conditions) were recruited and interviewed.

Scambler's hidden distress model of stigma,<sup>42</sup> was used as a theoretical framework to develop the interview guide and analyze data. The framework categorized the experiences of stigma into two types: enacted (actual experiences of stigmatizing acts, attitudes, and behavior from others) and felt stigma (acceptance of stigmatizing social views and resultant feelings of shame [internalized stigma] and fear of being vilified because of the stigmatizing trait [anticipated stigma]).<sup>43</sup> These categories of stigma experiences are embedded within the socio-ecological levels where stigma exists at structural, interpersonal, and individual levels of the society.<sup>5</sup> Enacted stigma occurs at structural and interpersonal levels,<sup>14,44</sup> and felt stigma is experienced at the individual level.<sup>14,45</sup>

The interview guide was developed on the basis of the theoretical framework on Scambler's hidden distress model of stigma,<sup>42</sup> and multiple consultations with research experts (three from Athena institute, Vrije University Amsterdam, the Netherlands and two from the Faculty of Psychology, Atma Jaya Catholic University, Indonesia), and representatives from nongovernmental organizations and the different disease groups. Pilot interviews were first conducted with four participants (one from each health condition) to test the applicability and appropriateness of the interview guide and the interview technique. The interview guide included open questions on the experience of living with a stigmatized health condition, the experiences of stigma as a result of the health condition, and the resultant consequences of stigma. The interview guide was subsequently refined and adjusted by further outlining the questions on the experiences of stigma into structural (stigmatizing policies and systems in the society), interpersonal (stigma in family and social circles), and intrapersonal (self-perception of stigma) levels. The respondents were approached and asked to participate in the study. Those who agreed were either interviewed at their homes or in nongovernmental organization offices privately. The interviews started in an exploratory manner asking about the general daily experience of living with their health

condition, progressed toward more in-depth questions on specific examples of their personal experiences with stigma and its consequences, and lasted an average of one hour. In-depth probing was conducted until response saturation. Data were collected by a team of one Indonesian research associate from Vrije University Amsterdam and two research assistants from Atma Jaya Catholic University in Indonesia language under the supervision of the main researcher. The research team were trained on interview techniques and strategies for qualitative data collection prior to fieldwork (in the first week of March). Data were recorded electronically, transcribed verbatim, translated, managed, and analyzed with the qualitative software package *Atlas.ti*.

Data were analyzed through thematic content analysis,<sup>46</sup> and data were iteratively coded and thematically categorized using an integrative inductive-deductive approach,<sup>47</sup> to derive the inference. The transcripts were coded and thematically categorized into two, namely, experiences and consequences of stigma. The experiences of stigma were deductively categorized on the basis of the underpinning theory of Scambler's hidden distress model of stigma.<sup>42</sup> The codes were first categorized into three different socioecological levels, e.g., structural, interpersonal, and intrapersonal, levels, by using the deductive approach and then subcategorized into enacted stigma under the structural and interpersonal levels and felt stigma (internalized and anticipated) under the intrapersonal level. The consequences of stigma were inductively derived and categorized on the basis of the emerging themes: social, behavioral, psychological, and medical consequences. The analytical process was peer debriefed and discussed at each stage to ensure the quality and validity of codes, categories, and themes.

The study was approved by the Ethics Committee of

Atma Jaya University (Approval ID: FR-UAJ-26-13/R0). Written consent was obtained from individual study participants. Refreshments were given to the participants and their transportation costs were refunded as a token of appreciation for their participation.

## Results

A total of 40 participants, with ten each with HIV, leprosy, schizophrenia, and diabetes, were interviewed. Of these participants, 21 were females (52.5%), 18 were males (45.0%), and 1 was a transgender (2.5%). The median age of the participants was 40.9 years (Standard Deviation 11.54) with an age range of 19 - 75 years. The mean duration of living with/having had the condition was 10.4 years (SD 5.8) with a range of 1 - 25 years. In terms of ethnicity, the majority (40%) of the participants were Javanese, followed by Sundanese (20%), Chinese (15%), and others (25%). Most of the participants were Muslims (62.5%), and the remaining participants were Christians (32.5%) and Buddhists (5.0%). The majority of the participants reached the senior high school level or higher (82.5%), and were employed (76.3%).

The key themes of the experiences of stigma and its consequences are presented in Figure 1. The experiences were deductively categorized into three different levels as per the socioecological level framework, e.g., structural, interpersonal, and intrapersonal levels. Participants experienced two distinct types of stigma, namely, the enacted stigma that manifested at structural and interpersonal levels, and felt stigma which manifested in the individual level. The experiences of stigma were reported at multiple levels of the society by all the participants affected by HIV, leprosy, and schizophrenia. Only six participants with diabetes reported that they experienced stigma, whereas four participants did not perceive any stigma because of their

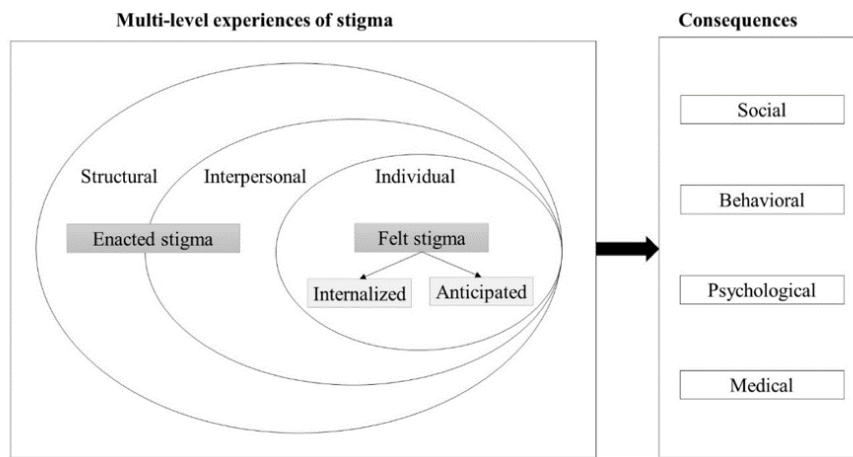


Figure 1. Key Themes of Experiences of Stigma and Its Consequences

condition.

The participants reported of experiencing enacted stigma because of existing policies and practices, and social and cultural norms at the structural level. People living with HIV and schizophrenia reported exclusionary policies and practices in health institutions. For example, participants with HIV reported that they were denied of treatment or refused to receive treatment after they knew their HIV status, were allowed in-house hospital admissions only in private rooms, and used overt practices to avoid contamination. Some participants with HIV and schizophrenia also reported severe human rights violations because of hospital policies. For example, one woman living with HIV recounted her experience of the hospital administration handing her a consent form for sterilization to sign right before the delivery of her child,

*"I was in a position where I could not refuse. I was only 22 years old then (in 2008). At first, I did not want to do it, but the doctor said if I did not want to (sign the consent form), he would not operate. I had my first child at 22 years old and got sterilized." (Female, HIV, AH010)*

Three people with schizophrenia talked about their experience of involuntary captivity and isolation practiced in a hospital as a way to subdue patients.

The participants reported that they experienced exclusionary policies in the job market. Three participants with diabetes indicated that they experienced discrimination in jobs that involved physical labor or heavy workload, which they were either not hired or excluded from participating because of their disease. People affected by leprosy with visible spotting or deformity stated problems in having a job in public and private sectors. Those who have HIV and schizophrenia and disclose their health status reported that they were rejected or dismissed from jobs. Most participants affected by HIV, leprosy, and schizophrenia stated their preference to either work in non-governmental organizations (NGOs) related to their respective health condition or open their own business to avoid stigma. Several people with schizophrenia reported that they worked as *Go-Jek* (online motorbike ride sharing service in Indonesia) drivers to minimize interactions with the employers and colleagues.

The participants also talked about how poverty further impacted their experience of stigma. They reported that the lack of finances limited their access to health care, thereby worsening their condition and its manifestations. One participant with HIV called it "double stigma" of being "sick" and "poor." However, some participants also talked about how some improvements are happening, such as *BPJS* (Indonesian National Health Insurance), which helps them and other poor people avail inexpensive medical treatment.

The participants also reported that they had adverse experiences of stigma because of existing socio-cultural, religious, and gender norms. People with/affected by HIV, leprosy, and schizophrenia reported that religious, superstitious, and mystical beliefs in the society, such as sin or bad deeds, curses, witchcraft, and influence of evil spirits, were the cause of their diseases. They also talked about how socially held stereotypes played a role in stigmatizing individuals with diseases. Those with HIV and leprosy also reported the fear of people about contracting the disease from them because of their lack of knowledge. The participants living with schizophrenia reported that the society perceived people with schizophrenia as "crazy" or "aggressive", leading to stigmatization and discriminatory practices against them. Three participants recounted their experience of being tied and shackled, which is an act called "*pasung*" in Indonesian, to restrain them. On the contrary, people with diabetes reported that they received support and acceptance from the society. They stated how diabetes was considered "normal" in the Indonesian society because many people in the community were more familiar with the disease. Four female participants with HIV and three with diabetes described how women were judged more harshly than men in the society and recounted of being considered irresponsible and vilified for making "bad decisions."

The participants described their experiences of stigma at an interpersonal level from health care professionals, friends, and family. All the participants except those with diabetes, reported their negative experiences with healthcare professionals. They were either discriminated against or disrespected because of their disease. The participants affected by leprosy reported that health care staff refrained from touching them; for instance, health care people would not shake hands with them. The participants with schizophrenia commented on feeling condescended by how healthcare workers treated them and talked to them—they felt like they were not adults or in control of their life. Those with HIV talked about how some health workers did not value and respect the knowledge, experiences, and views of patients. One participant said,

*"In this day and age, health care workers still think that they are the only ones with knowledge (on HIV-related issues) because they went to medical school. I rarely find a doctor who wants to accept inputs from us." (Female, HIV, AH015)*

Most participants talked about experiencing stigma and discrimination from family and friends. The participants reported that they were ridiculed and harassed by friends. Three participants affected by leprosy reported that they were being shunned because of visible spotting or deformity and called "ugly." One participant living with schizophrenia described how his

friends saw him take his medicine and told everybody he was using “*drugs (narcotics)*”. The participants with diabetes reported how friends and family intervened while they were eating and either stopped them or shamed them for eating unhealthy. Some participants reported that they felt stigmatized because of interference, but most of them considered the act as caring and considerate and did not feel stigmatized.

The participants affected by HIV, leprosy, and schizophrenia particularly talked about how their family felt ashamed and embarrassed because of their disease. They described how their families were fearful of others knowing about their disease and tried to conceal it from others. The participants also reported about the exclusionary behavior from their family members. One participant with HIV talked about how people in his family separated all kitchen utensils used by him and disinfected his bedding and clothes. The participants with schizophrenia reported that they were excluded from family discussions or important decision making. One participant said,

*“I was never involved in any important occasion at my home. For instance, during my nephew’s wedding, I was not involved to make any decisions. They did not trust me.” (Male, Schizophrenia, SS004)*

The participants reported that they felt stigma at an individual level in the form of internalization and anticipation of stigma. They described the internalized stigma in the form of acceptance and self-endorsement of negative stereotypes, shame, self-blame, and self-deprecation. Some participants affected by leprosy and schizophrenia reported that they agreed with and accepted the cultural and religious beliefs that their condition was because of their “sin,” “curses,” and “bad spirits.” The participants also reported that they identified with negative stereotypes associated with health conditions. One man with schizophrenia said,

*“I felt really down to know that I was mentally ill and was worried if I would ever be able to get better. Everybody knows that having schizophrenia equal to being mentally ill.” (Male, Schizophrenia, SS009)*

Most participants affected by HIV, leprosy, and schizophrenia were also embarrassed for having the disease and feeling useless. Some participants living with HIV and diabetes reported that they blamed themselves for their condition. Those living with HIV blamed themselves for their past behavior that led them to have HIV. Two participants with diabetes talked about how they blamed their eating habits and lifestyle for their condition.

The participants also reported that they experienced anticipation and fear that they might experience negative stigmatizing attitudes from others. The participants who disclosed their health conditions expressed their

impending fear of stigma and discrimination in the future. People affected by HIV, leprosy, and schizophrenia talked about their fear of people distancing themselves from them or being excluded from social settings if their health conditions were disclosed. One participant with diabetes talked about how she was scared of being pitied or ridiculed for having the disease and people might start attributing the condition to their weight, eating habits, or lifestyle choices.

According to the participants’ responses, the consequences of stigma were inductively categorized into four distinct categories, that were social, behavioral, psychological, and medical consequences. Most participants talked about social consequences, which primarily constituted of strained or severed relationships with friends and family, damaged reputation and social standing in the community, and limited work opportunity and career progression. Most participants with schizophrenia talked about how their relationships with their family and friends deteriorated because of their condition. One participant with schizophrenia recounted how his wife left him. Another participant talked about how his fiancée cancelled their wedding and broke up with him after knowing his condition. Most participants affected by HIV, leprosy, and schizophrenia talked about how their social standing and reputation were tarnished because of their disease status. Many participants, including two with diabetes, reported that their disease condition limited their prospects of having jobs or hampered chances of career progression or promotion in their existing jobs.

The participants reported that they encountered behavioral consequences that included shutting themselves off from their friends, family, and the society by either concealing their health condition or isolating themselves from the society. They also reported psychological consequences, including stress, anxiety, severe depression, and suicidal ideation. People living with schizophrenia and HIV reported psychological consequences the most. Those with schizophrenia reported the most instances of suicidal ideation and attempts, and those with HIV described stress, anxiety, and depressive symptoms as a result of stigma.

Participants affected by HIV, leprosy, and schizophrenia talked about two specific medical consequences, such as avoiding medical care and disrupting treatment. People living with HIV and schizophrenia talked about how stigma experienced in the healthcare settings deterred them from visiting certain health facilities or had to transfer to another hospital or change their doctors. Those affected by leprosy and schizophrenia talked about how stigma disrupted their treatment and adherence to medication. They described how superstitious beliefs made them leave their medical treatment and seek

alternative treatment from faith healers, shamans, and witchdoctors. One participant affected by leprosy talked about how disrupting his treatment led to his disability,

*“I was taking medicine (for leprosy), but because we (my family and I) all thought I was cursed, I stopped my medicine and consulted a faith healer instead. Now, I have a deformity in my leg.” (Male, Leprosy, AK004)*

## Discussion

This study explored the experiences of stigma among people living with/affected by HIV, leprosy, schizophrenia, and diabetes in Indonesia. The experiences and consequences of stigma were similar, but such consequences were more severe among people with HIV, leprosy, and schizophrenia. Those with diabetes either experienced no or less severe stigma. The experiences of stigma were evident in all three socio-ecological levels in the Indonesian society. Enacted stigma was experienced in health care, employment, social interactions, and within families at structural and interpersonal levels, and felt stigma in the form of internalized and anticipated stigma was reported at an individual level. The incidences of human rights violations were evident. The social, behavioral, psychological, and medical consequences of stigma were identified.

Even though the health conditions were different in nature and etiology, the experiences and consequences of stigma were similar. This finding was consistent with the works of Rao,<sup>10</sup> and Van Brakel,<sup>48</sup> who emphasized that the experiences of stigma associated with them were mostly the same despite the different characteristics, attributions, and origins of diseases. Studies on stigma have also found that the severity and intensity of such experiences may differ in terms of disease condition even though the experiences of stigma are similar.<sup>22,49,50</sup> This finding was evident from the study findings, which showed that people with diabetes experienced either no or less severe form of stigma compared with those with the three other conditions. Their experiences were mostly limited to judgments and comments from people around them. Even then, some of the affected people did not perceive such behavior as stigmatizing; instead, they believed that this behavior was a supportive and caring gesture for the good of their own health. This might have to do with the normalization of diabetes in the Indonesian society because of its higher prevalence and wider existence, considering that many families have members living with the condition.<sup>40,41</sup> Pitaloka and Hseih,<sup>40</sup> reported that Javanese women with diabetes perceived their condition as a normal part of their daily lives and considered it to be an ordinary illness that was not severe. A study conducted in Central Java, Indonesia showed that diabetes is largely hereditary, and other people em-

pathized with those who had the condition, even though the public had a negative perception about diabetes as a terrifying disease without cure and blamed people with diabetes for their dietary habits and sedentary lifestyle.<sup>41</sup>

For people with HIV, leprosy, and schizophrenia, the experiences of stigma were more severe and damaging. As the world's most populous Muslim-majority country, Indonesia not only has Islamic traditions and practices, but also has deeply rooted superstitious traditions and practices embedded in the local culture that can exacerbate stigma of these three diseases.<sup>4,51,52</sup> Islamic law prohibits homosexuality, extramarital sex, and the drug use, which force stigma and human rights violations toward people living with HIV that belong to the vulnerable groups.<sup>51,53</sup> Leprosy in Indonesia is often considered a result of black magic, curse, or sinful deeds in impoverished communities where superstitious beliefs are prevalent.<sup>4</sup> In case of schizophrenia, medical treatment opportunities are limited in rural areas in Indonesia, and people often resort to age-old practices, such as *pasung* (shackling of people with schizophrenia to subdue them), which violate the human rights of those affected.<sup>39,54</sup> People also attribute schizophrenia to possession by evil spirits or God's punishment, and consider *pasung* as the only way to cure diseases by confining a person until he/she becomes free of evil spirits.<sup>54,55</sup> The stigmatization of these conditions is unfortunately driven by cultural traditions and norms, existing exclusionary policies and practices in healthcare and employment sectors,<sup>11,38,39</sup> and by societal actors - healthcare workers, friends, family, and neighbors,<sup>38,56</sup> which corroborate the findings of this study. Consistent with the study findings, the experiences of felt stigma through internalization and anticipation of stigma are further known to intensify self-stigmatization.<sup>3,29,38</sup> Lusli, *et al.*,<sup>3</sup> found that Indonesians with leprosy usually internalize the shame and endorsement of the negative stereotype of having this condition. The internalization of shame was also reported in a study conducted in Indonesia among people living with schizophrenia and other mental illnesses.<sup>38</sup> Culbert, *et al.*,<sup>29</sup> reported about the fear of stigma among prisoners with HIV in Indonesia, and this condition affects their decision to disclose their condition to others.

The consequences of stigma were similar to those reported from other studies on stigma globally, including social consequences (e.g., isolation and severed relationship),<sup>11,57</sup> behavioral consequences (such as nondisclosure or concealment),<sup>19,35</sup> psychological consequences (such as stress, anxiety, depression and suicidal ideation),<sup>6,58</sup> and medical consequences (such as delay or disruption of treatment).<sup>3,18,20,59</sup> Studies have indicated that such consequences have an impact on the overall quality of life of individuals.<sup>2,15,59</sup>

Furthermore, they undermine the public health response and cause a negative impact on their overall effectiveness.<sup>18,19,21</sup>

The findings of this study have several implications for public health research and practice in Indonesia. First, the prospects of stigma reduction response at different levels of the society are clear. Studies should focus on structural and interpersonal levels to minimize enacted stigma; efforts to changing exclusionary policy, practices, and social norms and raising awareness and knowledge to change public perception of the diseases can be effective. For felt stigma at an individual level, specific interventions, such as psychosocial support and peer counseling, may help. Second, the findings have highlighted the importance of understanding and respecting the living experiences, experiential knowledge, and rights of people with health conditions. The findings warrant a paradigm change from a traditional medical approach in which affected people are considered “patients” or “beneficiaries” to a human rights-based approach in which patients are recognized as equals and key stakeholders with rights and ability to make decisions on issues that affect their lives at every level of the society. Third, considering the similarity in the experiences and consequences of stigma under the four conditions, the strongest approach in effectively responding to health-related stigma in the society might involve the combination of these different stigmatized health conditions and their shared experiences, knowledge, and lessons learned. However, researchers should study the feasibility and prospects for such an integrated and common stigma reduction intervention. Fourth, while responding to health-related stigma, individual differences (e.g., comorbidity, disease severity, etc.) should be acknowledged. Other social inequalities and oppressions that shape a person’s experience of stigma, such as gender and poverty, should be considered. A further study is needed to identify the most important factor that intersects with health-related stigma, and to design interventions that address these different inequalities along with health-related stigma, to effectively reduce stigma. Fifth, the findings indicated an integral role of the government in forging an alliance with advocacy groups, civil society, and NGOs to replace exclusionary policies and practices and to fight superstitious customs and traditions. Further, the instances of human rights violations also warrant government intervention to ensure all individuals with diseases protected. Another role of the government can include leveraging interagency collaboration to tackle stigma by integrating and uniting response previously siloed into different diseases and disciplines.

This study also has some limitations. This study only presents a general outline of stigma experiences and

consequences, to streamline the scope of research findings, but this study does not delve deeper into individual differences that may affect the experience and severity of stigma, such as disease severity, duration of living with the disease, disability, comorbidity, poverty, gender, sexuality, and age. Furthermore, this the study only focuses on the negative experiences of stigma and exclusion, while positive experiences of coping, resilience, and inclusion despite stigma were excluded.

## Conclusion

People living with HIV, leprosy and schizophrenia still face stigma and its adverse impact on the different facets of the Indonesian society. Those with diabetes either perceive no or less severe stigma. Exclusionary policies and practices, subjugating social norms, superstitious beliefs, and shame, blame and fear from societal actors cause the negative experiences of stigma among affected persons. They experience the social, behavioral, psychological, and medical consequences of stigma. The findings suggest a need for changes in policies and practices to prevent exclusion and human rights violation of stigmatized people and to combine advocacy efforts and public health responses to different diseases in an integrative united front to end stigma.

## Abbreviations

HIV: Human Immunodeficiency Virus; LMICs: Low-and middle-Income Countries; NGOs: Non-Governmental Organizations; *BPJS*: *Badan Penyelenggara Jaminan Sosial* (Indonesian National Health Insurance)

## Ethics Approval and Consent to Participate

The study was approved by the Ethics Committee of Atma Jaya University (Approval ID: FR-UAJ-26-13/R0).

## Competing Interest

Author declares that there are no significant competing financial, professional, or personal interests that might have affected the performance or presentation of the work described in this manuscript.

## Availability of Data and Materials

The data that support the findings of this study are available upon reasonable request from the corresponding author [II]. The data are not publicly available as it contains information that could compromise the privacy of research participants.

## Authors’ Contribution

Sarju Sing Rai, Irwanto, Ruth M H Peters, Elena V Syurina & Marjolein B M Zweekhorst were involved in the design and conceptualization of the study; Sarju Sing Rai, Annisa Ika Putri & Altana Mikhakhanova were involved in data collection; Sarju Sing Rai, Irwanto, Ruth M H Peters, Elena V Syurina, Annisa Ika Putri & Altana Mikhakhanova were involved in data analysis, discussed the final results and con-

tributed to the final manuscript.

### Acknowledgment

We would like to acknowledge the support from local NGOs and their staff members – *Forum Komunikasi Difable Cirebon (FKDC)*, *Yayasan Cahaya Jiwa*, *Persatuan Jiwa Sehat*, *Lentera Anak Pelangi*, *Komunitas Peduli Skizofrenia Indonesia (KPSI)*. We would also like to extend our gratitude to the project associate Ms. Sari Lenggogeni, research assistants—Caryn Yachinta and Shella Kostan, and resource persons—Catherine Thomas and Edwin Sutanto from Atma Jaya Catholic University, Jakarta, Indonesia. This work was supported by funding from the Erasmus Mundus Joint Doctorate (EMJD) Fellowship-Trans Global Health Consortium [2013-0039] received by the first author (SSR) and from Leprosy Research Initiative (LRI) project number 706.18.20.LRI received by the co-authors (I & RMHP).

### Additional Information

Sarju Sing Rai<sup>1,2</sup>, Irwanto<sup>3\*</sup>, Ruth M H Peters<sup>1</sup>, Elena V Syurina<sup>1</sup>, Annisa Ika Putri<sup>1</sup>, Altana Mikhakhanova<sup>1</sup>, Denise Naniche<sup>2</sup>, Marjolein B M Zweckhorst<sup>1</sup>

<sup>1</sup>Athena Institute, Faculty of Science, Vrije University Amsterdam, Amsterdam, The Netherlands; <sup>2</sup>Barcelona Institute for Global Health (ISGlobal), University of Barcelona, Barcelona, Spain; <sup>3</sup>Department of Psychology, Atma Jaya Catholic University, Jakarta, Indonesia

### References

1. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*. 2015; 105(5): 813-21.
2. Holzemer WL, Human S, Arudo J, Rosa ME, Hamilton MJ, Corless I, et al. Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the Association of Nurses in AIDS Care*. 2009; 20(3): 161-8.
3. Lusli M, Zweckhorst MB, Miranda-Galarza B, Peters RM, Cummings S, Seda FS, et al. Dealing with stigma: experiences of persons affected by disabilities and leprosy. *BioMed Research International*. 2015; 2015: 261329.
4. Peters RM, Dadun, Lusli M, Miranda-Galarza B, van Brakel WH, Zweckhorst MB, et al. The meaning of leprosy and everyday experiences: an exploration in Cirebon, Indonesia. *Journal of Tropical Medicine*. 2013; 2013: 507034.
5. Knaak S, Mantler E, Szeto A. Mental illness-related stigma in health-care: barriers to access and care and evidence-based solutions. *Healthcare Management Forum*. 2017; 30(2): 111-6.
6. Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open*. 2015; 5(11): e005384.
7. Schabert J, Browne JL, Mosely K, Speight J. Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic. *Patient*. 2013; 6(1): 1-10.
8. Cataldo JK, Brodsky JL. Lung cancer stigma, anxiety, depression and symptom severity. *Oncology*. 2013; 85(1): 33-40.
9. Else-Quest NM, LoConte NK, Schiller JH, Hyde JS. Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology & Health*. 2009; 24(8): 949-64.
10. Rao PS. Study on differences and similarities in the concept and origin of leprosy stigma in relation to other health-related stigma. *Indian Journal of Leprosy*. 2010; 82(3): 117-21.
11. van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, et al. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Global Health Action*. 2012; 5.
12. Turan B, Hatcher AM, Weiser SD, Johnson MO, Rice WS, Turan JM. Framing mechanisms linking HIV-related stigma, adherence to treatment, and health outcomes. *American Journal of Public Health*. 2017; 107(6): 863-9.
13. Sermittirong S, Van Brakel WH. Stigma in leprosy: concepts, causes and determinants. *Leprosy Review*. 2014; 85(1): 36-47.
14. Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Services Research*. 2010; 10: 80.
15. Gredig D, Bartelsen-Raemy A. Diabetes-related stigma affects the quality of life of people living with diabetes mellitus in Switzerland: implications for healthcare providers. *Health & Social Care in the Community*. 2017; 25(5): 1620-33.
16. Corrigan PW, Rao D. On the self-stigma of mental illness: stages, disclosure, and strategies for change. *Canadian Journal of Psychiatry*. 2012; 57(8): 464-9.
17. Farley-Toombs C. The stigma of a psychiatric diagnosis: prevalence, implications and nursing interventions in clinical care settings. *Critical Care Nursing Clinics of North America*. 2012; 24(1): 149-56.
18. Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*. 2013; 16 (3 Suppl 2): 18640.
19. Kane JC, Elafros MA, Murray SM, Mitchell EMH, Augustinavicius JL, Causevic S, et al. A scoping review of health-related stigma outcomes for high-burden diseases in low- and middle-income countries. *BMC Medicine*. 2019; 17(1): 17.
20. Stangl AL, Earnshaw VA, Logie CH, van Brakel W, L CS, Barre I, et al. The health stigma and discrimination framework: a global, cross-cutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*. 2019; 17(1): 31.
21. Kemp CG, Jarrett BA, Kwon CS, Song L, Jette N, Sapag JC, et al. Implementation science and stigma reduction interventions in low- and middle-income countries: a systematic review. *BMC Medicine*. 2019; 17(1): 6.
22. Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D, et al. Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *Lancet*. 2016; 387(10023): 1123-32.
23. Institute for Health Metrics. GBD profile: Indonesia. IHME, University of Washington; 2010 [updated 2018 Feb 20].
24. Vos T, Barber RM, Bell B, Bertozzi-Villa A, Biryukov S, Bolliger I, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*. 2015; 386 (9995): 743-800.



25. The Joint United Nations Programme on HIV/AIDS. Indonesia 2017; 2018.
26. World Health Organization. Global leprosy update, 2017: Reducing the disease burden due to leprosy 2017 [updated 2018 Aug 24].
27. International Diabetes Federation. Prevalence of Diabetes in Indonesia 2017 [updated 2018 May 12]; 2017.
28. Indonesian Ministry of Health. Riset Kesehatan Dasar 2013 [updated 2014 Feb 15]; 2014.
29. Culbert GJ, Earnshaw VA, Wulanyani NM, Wegman MP, Waluyo A, Altice FL. Correlates and experiences of HIV stigma in prisoners living with HIV in Indonesia: a mixed-method analysis. *Journal of the Association of Nurses in AIDS Care*. 2015; 26(6): 743-57.
30. Nurfalih F, Yona S, Waluyo A. The relationship between HIV stigma and adherence to antiretroviral (ARV) drug therapy among women with HIV in Lampung, Indonesia. *Enfermería Clínica*; 2019.
31. Irmayati N, Yona S, Waluyo A. HIV-related stigma, knowledge about HIV, HIV risk behavior and HIV testing motivation among women in Lampung, Indonesia. *Enfermería Clínica*; 2019.
32. Sianturi EI, Perwitasari DA, Islam MA, Taxis K. The association between ethnicity, stigma, beliefs about medicines and adherence in people living with HIV in a rural area in Indonesia. *BMC Public Health*. 2019; 19(1): 55.
33. Victoryna F, Yona S, Waluyo A. The relationship between stigma, family acceptance, peer support and stress level among HIV-positive men who have sex with men (MSM) in Medan, North Sumatera, Indonesia. *Enfermería Clínica*; 2019.
34. Desyani NLJ, Waluyo A, Yona S. The relationship between stigma, religiosity, and the quality of life of HIV-positive MSM in Medan, Indonesia. *Enfermería Clínica*. 2019.
35. Peters RMH, Hofker ME, van Brakel WH, Marjolein ZBM, Seda FSSE, Irwanto I, et al. Narratives around concealment and agency for stigma-reduction: a study of women affected by leprosy in Cirebon District, Indonesia. *Disability, CBR & Inclusive Development*. 2014; 25(4).
36. Dadun D, Peters R, Lusli M, Miranda-Galarza B, van Brakel W, Zweckhorst 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. *Disability, CBR & Inclusive Development*. 2016; 27(3).
37. Lusli M, Peters R, van Brakel W, Zweckhorst M, Iancu S, Bunders J, et al. The impact of a rights-based counselling intervention to reduce stigma in people affected by leprosy in Indonesia. *PLoS Neglected Tropical Diseases*. 2016; 10(12): e0005088.
38. Subu MA. Persistent taboo understanding mental illness and stigma among Indonesian adults through grounded theory. *Université d'Ottawa/University of Ottawa*; 2015.
39. Human Rights Watch. Living in Hell: Abuses against People with Psychosocial Disabilities in Indonesia. USA: Human Rights Watch; March 2016 [updated 2016 Mar 16].
40. Pitaloka D, Hsieh E. Health as submission and social responsibilities: embodied experiences of Javanese women with Type II Diabetes. *Qualitative Health Research*. 2015; 25(8): 1155-65.
41. Pujilestari CU, Ng N, Hakimi M, Eriksson M. "It is not possible for me to have Diabetes"-community perceptions on Diabetes and its risk factors in Rural Purworejo District, Central Java, Indonesia. *Global Journal of Health Science*. 2014; 6(5): 204-18.
42. Scambler G. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*. 2004; 2(1): 29-46.
43. Weiss MG. Stigma and the social burden of neglected tropical diseases. *PLoS Neglected Tropical Diseases*. 2008; 2(5): e237.
44. Hatzenbuehler ML. Structural stigma: research evidence and implications for psychological science. *American Psychologist*. 2016; 71(8): 742-51.
45. Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: a systematic review and meta-analysis. *Social Science & Medicine*. 2010; 71(12): 2150-61.
46. Weber RP. Basic content analysis. 2nd ed. London: Sage Publications Ltd; 1990.
47. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*. 2006; 5(1): 80-92.
48. van Brakel WH, Cataldo J, Grover S, Kohrt BA, Nyblade L, Stockton M, et al. Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention. *BMC Medicine*. 2019; 17(1): 13.
49. Ebnetter DS, Latner JD. Stigmatizing attitudes differ across mental health disorders: a comparison of stigma across eating disorders, obesity, and major depressive disorder. *The Journal of Nervous and Mental Disease*. 2013; 201(4): 281-5.
50. Pachankis JE, Hatzenbuehler ML, Wang K, Burton CL, Crawford FW, Phelan JC, et al. The burden of stigma on health and well-being: a taxonomy of concealment, course, disruptiveness, aesthetics, origin, and peril across 93 stigmas. *Personality and Social Psychology Bulletin*. 2018; 44(4): 451-74.
51. Suhardjo K, Irwanto. Tumbuh bagai ilalang: perjalanan transformatif dalam diskriminasi dan kekesaran – studi deskriptif proses belajar transformatif waria dan gay pekerja seks di Jakarta. Jakarta: Universitas Katolik Indonesia Atma Jaya; 2018.
52. Triawan AdR. Jadi, kau tak merasa bersalah!? Studi kasus diskriminasi dan kekerasan terhadap LGBTI. Jakarta: Arus Pelangi; 2018.
53. Uddin AT. Religious freedom implications of sharia implementation in Aceh, Indonesia. *University of Saint Thomas Law Journal*. 2010; 603.
54. Laila NH, Mahkota R, Krianto T, Shivalli S. Perceptions about pasung (physical restraint and confinement) of schizophrenia patients: a qualitative study among family members and other key stakeholders in Bogor Regency, West Java Province, Indonesia 2017. *International Journal of Mental Health Systems*. 2018; 12: 35.
55. Irmansyah I, Prasetyo YA, Minas H. Human rights of persons with mental illness in Indonesia: more than legislation is needed. *International Journal of Mental Health Systems*. 2009; 3(1): 14.
56. Nurjannah I, FitzGerald M, Foster K. Patients' experiences of absconding from a psychiatric setting in Indonesia. *International Journal of Mental Health Nursing*. 2009; 18(5): 326-35.
57. Rose D, Willis R, Brohan E, Sartorius N, Villares C, Wahlbeck K, et al. Reported stigma and discrimination by people with a diagnosis of schizophrenia. *Epidemiology and Psychiatric Sciences*. 2011; 20(2):

- 193-204.
58. Herek GM, Saha S, Burack J. Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology*. 2013; 35(1): 41-54.
59. Lustosa AA, Nogueira LT, Pedrosa JI, Teles JB, Campelo V. The impact of leprosy on health-related quality of life. *Revista da Sociedade Brasileira de Medicina Tropical*. 2011; 44(5): 621-6.