

BMJ Open Stigma towards leprosy across seven life domains in Indonesia: a qualitative systematic review

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ABSTRACT

Objective To provide knowledge about the domains of life affected by stigma towards leprosy in Indonesia, including its manifestations, driving factors and consequences.

Design Qualitative systematic review.

Study selection PubMed, CINAHL, ProQuest, Taylor&Francis and Google Scholar were used to systematically search studies with qualitative component that were conducted in Indonesia and published from January 2000 to December 2020 in English or Indonesian language. The search was started in November 2020 and reran in April 2021. Quality assessment and thematic synthesis were applied.

Data extraction Of the 3184 studies, 37 manuscripts were reviewed. Information relating to study characteristics, stigma domains and types following Weiss Extended Scambler's Hidden Stress Model, stigma consequences and drivers were extracted.

Results Seven themes were identified. Three themes—community, domestic and intimate relationships—impacted private domains. Four themes—health, economics, education and public entitlements—concerned public domains. Studies mainly discussed enacted stigma rather than anticipated and internalised stigma. Ten stigma-driving factors were found, ranging from negative and positive concepts linked with the condition to aspects not related to the disease process. Five areas of consequences were shown. Impact on public rights, such as education, was very minimally explored, although school absence was often mentioned. Stigma manifestation, drivers and consequences in most public domains were least explored.

Conclusion Leprosy-affected persons in Indonesia experienced and felt stigma in private and public domains. Disease-related aspects, the culture and history of a particular region are linked with stigma manifestations. Approaches in one domain can affect another domain. More exploratory studies are needed in the endemic areas outside Java, especially considering both the lack of studies there and the unique culture of each Indonesian region.

INTRODUCTION

Though a treatment for leprosy has existed for decades,¹ life as a leprosy-affected person (LAP) has never been easy.² A strong stigma is attached to leprosy. Studies have shown that the life burden of affected persons is

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Studies written in both English and Indonesian are included to provide richer information about the Indonesian context and to complement previous reviews.
- ⇒ Findings were derived from various sources including scholarly journal articles and academic theses.
- ⇒ In textual analysis of qualitative studies, differences in meaning with the original author of the article are possible, although this risk was minimised by the fact that all researchers were Indonesian and because an attempt to reconcile discrepancies was made.

greatly influenced by stigma rather than the disease itself. Stigma affects not only people infected but also those affiliated with them.³ This is due to perceptions of leprosy as a contagious disease, a consequence for violation of moral or divine instruction⁴ and a debilitating disease marked by paralysis.⁵ These concepts still exist. Therefore, LAP's experiences of rejection, exclusion and the inability to disclose their condition can be found in recent literature,^{4 6–9} including in Indonesia.^{8 9}

In Indonesia, leprosy has a long history and remains a burden. For centuries, leprosy has affected all five of Indonesia's big islands.¹⁰ Although significant improvements in leprosy treatment in Indonesia have caused a gradual decline in cases, the decline in the number of LAPs has been slow over the last decade.¹¹ According to the latest report, Indonesia has the third highest number of leprosy cases globally, after India and Brazil.¹² Ten out of 32 Indonesian provinces and 142 districts/cities have not yet reached elimination.^{11 13} One cause for this is stigma and discrimination.¹³

Knowledge of stigma towards LAPs in the context of Indonesia is needed. Jones *et al* and Yang *et al* emphasise that stigma can be understood through examining norms surrounding what is disliked and unwanted in the local social setting.^{14 15} Indonesia is

culturally rich, as reflected in its 300 ethnic groups spread across 17504 islands and 32 provinces.¹⁶ Because the spread of leprosy is not centralised in a specific part of the country, there is likely variation pertaining to leprosy-related stigma throughout the country. Reviews on this topic were difficult to find, particularly in the international literature.⁸ In addition, recent reviews in the area of stigma and leprosy did not include Indonesian language studies, and appeared to generalise findings from different contexts, mainly from English-language literature.^{3 17} This review aims to fill that knowledge gap. The study identified, synthesised and discussed qualitative literature in the field of leprosy in Indonesia in order to provide knowledge about the domains of life affected by stigma towards leprosy-affected people in Indonesia, including stigma manifestations in each domain, driving factors and consequences.

METHODS

Literature search

Eligibility criteria

Inclusion criteria were qualitative studies and mixed-method studies with a qualitative component conducted in Indonesia and published in Indonesian and English. Only studies using primary data, and in which a full-text online copy was available, were incorporated. Publication types included were peer-reviewed scholarly articles from national and international journals and grey literature (ie, academic theses or dissertations and manuscripts residing in university repositories in Indonesia), published within the past 20 years (2000–2020).

Search strategy

This search was guided by a PICO-formulated research question: ‘What are the leprosy-affected persons’ (population) domains of life affected by stigma, including stigma manifestations, driving factors and consequences (interest) in Indonesia (context)?’ This review complies with Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline.¹⁸ Studies were searched in PubMed, CINAHL, Taylor and Francis, ProQuest Databases and Google Scholar (see online supplemental material 1, Syntaxes for search). The use of Google Scholar complemented literature findings, since many local studies, written in Indonesian, were absent from other databases. Google Scholar is also connected with a large amount of grey literature from local universities’ repositories and local peer-reviewed journals.

Study selection

First, titles and abstracts of retrieved literature were screened to remove duplicates. Studies not in line with eligibility criteria were removed. Next, study quality was appraised using the Critical Appraisal Skills Programme (CASP) tool for qualitative research.¹⁹ CASP consists of 10 questions which discusses three broad issues in the qualitative study: results’ validity, quality and usefulness. Each

question comprises three answers, for which researchers used a scoring system: 1 for ‘yes’ and 0 for ‘no’ or ‘can’t tell’. In the table presentation (see online supplemental material 2, CASP score for the reviewed studies), ‘can’t tell’ is distinguished from ‘no’. Studies not addressing at least six criteria of CASP were not included in synthesis. Discrepancies between researchers were resolved through discussion.

Data extraction and analysis

Extraction and synthesis of the data were conducted. The following characteristics were extracted: study design and method, study perspective, number of participants, age range and study location. Extraction also included variables reflecting the review domains: type of stigma (internalised, anticipated or enacted) following Weiss’s extended scambler’s hidden stress model,²⁰ setting of stigma, consequences of stigma and drivers of stigma. Thematic synthesis was used to analyse these data.²¹ The first step was free line-by-line coding of text, guided by aforementioned review domains. Then, organisation of codes under each review domain was conducted. Codes were grouped into descriptive themes. Finally, analytical themes were generated to emphasise experience in each stigma-affected domain by reviewing findings under each setting affected. Literature was read repeatedly to ensure all concepts needed to answer research objective were mapped. Each step was done manually by YMM, then reviewed by ER and ATD. Paper, pen and Microsoft Excel were used in the process. Final descriptive and analytical themes derived from review were discussed and agreed upon between reviewers (YMM and ER). In addition, a coverage analysis was conducted to search knowledge gaps in the affected life domains.

Patient and public involvement

Patient and public involvement was not applicable, as it was not appropriate or possible to involve patients or the public in the design, conduct, reporting, or dissemination plans for a review study.

RESULTS

Search results

The literature finding (figure 1) resulted in 3184 studies, of which 2375 were left following removal of duplicates. From screening of titles and abstracts, 2088 studies were excluded. A full-text assessment for eligibility was conducted for 287 articles. Remaining articles for CASP appraisal included 47 total studies, including four eligible articles from serendipitous findings. After CASP appraisal (see online supplemental material 2), 37 studies remained for synthesis.

Description of the included studies

The majority of the 37 studies (table 1) had been published in the past 5 years, from 2015 to 2020 (n=28). Most were qualitative (n=34). Three were mixed methods.

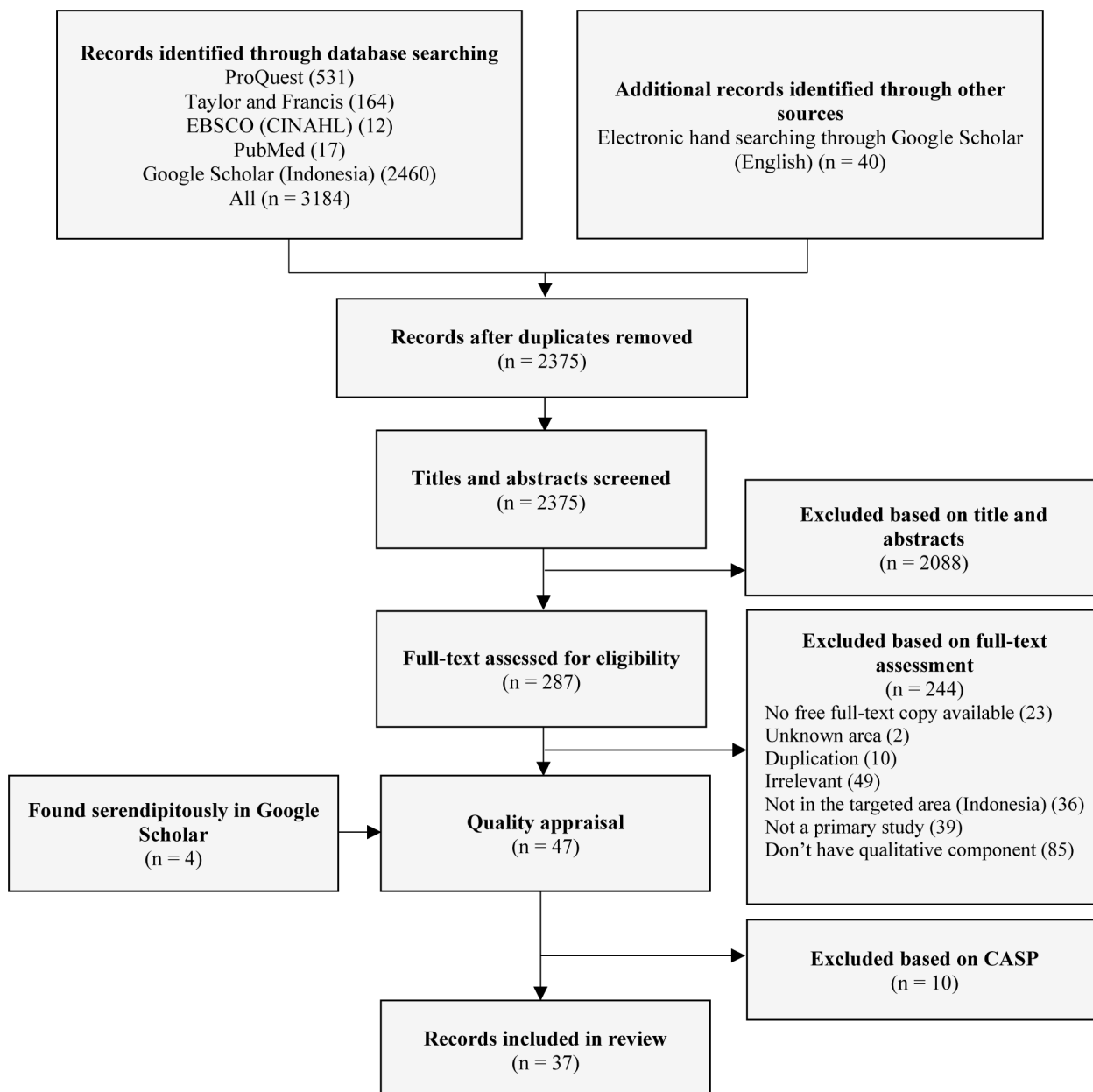


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram depicting the study selection process.

Only a few (n=17) clearly stated the design used. Phenomenology was used most often (n=9). Others were case studies (n=6), comparative ethnographies (n=1) and life history (n=1), respectively. The majority took place in Java Island (n=29). A limited number of studies were conducted from provinces outside Java, that is, South Sulawesi (n=5) with one study each from North Maluku, North Sumatera and West Papua provinces. Some studies did not provide detailed information about frequency of data collection, yet at least 560 interviews and 27 focus groups were identified from the reviewed literature. Twenty-one studies were published in Indonesian and 16 in English. Twenty-six were journal articles and 11 studies were academic theses.

Synthesis

Domains of life penetrated by stigma manifestations, drivers and consequences towards LAP in Indonesia were synthesised (table 2). The seven impacted domains were 'community', 'domestic', 'intimate relationship', 'health', 'economic', 'education' and 'public entitlements'. Seven themes were developed to explain stigma manifestations, drivers and consequences in each domain. The description of stigma manifestations (see online supplemental material 3, Description of stigma manifestations towards LAPs in Indonesia), 10 categories of stigma drivers on LAP in Indonesia (see online supplemental material 4, Description of stigma drivers towards LAPs in Indonesia) and 5 areas of stigma consequences were also elaborated

**Table 1** Description of studies included in the review

Research (first author, year)	Province	City/district	Study design, type	Data collection method(s)	Study perspective(s)	Age criteria of LAP included in the research
Bana, IA, 2014 ²⁹	East Java	Mojokerto	Life history, qualitative	Interviews	LAP	Adult
Arisal, 2020 ⁴³	South Sulawesi	Makassar	Design not stated, qualitative	Interviews, observation and documentation	LAP, family and community	Adolescent
Armaijn, 2019 ⁴⁴	North Maluku	Ternate	Design not stated, qualitative	Interviews	LAP	Adult
Aulia, 2019 ⁵⁵	East Java	Mojokerto	Design not stated, qualitative	Interviews and observation	LAP and health worker	Age not clearly addressed, possibly adult
Dadun, 2016 ³⁰	West Java	Cirebon	Design not stated, qualitative	Interviews and focus group	LAP, family, community, religious leader, health worker, social and business worker	Age not clearly addressed, possibly adult
Dary, 2017 ²⁴	Central Java	Jepara	Phenomenology, qualitative	Interviews	LAP and health worker	Adult, adolescent
Fajar, 2002 ⁴⁵	East Java	Gresik	Design not stated, mixed methods	Interviews	LAP	Adult
Hidayat, 2020 ⁴⁷	East Java	Sumenep	Phenomenology, qualitative	Interviews	Community	Adult
Huda, 2015 ⁴⁶	East Java	Sampang	Design not stated, qualitative	Interviews and observation	LAP, community and health worker	Adult
Indow, 2019 ⁵²	West Papua	Manokwari	Case study, qualitative	Interviews	LAP	Adult
Jatimi, 2020 ⁵⁴	East Java	Sumenep	Phenomenology, qualitative	Interviews	LAP	Adult
Jufriyanto, 2020 ²⁵	East Java	Pamekasan	Phenomenology, qualitative	Interviews	LAP	Adult
Kusharnanto, 2013 ³¹	Central Java	Blora	Design not stated, qualitative	Interviews, observation and documentation	LAP	Adult
Lusli, 2015 ²	West Java	Cirebon	Design not stated, qualitative	Interviews and focus groups	LAP	Age not clearly addressed, possibly adult
Lusli, 2016 ³³	West Java	Cirebon	Design not stated, mixed methods	Interviews at baseline and post	LAP	Age not clearly addressed, possibly adult
Lusli, 2017 ³²	West Java	Cirebon	Design not stated, qualitative	Interviews and focus group	LAP, family (caregiver) and counsellors	Age not clearly addressed, possibly adult
Marbaitis, 2012 ⁴⁹	East Java	Gresik	Case study, qualitative	Interviews and observation	LAP and family	Adult
Nainggolan, 2017 ³⁴	Banten	Tangerang	Case study, qualitative	Interviews and documentation	LAP, community, health worker and social worker	Adult
Najmuddin, 2013 ⁵⁰	South Sulawesi	Makassar	Phenomenology, qualitative	Interviews	LAP	Age not clearly addressed, possibly adult
Peters, 2013 ⁸	West Java	Cirebon	Design not stated, qualitative	Interviews and focus group	LAP, family, community, religious leader and health worker	Adult, child
Peters, 2014 ⁹	West Java	Cirebon	Design not stated, qualitative	Interviews	LAP	Adult
Peters, 2016 ³⁵	West Java	Cirebon	Design not stated, qualitative	Interviews	LAP	Adult
Pribadi, 2018 ³⁶	East Java	Pasuruan	Case study, qualitative	Interviews, observation and documentation	LAP, family and community	Adult
Rai, 2020 ⁵³	West Java	Cirebon	Design not stated, mixed methods	Interviews	LAP	Adolescent, adult
Rai, 2020 ³⁷	West Java	Cirebon	Design not stated, qualitative	Interviews	LAP	Adolescent, adult
Romadhon, 2020 ³⁸	East Java	Sampang and Mojokerto	Comparative ethnographic, qualitative	Interviews and observation	LAP, family, community and health worker	Age not clearly addressed, possibly adult
Saing, 2016 ³⁹	South Sulawesi	Palopo	Design not stated, qualitative	Interviews and observation	LAP, community, health worker and government worker	Age not clearly addressed, possibly adult
Sandi, 2018 ²⁷	East Java	Ngawi	Phenomenology, qualitative	Interviews	LAP	Adult

Continued

Table 1 Continued

Research (first author, year)	Province	City/district	Study design, type	Data collection method(s)	Study perspective(s)	Age criteria of LAP included in the research
Schuller, 2010 ⁴⁰	South Sulawesi	Gowa and Maros	Design not stated, qualitative	Interviews and focus group	LAP, community and religious leader	Adult
Siregar, 2018 ²³	West Java	Depok	Phenomenology, qualitative	Interviews and observation	Family	Adult
Sodik, 2016 ⁴¹	East Java	Trenggalek	Design not stated, qualitative	Interviews and observation	LAP, family, community and organisation (coworker)	Adult
Susanto, 2017 ⁴⁸	East Java	Jember	Phenomenology, qualitative	Interviews	LAP	Adult
Tarigan, 2019 ⁵¹	North Sumatera	Karo	Design not stated, qualitative	Interviews, observation and documentation	LAP	Adult
Verayanti, 2016 ²²	South Sulawesi	Makassar	Case study, qualitative	Interviews, observation and documentation	LAP, family, community and health worker	Adolescent, adult
Wahyuni, 2017 ²⁸	East Java	Sumberglagah	Case study, qualitative	Interviews	LAP	Adult
Widodo, 2018 ⁴²	East Java	Nganjuk	Design not stated, qualitative	Interviews, observation and documentation	LAP, community and health worker	Adult
Yudanagara, 2020 ²⁶	Central Java	Jepara	Phenomenology, qualitative	Interviews	LAP	Adult

LAP, leprosy-affected person.

(see online supplemental material 5, Description of stigma consequences on LAPs in Indonesia). Next, findings were explained narratively to enable comprehension of the effect of stigma in each domain of the LAP's life. In each domain, stigma manifestation and driving factors were addressed first, followed by consequences.

Stigma in private domains

Community: difficult relationship and alterations in social standing
LAPs in Indonesia face many difficulties in building a satisfactory relationship with their communities, indicating an effect on their social standing. Issues were experienced with friends,^{22 23} neighbours^{8 24–26} or others in the hometown.²⁴ These issues were not limited to adults.^{27 28} Enacted,^{2 8 9 23–48} anticipated^{2 8 9 24 26–28 35 37 44 45 49 50} and internalised stigma^{2 8 9 22 23 26–28 33 36 40 43 46 51} were linked to this.

Stigma manifestation and driving factors at the community level

Forms of enacted community stigma were avoidance meeting,^{2 28 29 32 35 45 50} visiting or hosting,^{8 26 41 46} greeting,²⁷ talking with,^{42 44 47 50} being physically near,^{23 29 33 37 47} having contact with^{8 41 42 52} and even looking at LAPs.²⁶ Rejection and hesitation toward LAPs were experienced with an unreturned smile and hand offer,^{2 8 27} an insincere handshake gesture,²⁶ a recitation of prayer over the food made by the LAP,⁴⁶ an unwillingness to live in the same neighbourhood^{24 34 38 46} and to be immersed in the same body of water.²⁸ Exclusions were mentioned.^{22 27 28 33 41 43 45 50} These included restrictions on community participation² and an absence of invitations to gatherings.^{28 40 42} LAPs also experienced expulsion,⁴⁷ suggestions to leave the community,²⁴ gossiping,^{28 30 32} verbal mockery^{22 27 28 30 31 37 45 48 51}

and non-verbal insults such as people covering their noses and spitting when passing the LAP's house.²⁶

Drivers of these enacted stigma were associated with physical factors,^{2 22 25 28 29 37 39 47 51–53} fear of contagion,^{25 27 42 46 52} religious or mystical reasons,^{26 37 41 46} local connotations of the word 'leprosy' labelling the disease as fatal, ugly, insulting or worthy of ignoring,^{40 45} inhabiting the residential area known for leprosy,³⁸ health worker home visits^{8 33} and inadequate social rehabilitation following release from treatment.³⁴ Conditions unrelated to leprosy, such as poor financial conditions,⁵³ being a woman, or belonging to an ethnic or religious minority, were also linked to unfair treatment.⁴³

The anticipated stigma among LAPs in the community domain were fear of avoidance,^{2 8 9 37 44 49} rejection,^{28 32 44} exclusion,^{37 44} insult,^{2 8 9} rumours⁹ and irritating others by initiating conversation.²⁶ Limited studies mentioned reasons for this anticipated stigma, that is, changes in physical feature,^{28 33} heredity,⁵⁰ beliefs that leprosy is contagious, a curse, a spell, a trial or a sin,⁵⁰ and negative past experiences in the community.²⁶

Internalised stigma include self-labelling, self-deprecation and shame. LAPs perceived themselves as disgusting,²⁸ dirty,³³ dangerous,³³ contagious,²⁸ objects of charity,⁴⁰ incurable,⁸ different⁵⁴ and inferior.⁴³ They perceived that they could not expect friendliness⁸ and mentioned being an enemy of the community.⁴⁶ LAPs in this stage could feel others' fear of them,²⁶ felt awkward gathering with others,⁵¹ and viewed self-retraction from the community as reasonable.⁹ Physical appearance was the most repeated reason for internalised stigma.^{22 33 36} Others included beliefs about disease transmission⁹ and witnessing a healthcare worker's (HCW) avoidance.⁸

**Table 2** Domains, manifestations, consequences and drivers of stigma towards LAPs in Indonesia

Research (first author, year)	Domains where stigma impacts*	Stigma manifestations	Stigma consequences on LAPs	Stigma drivers
Al, 2014 ²⁹	C, D, IR, H and PE	Enacted, anticipated and internalised	Social behaviour, psychological	Fear of contagion and physical factors
Arisal, 2020 ⁴³	C, D, IR and EC	Enacted and internalised	Social behaviour, psychological and occupational/financial	Social background and inability to perform gender role
Armajijn, 2019 ⁴⁴	C, D, IR, EC, ED and PE	Enacted, anticipated and internalised	Social behavioural, psychological, health	Physical factors and fear of contagion
Aulia, 2019 ⁵⁵	H	Enacted and internalised	Psychological, health	Fear of contagion, social and health assistance factors, physical factors, and religious and/or mystical reason
Dadun, 2016 ³⁰	EC, IR and H	Enacted, anticipated and internalised	Social behaviour, psychological, occupational/financial	Social background, fear of contagion, physical factors, and religious and/or mystical reason
Dary, 2017 ²⁴	C, D and IR	Enacted and anticipated	Social behaviour, psychological	Religious and/or mystical reason, fear of contagion and physical factors
Fajar, 2002 ⁴⁵	D, IR, C, ED and PE	Enacted and anticipated	Health	Local connotation for LAP, religious and/or mystical reason, physical factors, and social and health assistance factors
Hidayat, 2020 ⁴⁷	C	Enacted	No consequence mentioned	Fear of contagion, physical factors, hereditary factor, and religious and/or mystical reason
Huda, 2015 ⁴⁶	C and IR	Enacted and internalised	No consequence mentioned	Hereditary factor, beliefs around prognosis, fear of contagion, and religious and/or mystical reason
Indow, 2019 ⁵²	D and C	Enacted, anticipated and internalised	Psychological	Physical factors and fear of contagion
Jatimi, 2020 ⁵⁴	D and C	Enacted, internalised	Social behaviour, psychological	Inability to perform social role and physical factors
Jufriyanto, 2020 ²⁵	C and D	Enacted	No consequence mentioned	Fear of contagion and physical factors
Kusharnanto, 2013 ³¹	C, EC ED and H	Enacted, anticipated and internalised	Social behaviour, psychological, occupational/financial and education	Physical factors and fear of contagion
Lusli, 2015 ²	C, D EC and H	Enacted, anticipated and internalised	Social behaviour, health, psychological, occupational/financial	Physical factors and fear of contagion
Lusli, 2016 ³³	C, D, IR, EC and ED	Enacted, anticipated and internalised	Social behaviour, psychological, health, occupational/financial	Physical factors, incapability to perform social role, and social and health assistance factors
Lusli, 2017 ³²	D, IR, EC and ED	Enacted and internalised	Social behaviour, psychological health, occupational/financial, education	Hereditary factor, religious and/or mystical reason, beliefs around prognosis, inability to perform social role, fear of contagion and social background
Marbaits, 2012 ⁴⁹	C and H	Anticipated and internalised	Social behaviour, psychological, health	social and health assistance factors, hereditary factor and beliefs around prognosis
Nainggolan, 2017 ³⁴	C, D, IR, EC and H	Enacted and internalised	Social behaviour, occupational/financial, psychological	Religious and/or mystical reason, physical factors and social and health assistance factors
Najmuddin, 2013 ⁵⁰	C, H and EC	Anticipated and internalised	Psychological, health, occupational/financial	Physical factors, Inability to perform social role, local connotation for LAP, hereditary factor, fear of contagion, religious and/or mystical reason, beliefs around prognosis
Peters, 2013 ⁸	D, C, EC, ED and H	Enacted, anticipated and Internalised	Social behaviour, psychological occupational/financial, health, education	Physical factors, social and health assistance factors and fear of contagion
Peters, 2014 ⁹	D, C and EC	Enacted, anticipated and internalised	Social behaviour, psychological, health	Physical factors and fear of contagion

Continued

Table 2 Continued

Research (first author, year)	Domains where stigma impacts*	Stigma manifestations	Stigma consequences on LAPs	Stigma drivers
Peters, 2016 ³⁵	C, D and EC	Enacted and anticipated	Social behaviour, psychological, occupational/financial	Physical factors
Pribadi, 2018 ³⁶	C, EC and PE	Enacted and internalised	Social behaviour, psychological, health	Physical factors
Rai, 2020 ⁵³	C and H	Enacted and internalised	Psychological	Religious and/or mystical reason, physical factors and social background
Rai, 2020 ³⁷	C, D and H	Enacted, anticipated and internalised	Social behaviour, health	Religious and/or mystical reason, fear of contagion and physical factors
Romadhon, 2020 ³⁸	C, EC and H	Enacted, anticipated and internalised	Social behaviour, health	Residential area
Saing, 2016 ³⁹	C	Enacted	No consequence mentioned	Physical factors, Fear of contagion, Beliefs around prognosis
Sandi, 2018 ²⁷	D, C, IR and H	Enacted, anticipated and internalised	Social behaviour, psychological, health	Physical factors, Fear of contagion
Schuller, 2010 ⁴⁰	C, D and IR	Enacted, anticipated and internalised	Social behaviour, psychological	Inability to perform social role, physical factors, religious and/or mystical reason, hereditary factor and local connotation for LAP
Siregar, 2018 ²³	D, C, EC and H	Enacted, anticipated and internalised	Social behaviour, psychological, occupational/financial, health	Fear of contagion
Sodik, 2016 ⁴¹	C	Enacted	Social behaviour, psychological	Religious and/or mystical reason and fear of contagion
Susanto, 2017 ⁴⁸	C	Enacted	Social behaviour	No drivers mentioned
Tarigan, 2019 ⁵¹	C, D, EC, H and ED	Enacted, anticipated and internalised	Social behaviour, psychological, occupational/financial, health, education	Physical factors and inability to perform social role
Verayanti, 2016 ²²	D, C and EC	Enacted and internalised	Social behaviour, psychological, occupational/financial	Local connotation for LAP, and physical factors
Wahyuni, 2017 ²⁸	C, D, IR, EC, H, PE and ED	Enacted, anticipated and internalised	Social behaviour, psychological, health, education	Physical factors, fear of contagion and residential area
Widodo, 2018 ⁴²	C and EC	Enacted	Social behaviour, occupational/financial	Fear of contagion and beliefs around prognosis
Yudanagara, 2020 ²⁶	C, D, EC and PE	Enacted, anticipated and internalised	Social behaviour, psychological, occupational/financial	Religious and/or mystical reason, physical factors and fear of contagion

*Community (C) denotes relationship with neighbours, friends and community members; domestic (D) denotes impacts in household affairs, family roles, relations with family member and relatives; intimate relationship (IR) indicates issues around spouse or romantic relationship; health (H) indicates healthcare worker approach, ambience in health facility and effect of disfigurement for healthcare; economic (EC) denotes income-related aspects and coworker relationship; education (ED) indicates responses from school society; public entitlement (PE) denotes access to and acceptance in public transport, market, kiosk and worship place. LAP, leprosy-affected person.

Stigma consequences in the community level

Stigma in the community domain impacted LAP's mental and physical health, social behaviour and financial status. LAPs experienced sadness,^{2 22 26 27 33} stress,^{26 49} hurt,^{22 26 31} self-blame,³³ loneliness,^{24 33} irritation,³⁶ feelings of being unsafe,⁴³ inability to imagine a future,³³ loss of passions³⁰ and suicidal thoughts and actions.^{9 26 33 49} These effects could linger at length.⁸ At the social behavioural level, LAPs faced difficulty making friends,^{2 26} and practicing local greetings or gestures.^{2 42} They isolated

themselves,^{2 8 22 24 27 28 33 36 37 48 49} felt reluctant to share emotional burdens with others² or to become close with new people.²⁶ They lacked motivation for social activities,⁸ became passive at home,² reduced activities outside^{8 27 51 53} or if they did venture out, concealed this from family.³⁵ If LAPs participated in activities outside, they hid deformities by concealing hands under armpits and wearing long pants, long sleeves, hijabs or hats.^{28 44} Due to stigma, LAPs' social standing and reputation declined in the community.³⁷ LAPs might choose to leave or have family suggest

leaving the neighbourhood and moving to another community in search of acceptance.^{22 31 34} Stigma in the community domain also endangered physical health. LAPs concealed their disease status,^{2 9 23 37 45 50} even from family members,³⁵ denied symptoms,^{45 49} lied about the disease,^{23 44} self-mutilated,⁹ rejected HCWs' home visits,³³ hesitated or secretly sought treatment,^{44 45} and feared going to the health centre.⁴⁵

Domestic: devaluation of status, roles and control over own body

Diminished social status of LAPs occurred within the family. This manifested in enacted,^{2 8 9 22 23 25–29 32–34 37 40 44 45 54} anticipated^{8 9 23 29 33 40 44 52} and internalised stigma.^{2 28 32 40 44 51 54}

Stigma manifestation and driving factors at the domestic level

Studies noted feelings of embarrassment at having LAPs as family members and attempts to conceal their diagnoses.^{22 37 45} LAPs also received unpleasant treatment from their children.^{25 28 45} Children hesitated to perform the 'Salim' tradition (a form of respectful greeting to parents or older people in some regions of Indonesia) to affected parents,²⁸ requested parent hide when peers visited the house,²⁸ and stopped attending school because of shame over the affected parents.⁴⁵ In the house, LAP experienced negative comments and exclusion from household roles^{2 33 40} and were not allowed to touch family members.^{9 32 33 44} Unwelcoming gestures⁴⁵ even after LAPs were declared cured,^{26 34} feelings that family members feared talking with LAPs,²³ avoidance from extended family members,^{23 24} siblings,^{27 29} and in-laws²⁴ also occurred. In times of illness, an affected elderly felt no family members was willing to visit.⁸ Other manifestations were exclusion from family events,⁴⁰ expulsion from home,⁴⁵ and forms of separation illustrating reduced bodily autonomy such as separate cutlery, beds, clothes^{40 45} and houses,^{45 54} demands that LAPs to clean their belongings,^{40 45} and restricting LAPs from bathing.²⁷ Enacted stigma in the domestic domain was driven by LAP's physical appearance,^{24 28} long-held local connotations about LAPs,⁴⁵ concern over blood transmission,²³ ineffective post-treatment rehabilitation for LAPs and their families,^{34 45} and community beliefs that leprosy is a curse or sin²⁴ in turn inducing familial fear of reputational damage due to the presence of the LAP.⁴⁵

Anticipated stigma in the domestic domain manifested in fear of avoidance,^{23 44} exclusion,⁴⁴ negative comments,^{25 2} and other reactions.⁵² Concerns over inability to perform gender roles,³³ restrictions on touching children,⁹ and humiliation faced by family members were mentioned.⁴⁰ Almost no studies discussed driving factors for anticipated stigma in the domestic domain. One reason may be beliefs that leprosy is an incurable curse.⁴⁰

Devaluation of domestic roles and status were also reflected in internalised stigma. LAPs expressed shame with family members,²⁸ self-doubt when carry out family responsibilities³² for example, breastfeeding, touching children, cooking, or meeting a financial need.⁹ The literature also described LAP's seeing themselves as burdens

or trouble-makers,^{2 40 49 54} irresponsible breadwinners,⁵¹ and sources of transmission to family.^{9 44} Self-stigma was also shown in withdrawal from family and separation of eating utensils and laundry.⁴⁴ Fear of transmission,⁴⁴ failure to enact gender roles,^{28 40 54} and changes to appearance²⁸ were found to promote these behaviours.

Stigma consequences at the domestic level

Stigma in the domestic domain caused mental, social, and health impacts. Mentally, LAPs experienced sadness,^{8 26 32 34 51 52} frustration,^{26 34} disappointment,^{26 51} anger,³⁴ despair,³² loneliness,^{24 32} hopelessness,³⁴ guilt,^{40 54} and shame.⁵¹ At the social-behaviour level, 'distance' from family members was felt.³² LAPs isolated themselves from family,³⁴ chose not to communicate with them,^{2 23} or moved elsewhere.^{22 26 34} Stigma at this domain also brought health risks. LAPs concealed and lied about the disease to the family,^{33 44 52} not routinely taking medicine,⁴⁵ while neglecting personal hygiene.²⁷

Intimate relationship: trouble in having a life partner

Enacted,^{24 28 29 32 34 40 43–46} anticipated,^{30 33} and internalised stigma^{28 40} affected LAP's chances at romantic partnership, marriage, or preservation of existing marriage. Stigma may also impact LAP's family members' ability to have a life partner.⁴⁰

Stigma manifestation and driving factors T the intimate relationship level

In enacted form, studies noted family rejections of LAP's romantic relationships. Disapproval at marriage to an affected person,³⁴ a non-affected person,²⁹ or a person who has a family history of leprosy^{40 45 46} were mentioned. Findings revealed one cancellation of a planned marriage^{34 46} even after an official declaration that leprosy had been 'cured'³⁴ and one romantic relationship that was ended.³⁴ Married LAPs reported avoidance from a spouse,^{24 32} family members' urgings to divorce after diagnoses,^{33 45} and an expulsion from parent-in-law.⁴⁵ Reasons for this behaviour ranged from beliefs that leprosy is inherited^{40 46 47 50} or a curse,²⁴ to local connotations of leprosy as ugly or insulting disease,⁴⁵ to fear of harming familial reputation,^{45 46} effort to protect the family name,⁴⁶ and concern over contagiousness.^{24 29} One study noted that women might face particular problems finding a life partner, due to a stereotype that affected women cannot serve their husband and household optimally.⁴³

There is a lack of research discussing anticipated and internalised stigma within this domain. Fears of partners leaving or avoiding LAP's were forms of anticipated stigma.^{30 33} Internalised stigma manifested in feelings of shame around building relationships⁴⁰ or in fears of being unwanted in marriage.²⁸ Physical appearance was reported as the cause for these fears.^{28 40}

Stigma consequences at the intimate relationship level

Issues in intimate relationships resulted in physical, mental, and social risks. Studies mentioned negative emotions such as sadness,³² stress,³⁴ despair,²⁷ feelings

of being stuck or unfulfilled,³⁴ and suicidal thinking.⁴⁴ In social life, changes occurred in relationships among family members, leading LAP's to leave their households.³⁴ Risks in health may occur when LAPs hide their disease from a partner.³³

Stigma in public domains

Health: challenges in healthcare-seeking and disfigurement effect

Stigma in the health domain was demonstrated by the behaviour of people at health facilities and by LAP's responses to disease development. Enacted,^{8 23 27 28 30 37 55} anticipated,³⁸ and internalised stigma^{31 49 51 55} were found.

Stigma manifestation and its driving factors in the health level

Enacted stigma was demonstrated among HCWs who refrained from handshaking or physical contact with LAPs,^{8 28 30 37} delayed health service,^{27 30} hesitated,⁵⁵ or declined to perform treatment,^{27 55} and delivered hurtful words.⁵⁵ LAPs experienced staring from visitors at the health facility as well as HCW stigma.²³ Furthermore, prioritising of men over women in health settings occurred.⁴³ Physical appearance,²⁸ concern about transmission,^{23 30 55} general insensitivity within the healthcare centre,⁵⁵ and a belief in men's greater competence and capability⁴³ were all cited as driving factors in enacted stigma. The concern of HCW about negative reactions from family members when handling LAP may also explain why their approach was perceived unpleasant by LAP.³⁰

An anticipated form of stigma in the health domain was fear of being associated with leprosy if visiting a free health event in the local area.³⁸ This fear was likely facilitated by a communal desire to reject a stereotype surrounding their territory (Mandangin Island), where the free health clinic was held. For generations, the area has been known to many as an 'island for leprosy-affected'.³⁸

In the health domain, physical appearance effects related to leprosy and its treatment were linked to internalised stigma among LAPs. Disfigurement produced feelings of shame when meeting HCWs or visiting the healthcare facility,^{31 51 55} reinforced beliefs that leprosy cannot be healed,^{8 49} and caused feelings of being an 'eternal patient' after completing treatment.⁵⁰ Changed appearances also led to stigma in all other domains.

Stigma consequences at the health level

Stigma in the health domain produced health and psychological implications. Unpleasant actions from HCWs produced trauma,⁵⁵ stoked fears of universal hostility,⁸ prompted further negative feelings towards HCWs,^{27 55} and reduced confidence in meeting HCWs, leading to worsening of disease.⁵⁵ Feelings of being an 'eternal patient' also left LAPs frustrated and pessimistic, causing them to avoid treatment⁴⁹ and abandon personal health.⁵⁰

Economic: lack of motivation and opportunity

In the economic domain, enacted,^{2 8 22 23 30 32 33 35 36 42-44 51} anticipated,⁹ and internalised stigma^{2 8 22 26 31 34 50} were

linked to difficulty accessing jobs and to a reduced desire to be productive.

Stigma manifestation and its driving factors at the economic level

Enacted stigma in the economic domain manifested in a lack of job opportunities,^{27 30 43 44 51} rejection when applying for jobs,² family members' suggestions to resign,⁸ firings,^{8 22 27} temporary suspensions until recovery,³⁶ exclusion and avoidance from co-workers,³² awkwardness or avoidance from customers,^{8 35 51} and lowered opportunities for financial support in business.³⁰ Physical appearance,^{2 51} concerns about contagiousness,⁸ bank loan organisational policy,³⁰ and gender discrimination⁴³ were reasons for these experiences.

In the economic domain, only one anticipated stigma was found: fear of customers' avoidance.⁹ Internalised stigma showed in declining drive towards productivity. LAPs sensed that they would be unable to do or find jobs,^{26 31} or would be unfit for jobs.^{22 34} They stopped working,⁸ labelling themselves as fit only to beg⁵⁰ or become objects of charity.² Feelings of shame over working in daylight²⁶ also suggest internalised stigma. These internalisations were intensified by changes in appearance,^{2 26} disability,²² decreased physical performance,^{8 31} and community stigma²² including a local association between LAPs and chronic disease, wounds, begging, and poverty.⁵⁰

Stigma consequences in the economic level

Stigma impacted the occupational, financial, social, mental and health status of LAPs. They experienced loss of customers,^{8 51} bankruptcy,³² mismatch between current and potential work,²² and limitations on work (eg, working only at night) in order to avoid being noticed.²⁶ Unemployment may cause poverty and criminal behaviour,³⁰ dependence on external aid,^{22 33} begging,^{22 43} deprioritising treatment,²⁸ worsening health,³⁶ self-labelling as a permanent patient² and decisions to reside in the place where LAP's were previously treated.²⁶ Psychologically, LAPs felt discouragement,^{28 32} self-doubt,^{31 34} lack of passion,³⁰ frustration³³ and suicidal thoughts or attempts.^{32 44} Stigma in the economic domain also caused LAPs to conceal their disease from customers.⁹

Education: constraints in education access and development

Stigma manifestation and driving factors at the educational level

In the education domain, enacted stigma emerged in the form of insults,^{8 27 28 33} others' physical distance,^{8 32} gossip when a student's parents contracted leprosy,⁴⁴ and a school bus avoiding the area where many LAPs lived.²⁸ Some drivers mentioned were fear of contagion and presence of visible affected skin.²⁸

LAPs felt anticipated stigma, such as fear of mockery or avoidance,⁸ or fear of their child's being shunned by schoolmates.²⁸ Internalised stigma in the education domain manifested in feelings of shame when attending school.^{28 33} No studies clearly articulated the drivers of these behaviours. However, these felt stigma may be influenced by limited school options near many LAP's

residential area.²⁸ This prevents an infected child from changing schools, so that they bear stigma throughout their education.²⁸ The importance of education in Indonesian society may also increase education-related stigma.⁸

Stigma consequences in the education level

Indonesian children who were infected with leprosy, or whose family members had leprosy, were reported to leave school temporarily or permanently.^{8 28–30 32 33 45 49 50} Others continued their education but described feeling shame²² or hiding their condition from school authorities.²⁸ Studies of stigma in the education domain focused entirely on school attendance and participation.

Public entitlements: ‘distance’ to market, transportation and places of worship

Stigma manifestation and driving factors at the public entitlements level

Stigma towards LAPs decreases access to public facilities. LAPs experienced unfair treatment at small shop and markets, on public transportation, and in places of worship. At the small shop and market, some sellers refused to sell to the LAP^{28 29} and LAPs experienced staring.²⁸ LAPs were expelled from public transportation,^{29 45} and had difficulty accessing transportation from their residential area.²⁸ In places of worship, LAPs experienced exclusion and others’ unwillingness to physically approach.^{44 45} Reasons cited for these forms of enacted stigma were physical appearance,²⁸ fear of transmission,²⁸ and local connotations attached to LAPs.⁴⁵

Feelings of shame in public could reflect internalisation of stigma. For example, studies mentioned embarrassment about appearing at places of worship.^{28 36} Reasons for this included physical changes such as darkened skin³⁶ and deformities.²⁸ Requirements that footwear be removed before praying also increased this hesitation, because of the possibility that a deformity in the foot might be seen.²⁸

Stigma consequences at the public entitlements level

Suicidal thoughts was reported as a psychological impact of discrimination in public entitlements such as religious settings and public transportation.⁴⁴ Other consequences of stigma in this domain could not be found.

Coverage of stigma-affected domains

Online supplemental material 6 (Coverage of domains impacted by stigma in included literature) shows coverage of the domains in the reviewed studies. This table reveals how extensive research has discussed the stigma affecting each domain LAPs lives in Indonesia.

DISCUSSION

This review aimed to systematically retrieve qualitative evidence on leprosy-related stigma in Indonesia. Drawn from literature, the synthesis reveals seven domains of life penetrated by stigma in Indonesia: community, domestic,

intimate relationship, health, economic, education and public entitlements.

The community domain was the most extensively studied of these domains in Indonesia. Stigma in the domestic, intimate relationship, health and economic domains had also received attention. Forms, drivers and consequences of stigma were the least explored in the education and ‘public facilities’ domains, indicating lack of concern, knowledge and research. Internalised and perceived stigma were more difficult to identify in the literature relative to experienced stigma.

Stigma drivers were not always related to negative concepts associated with the disease concepts. Other factors, such as HCW visit and economic struggles, were also found to induce stigma. These results imply that causes of stigma can be broad, including factors apparently unrelated to disease as well as seemingly positive ones. Thus, antistigma interventions for LAP must account for these broad influences. In terms of research, this would complement a previous global approach review.⁵⁶

This study recommends that efforts to reduce leprosy-related stigma in Indonesia must affect all seven domains. This is not only because the consequences of stigma in each domain were upsetting and at times violated human rights, but also because the aforementioned results show that events in one domain influenced others. For example, avoidance from HCWs (health domain) promoted feelings of social unworthiness in LAPs (community domain),⁸ and avoiding health facilities increased risk factors for stigma in community interaction.²⁸

The aforementioned may also be an addition to the recent health and stigma discrimination framework by Stangl *et al.*⁵⁷ The stigmatisation process may be fuelled not only by stigma manifestations and drivers but also by stigma consequences and outcomes. Moreover, the findings of this study would mean that stigma across domains is inter-related, suggesting that antistigma programmes should be performed simultaneously in all impacted domains.

These findings offer suggestions regarding the focus of antistigma programmes in each domain. In community life, an open environment for LAPs to participate in meaningful practices, such as greetings, is needed. Cultural leaders may become involved in restructuring long-held local labels for LAPs. In the domestic domain, programmes should focus on marital prospects, quality of marital life, family roles and family cohesiveness. In the public domains, particularly healthcare services, programmes should focus on preventing disability and improving HCWs’ manner. HCWs should be trained in sharing bad news and offering therapeutic communication to the LAP and families, especially during diagnosis. HCWs should also offer support to family members, caregivers and key decision makers on how to care for and communicate with LAP during and after treatment. Finally, HCWs should ensure adequate rehabilitation after therapy is completed. In the economic domain, programmes should focus on providing jobs and

preventing job loss, including building awareness among employers. Programmes in the education domain should focus on creating friendly school environments for LAPs or family members of LAPs. Regarding public entitlements, access to the market, transit and religious sites, as well as acceptance and equal treatment in these places, are required.

Qualitative studies in 9 out of 10 leprosy-endemic provinces (using 2017 data)¹³ are scarce. This suggests the need for exploratory studies on the experiences of LAPs in at-risk populations. Such studies would increase contextual awareness for the larger public, practitioners and researchers. Knowledge of stigma in the domains of education and public entitlements in Indonesia is needed. Views and experiences from children and key persons in the structural field, both private and government-owned, are also essential.

Limitations

There are several limitations on this study. First, before it was conducted, systematic review was not registered on the relevant platform, though a search on registered reviews was carried out to prevent duplication. Second, in terms of study searching, only online databases and open-access literature were used. Next, some articles were obtained from local peer-reviewed journals that were not yet indexed in international databases. Grey literature, known to lack peer-reviewing, were also analysed. The authors did not exclude such literature in their search in order to obtain more knowledge and include more Indonesian language-written literature, which is difficult to find in international databases. To ensure all reviewed literature met quality requirements, authors performed quality checking with CASP. CASP is one of the most-used tools for quality appraisal⁵⁸ and is endorsed by Cochrane,⁵⁹ yet authors believed risk bias could still occur because the final essential criteria for deciding minimum required quality can be subjective.⁶⁰ Furthermore, CASP appeared less sensitive to validity than other tools such as the Evaluation Tool for Qualitative Studies (ETQS) and the Joanna Briggs Institute (JBI). Finally, although risk of bias in the interpretation of meanings was minimised by the researchers, who were all Indonesian and used a consensus step to resolve discrepancies, it should be noted that text analysis of qualitative studies may still reflect differences in meaning relative to the original author of the article.

CONCLUSION

LAPs in Indonesia felt internalised, anticipated and experienced stigma in both private and public domains. These domains included intimate relationship, domestic, neighbourhood, occupational, educational, healthcare and other essential public settings. Stigma in the community domain, and experienced-type stigma, appeared most prominently in qualitative research conducted in Indonesia. Ten categories of stigma drivers and five

areas of stigma consequences were found. Antistigma programmes should address all domains, adapting to each one's unique challenges, including stigma generators specific to the local culture. Further research is needed to explore the stigma felt and experienced by LAPs, its determinants, and its consequences outside Java provinces, in education and in public entitlements. Future studies may also find whether stigma experienced in one domain worsens feeling of stigmatisation in others.

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