

Cultural validation of a new instrument to measure leprosy-related stigma: the SARI Stigma Scale

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Summary

Background: There is a need for comprehensive, valid and reliable instruments to assess leprosy-related stigma. This paper presents the process of the cross-cultural validation of an instrument in Cirebon District, Indonesia initiated by the Stigma Assessment and Reduction of Impact (SARI) project.

Methods: The Berger Scale was initially developed to assess HIV/AIDS-related stigma. This study explores the conceptual, item, semantic, operational and measurement equivalence of this scale for leprosy. The process included a qualitative study, translation and back-translation, training of interviewers, a pilot and the main data collection. We aimed for a sample of 154 people affected by leprosy with 60 repeat interviews. They were selected through convenience sampling.

Results: The original scale showed acceptable conceptual equivalence, but insufficient item, semantic and operational equivalences. For instance, there were irrelevant HIV-related items and the respondents found it difficult to indicate their level of agreement with the given statements. Major adjustments were necessary, leading to a new version of the scale. The measurement properties of the new version showed good internal consistency (Cronbach's alpha 0.88); no floor or ceiling effects; and a good reliability (intra-class correlation coefficient 0.75).

Conclusion: Due to the many adjustments we decided to rename the instrument to SARI Stigma Scale. The scale is comprehensive, reliable and culturally valid to assess four aspects of stigma among persons affected by leprosy in a setting like Cirebon District. Further research will determine whether this instrument is valid in other settings, cultures and with other neglected tropical diseases.

Introduction

Stigma plays a role in a variety of diseases – chronic and infectious – in all countries in the world. In many countries diseases like lymphatic filariasis, Buruli ulcer, leprosy, tuberculosis and HIV/AIDS are stigmatised.^{1–6} Health-related stigma can have a serious impact on the persons affected and on their family members.³ Stigma has been shown to lessen opportunities in life and hamper the fulfilment of human rights.^{7,8} This situation has encouraged experts and scholars to try and understand the causes of stigma and find solutions to reduce the impact of stigma. The interest of scholars in health-related stigma has increased over the last three decades, which can be seen in the increase of citations. These increased from 28 in 1987 to 553 in 2007.³ A simple search for ‘stigma AND health’ in 2016 resulted in more than 500,000 articles and books, of which more than 19,000 make a reference to leprosy. It has to be noted that relatively few have leprosy-related stigma as their main focus. The increased interest of scholars also contributed to an increase in the number of tools, scales and questionnaires to assess health-related stigma and to understand the implications of stigma. In 2003, van Brakel reviewed 15 articles on instruments to assess leprosy-related stigma.⁹ Three years later, a similar review was conducted in which 63 articles were found that describe the assessment of health-related stigma.¹⁰

Leprosy is a disease for which stigma and the assessment of stigma is particularly important. Stigma has been shown to cause participation limitations, shame, problems related to marriage and difficulties in employment.^{11–16} It thus has a negative impact on the quality of life of people affected by leprosy and on their socioeconomic status.^{15,17–19} Various instruments have been developed or modified to assess leprosy-related stigma, such as the Explanatory Model Interview Catalogue (EMIC),^{14,20} Participation scale²¹ and Internalized Stigma of Mental Illness (ISMI).²²

A scale that has not yet been used in the field of leprosy, but that seemed to have added value due to its comprehensiveness, is the Berger HIV Stigma Scale. The Berger HIV Stigma Scale was shown to have a high internal consistency with Cronbach’s alphas between 0.90 and 0.93 for the subscales and 0.96 for the 40-items together.²³ The Berger HIV Stigma Scale has been adapted for use in several countries such as Peru, United Kingdom and Puerto Rico.^{24–26} Stevelink *et al.* conducted an extensive review on stigma scales and found four other versions of the Berger HIV Stigma Scale, consisting 32, 21, 17 and 10 items.²⁶ They concluded that content validity, internal consistency were acceptable, but that construct validity, responsiveness and reliability were not tested or inconclusive.²⁶

The SARI project, which aimed to design, implement and test the effectiveness of stigma reduction interventions among people affected by leprosy and community members, needed good, valid instruments. The project selected the Berger HIV Stigma Scale and submitted it to cross-cultural validation because it had been developed for a different disease in a different setting and culture. This paper describes the cross-cultural validation process of the Berger HIV Stigma Scale in Cirebon District, Indonesia. We applied a framework that assesses the

equivalence of different aspects of the instrument between its original version and the new translated version. This includes an assessment of the psychometric properties. Indonesia is a multi-cultural country, with a wide variation of cultures and languages, which is also reflected in the study area. This posed a challenge as the study involved people of different cultural backgrounds who may not all conceptualise stigma in the same way.²⁷ This makes the equivalence study even more interesting and important.

Methods and materials

STUDY DESIGN

The SARI project used a cluster-randomised controlled trial design with three pairs of stigma reduction interventions. This sub-study was a cross-sectional instrument validation study.

Study Area

The validation study was conducted in Cirebon District, West Java, Indonesia. Cirebon District has a population of 2.6 million and is high endemic for leprosy. Every year around 250–300 new cases are detected.

Research team

This study was executed by one postdoc researcher, three PhD students and ten research assistants from Cirebon or neighbouring districts who spoke the local languages.

Instrument

Berger HIV Stigma Scale was specifically developed to assess HIV/AIDS stigma. In its original version it has 40 items, grouped into four domains: personalized stigma, disclosure stigma, negative self-image and public attitudes.²³ The items of the Berger HIV Stigma Scale are statements with four response options and corresponding score: strongly disagree = 1, disagree = 2, agree = 3 and strongly agree = 4.

Study population, sample size and sampling method

The study population comprised people affected by leprosy from Cirebon District. Subjects were eligible to participate in the validation study if they were 1) aged between 15 and 65, and 2) under treatment for leprosy or released from treatment, 3) resident in Cirebon District. There was one exclusion criterion: difficulties in communication.

To achieve adequate power for the various statistical calculations to determine the measurement equivalence, it was estimated that a sample of at least 154 people affected by leprosy was needed in the main quantitative part of the study. This corresponds to 7 times the number of items as recommended as a minimum sample size needed for factor analysis by Terwee *et al.*²⁸ To achieve an adequate sample size for the reliability calculation, at least 50 repeated measurements are necessary.²⁸ This is based on an intra-class correlation coefficient of 0.80 and a confidence interval of 0.70–0.90.

PROCESS

The cross-cultural validation covered several phases. An exploratory study was conducted to increase our understanding of the concept of stigma in the target population and the leprosy situation in Cirebon District. The second phase started with the translation and back translation of the Berger HIV Stigma Scale to ensure that all concepts and terminology in the translated instrument had a similar meaning as in the original instrument. In the third phase, 15–20 respondents affected by leprosy or disability were invited to test the instrument. The research assistants administered the scales for the first time and a discussion was held, during which the items were checked one by one for coherence, understanding and terminology. Together, alternatives for unclear or difficult words were discussed and selected. In the fourth phase, the revised version was tested in a pilot study with people affected by leprosy. Lastly, the quantitative validation study was conducted. People affected by leprosy were interviewed at the health centres (HC), in the different sub-districts of Cirebon District.

Cultural equivalence assessment

The framework used for this study used the model for cultural validity testing of Stevelink *et al.*⁴ who integrated Herdman's model²⁹ with measurement property standards of Terwee *et al.*²⁸ (see Appendix 1). In this study the conceptual, item, semantic and operational equivalences were assessed through the exploratory study, a translation process, discussion among experts, pre-testing with the target population, a pilot study and daily discussions with the research team at the office. Missing values were seen as an indicator of difficulty and acceptability of items among population study. The measurement equivalence was evaluated by testing the psychometric properties according to the quality criteria developed by Terwee²⁸ (see Appendix 2 for more information). The hypothesis that we formulated can also be found in Appendix 2. The socio-demographic characteristics of the sample are described using basic descriptive statistics. A mean and standard deviation (SD) were used to describe each item of the scale. Missing values in the individual items of the scale were replaced by the mean of that items. We analysed only the respondents who used *Bahasa Indonesia* language during the interview. For this study we used public domain software Epi Info 3.5 for data entry and management, and Stata 12 for the analysis of the psychometric properties.

ETHICAL CONSIDERATIONS

The study was approved by the ethical committee of Atma Jaya University in Jakarta. Informed consent was obtained from all participants. The study guarantees the confidentiality of the content of the data provided by the participants. A token of appreciation was given after an interview was conducted.

Results

CONCEPTUAL EQUIVALENCE

The explorative study found that the term 'stigma' does not common in *Bahasa Indonesia*. However, the phenomenon of stigma as such is prevalent among people affected by leprosy and community members. Dimensions of stigma such as being reluctant to disclose one's leprosy

status, exclusion or rejection, blame and devaluation, diminished self-esteem, and social impact on family and economic impact among people affected by leprosy were all mentioned or recognised by respondents in Cirebon District. The three quotes below illustrate this:

Everybody who sees her is asking: what is the disease? They say: “Don’t play with [name child], you will get infected” and sadly not only the neighbours treat us like that but it comes from our family as well (FGD, mother of affected child)

I am afraid of being infected if I shake hands with them. However, if I do not shake hands, I am afraid it offends them. It is complicated you know. (Community member, male, 31)

We learned from the hospital that when somebody gets leprosy they will be quarantined. So since a lot of people here are poor and can’t access the hospital, they just quarantine and exclude people affected by leprosy somewhere else, not in hospital. (Community leader, male, 44)

Some community members avoid people affected by leprosy, tend not to want to shake hands and relate the disease to supernatural and moral causes.

The words to describe the four domains in the Berger scale are less common in the field of leprosy-related stigma, where the definition and framework of Weiss³ is commonly used. Therefore, we decided to change some of the domain names, though the meaning corresponds to the description of Berger *et al.*²³ Personalised stigma was changed to ‘Anticipated stigma’, negative self-image was changed to ‘Internalized stigma’, public attitudes was changed to ‘Experienced stigma’, and disclosure concerns remained the same.

ITEM EQUIVALENCE

We excluded items that related to the specific route of transmission of HIV and items with a specific sexual connotation and kept those that were not HIV/AIDS-specific. In total 18 items were excluded: nine items on personalised stigma (24, 25, 27, 30, 31, 32, 35, 38, 40), three items on disclosure concerns (1, 6, 37), three items on negative self-image (3, 6, 23), and six items on public attitude (10, 11, 16, 19, 31, 40). This resulted in a scale with four domains, but only 22 items or statements (see Table 3). During the pre-testing, participants reported that they recognised the value and relevance of all 22 items in the instrument. Some participants mentioned that they had experienced most of the issues. We found no items that offended the respondents.

SEMANTIC EQUIVALENCE

Discussions involving experts, research assistants and people affected by leprosy showed that several words or phrases were hard to understand. First, participants were confused regarding the phrase ‘*being not as good a person as others*’. They were not sure whether it referred to the physically appearance, capacity or behaviour. The team decided it referred to the moral aspects and agreed on how they would explain this to the interviewee. Second, the word ‘*uncomfortable*’ created challenges. In *Bahasa Indonesia* uncomfortable was translated as ‘*tidak nyaman*’. ‘*Nyaman*’ refers to feeling ‘*free, secure, without fear or feeling relief*’ and ‘*tidak*’ refers to ‘*no or not*’. The research assistants had some difficulties explaining the word

to the interviewees, but nevertheless agreed that it was the best word in this context. Third, another phrase that was difficult to translate was *'being treated like a public nuisance'*. In the end it was decided to use *'pengganggu masyarakat'* or *person who makes the community feel insecure and uncomfortable*. Fourth, the research assistants felt there was overlap between three items *'do people physically back away?'*, *'do people keep a distance from you?'* and *'do people seem afraid of you?'* and needed some extra discussion among each other to distinguish between the three items. Fifth, the phrase *'to feel set apart and isolated from the rest of the world'* was not known in the context of the Indonesian community. It was not easy to relate to the *'rest of the world'*. We therefore adapted this phrase to *'being apart and isolated from the community'*. None of the other items created semantic challenges nor did we find other items that were unsuitable for use in the community with regard to culture or customs.

OPERATIONAL EQUIVALENCE

During the pilot it became clear that it was very difficult for most respondents to understand the statement format of the Berger HIV Stigma Scale. The research assistants had to explain and repeat the items many times to the respondents. The response was difficult to obtain since the respondents did not seem to get used to the format. It was time consuming, sometimes leading to uncomfortable situations and provoking leading prompts from research assistants. The respondents seemed to doubt their perspective on the statement and frequently answered 'agree' or 'disagree', with hardly any answers expressing strong disagreement or strong agreement. The format was designed for self-administration. When the interviewer used the first person in reading out the items, the interviewees thought the statement referred to research assistants, rather than to themselves.

Because of this problem, the items were changed into a question format. Each statement was divided into two questions. The first question asks whether something has occurred to them. The response options are: 1) 'no', 2) 'yes', 3) 'don't know' and 4) 'not relevant'. If the answer is 'yes', a second question is asked about the frequency of occurrence. The response options are: 1) 'always/often' (score 3), 2) 'sometimes' (score 2), and 3) 'rarely/once' (score 1) (see appendix). This format was piloted and the research assistants reported that the interviewees found the new format much easier to understand and subsequently responded faster.

MEASUREMENT EQUIVALENCE

Characteristics of the participants

A total of 590 respondents participated in this study. Of these, 198 (34%) were omitted from the analysis because the interviews were administrated in a language other than *Bahasa Indonesia*. The data of the remaining 392 respondents was analysed. Of these respondents, 37% were women, the age ranged from 15–65 with an average age of 35 (SD 13.9). Most finished at least elementary school (91%), and had a job, such as paid work (35%) owning a business or being a farmer (29%) (see Table 1).

Item characteristics

The total score of the new scale had a mean of 19.4 (range 0–66), 95% CI 18.1–20.6. The distribution of the total score is normal, with Kurtosis 2.97 and Skewness 0.61. Only five of

Table 1. Socio-demographic characteristics respondents

Variable	People affected by leprosy (<i>n</i> = 392)
Sex	
Female	143 (36.5)
Male	249 (63.5)
Age	
> 29	159 (40.6)
30–39	88 (22.4)
40–49	58 (14.8)
50–59	60 (15.31)
> 60	27 (6.9)
Education	
Illiterate/not finished elementary school (ES)	36 (9.2)
Finished ES	217 (55.4)
Finished secondary school/college	139 (35.5)
Occupation	
Paid work	137 (34.9)
Own business/farmer	115 (29.3)
Non-paid work	59 (15.1)
No work	79 (20.2)

the 22 items had missing values, the percentage of missing values for each of these items was less than 1%. Respondents answered ‘*not relevant*’ only rarely (0–4%), but ‘*don’t know*’ relatively frequently. Item 19 (‘*do people affected by leprosy lose their job if the employer finds out about it?*’) was answered most frequently with ‘*don’t know*’ (32%), followed by item 7 (‘*do people act as if it is your fault?*’) (27%) and item 22 (‘*do people feel uncomfortable around person affected by leprosy?*’) (20%). Table 2 shows the distribution of each total sub-score.

The mean total sub-score for the domain Experienced stigma is relatively low compared to the other domains. Table 3 shows the mean scores of all 22 items on the scale.

Internal consistency. The internal consistency analysis showed a Cronbach alpha for the scale of 0.88; The sub scale analysis yielded similar levels of alphas; sub-scale 1 ‘Experienced stigma’ 0.82; sub-scale 2 ‘Disclosure concerns’ 0.79; sub-scale 3 ‘Internalized stigma’ 0.79 and sub-scale 4 ‘Anticipated stigma’ also 0.79.

Table 2. Mean scores of the full scale and each of the sub-scales (*n* = 392)

	Mean	Median	Min	Max	95% CI
Full scale	19.4	18	0	66	18.1–20.6
Domains					
Experienced stigma (8 items max score 24)	2.6	0	0	21	2.20–3.04
Disclosure concerns (4 items max score 12)	5.8	6	0	12	5.41–6.23
Internalized stigma (6 items max score 18)	7.0	6	0	18	6.51–7.52
Anticipated stigma (4 items max score 12)	3.9	3	0	12	3.51–4.26

Table 3. Descriptive statistics of the items of the new scale (range per item 0–3) ($n = 392$)

#	Items	Mean	SD
Experienced stigma			
1	Do some people who know you have (had) leprosy keep more distance from you?	0.37	0.85
2	Do you regret having told some people that you have (had) leprosy?	0.47	0.96
3	Do people you care about stop contacting you after learning you have (had) leprosy?	0.14	0.58
4	Did you lose friends by telling them you have (had) leprosy?	0.33	0.85
5	Do people avoid touching you once they know you have (had) leprosy?	0.31	0.77
6	Do people have physically back away from you when they learn you have (had) leprosy?	0.29	0.78
7	Do people act as though it's your fault you have (had) leprosy?	0.37	0.83
8	Do people seem afraid of you once they learn you have (had) leprosy?	0.33	0.81
Disclosure concerns			
9	Are you careful who you tell that you have (had) leprosy?	1.63	1.32
10	Do you feel the need to hide your leprosy status?	1.47	1.35
11	Do you believe telling someone you have (had) leprosy is risky?	1.32	1.26
12	Do you worry that people may judge you when they hear you have (had) leprosy?	1.40	1.32
Internalized stigma			
13	Do you feel guilty because you have (had) leprosy?	1.15	1.28
14	Do you feel you are not as good a person as others because you have (had) leprosy?	1.43	1.30
15	Are you embarrassed that you have (had) leprosy?	1.54	1.31
16	Does having (had) leprosy make you feel unclean?	1.51	1.25
17	Do you feel set apart and isolated from the community since learning you have (had) leprosy?	0.42	0.96
18	Does having (had) leprosy make you feel that you are a bad person?	0.96	1.21
Anticipated stigma			
19	Do people affected by leprosy lose their jobs when their employers find out?	0.98	1.23
20	Are people affected by leprosy treated like a public nuisance?	0.63	1.07
21	Do people think that a person affected by leprosy is disgusting?	1.24	1.28
22	Do people feel uncomfortable around someone affected by leprosy?	1.03	1.22

The results of the factor analysis (see Table 4) show that there are two items that did not load on the factor they were originally assigned to, one in the group 'Experienced stigma', and the other in the group Anticipated stigma. The analysis shows that the item, ('*Do you regret having told some people that you have (had) leprosy?*') originally in the Experienced stigma sub-scale, fits better in the Internalized stigma sub-scale. The item, ('*Do you feel set apart and isolated from the community since learning you have (had) leprosy?*') originally located in the Internalized stigma sub-scale, appears to fit better in the Experienced stigma sub-scale. Item 7 has a relatively low loading. Dropping this item increased the alpha of the domain, hence, this is what we decided to do. All others items fitted in the assigned sub-scales as expected.

We performed additional analyses of the two new domains resulting in the following alpha-scores: sub-scale 1, 'Experienced stigma' 0.84; sub-scale 3, 'Internalized stigma' is 0.79. The alpha of full instrument remained the same without item 7, namely 0.88.

Construct validity. We found a moderately positive correlation ($r = 0.46$, $P < 0.0001$) between the total score of the new scale and the P-scale and also moderate positive correlations between the sub-scales as hypothesised, except experienced stigma score and disclosure concerns, which had a weak positive correlation (Table 5). We found a weak

Table 4. Factor analysis of the new scale (4 factors) ($n = 392$)

#	Item	Experienced stigma	Disclosure concerns	Internalized stigma	Anticipated stigma
1	Do some people who know you have (had) leprosy keep more distance from you?	0-9747			
6	Do people have physically back away from you when they learn you have (had) leprosy?	0-9474			
5	Do people avoid touching you once they know you have (had) leprosy?	0-8392			
3	Do people you care about stop contacting you after learning you have (had) leprosy?	0-8244			
8	Do people seem afraid of you once they learn you have (had) leprosy?	0-6862			
4	Did you lose friends by telling them you have (had) leprosy?	0-6309		0-4161	
7	Do people act as though it's your fault you have (had) leprosy?	0-3582		0-3865	
2	Do you regret having told some people that you have (had) leprosy?			0-5509	
9	Are you careful who you tell that you have (had) leprosy?		0-9490		
10	Do you feel the need to hide your leprosy status?		0-7400		
12	Do you worry that people may judge you when they hear you have (had) leprosy?		0-6675		
11	Do you believe telling someone you have (had) leprosy is risky?		0-5890		
13	Do you feel guilty because you have (had) leprosy?			0-9523	
14	Do you feel you are not as good a person as others because you have (had) leprosy?			0-7741	
15	Are you embarrassed that you have (had) leprosy?			0-7131	
16	Does having (had) leprosy make you feel unclean?			0-6101	
18	Does having (had) leprosy make you feel that you are a bad person?			0-5012	
17	Do you feel set apart and isolated from the community since learning you have (had) leprosy?	0-6404			
20	Are people affected by leprosy treated like a public nuisance?				0-8749
21	Do people think that a person affected by leprosy is disgusting?				0-8394
22	Do people feel uncomfortable around someone affected by leprosy?				0-8294
19	Do people affected by leprosy lose their jobs when their employers find out?				0-6886

Table 5. Correlation, ICCs, and floor and ceiling of the domains of the new scale

	Experienced stigma	Internalized stigma	Disclosure concerns	Anticipated stigma
Correlation of the domains				
Experienced stigma	1			
Internalized stigma	0.50	1		
Disclosure concerns	0.15	0.45	1	
Anticipated stigma	0.40	0.45	0.43	1
ICCs				
Individual	0.75	0.69	0.54	0.65
CI 95%	0.64–0.83	0.56–0.79	0.38–0.67	0.52–0.75
Floor and ceiling effects				
Floor	54%	12%	18%	29%
Ceiling	0.50%	3%	12%	5%

negative correlation ($r = -0.37$, $P < 0.0001$) between the total score of the new scale and the WHOQOL.

Reproducibility. In total there were 93 repeated measurements. The ICC of the new scale was 0.75 (95%CI 0.64–0.83). Table 5 shows the ICCs per domain. The mean difference between interviewers was -1.51 (SD 9.53). This led to a $SEM_{\text{agreement}}$ of 6.74, which represents 10.2% of the score range. The $SDC_{\text{individual}}$ is 18.68 and SDC_{group} is 1.37.

Floor and ceiling effects. This study found no floor or ceiling effects for the new scale. Only 16 respondents (4.1%) scored the lowest possible score (0) and just 1 respondent (0.26%) reached the highest score of 58 points for a maximum of 66. Floor effects were found in three of the four sub-scales, but no ceiling effects were found as shown in Table 5.

Interpretability. The mean scores and corresponding confidence intervals of different sub-groups are shown in Table 3. There is no clear pattern. We observed that women have a higher total score than men, but this difference was not significant (mean difference 0.9; $p = 0.55$, t-test). We also examined the level of stigma by disability grade. The mean total stigma score of persons without leprosy-related disability was significantly lower than the mean total score of persons with disability grade 1 and 2 (mean difference 5.8; $P = 0.0001$). The difference between the mean total scores of persons with grade 1 and grade 2 disability was not significant ($P = 0.6584$). In Table 6 the sub scores by disability grade are provided. The mean score was highest for persons with visible impairment, except for the scores of Disclosure concern.

Discussion

The main aim of this study was to assess the cross-cultural validity of a leprosy version of the Berger HIV stigma scale among people affected by leprosy in Cirebon District, Indonesia. To our knowledge, it is the first time that this widely used scale was adapted to assess leprosy-related stigma and tested for its cross-cultural validity.^{24,30–33} Cross-cultural validation is

Table 6. Mean total score and 95% CI by demographic category and domain ($n = 392$)

Characteristic	N	Mean	95% CI
Demographic			
Sex			
Female	143	20.54	18.42–22.66
Male	249	18.68	17.08–20.28
Age			
> 29	159	19.53	17.52–21.54
30–39	88	19.45	16.93–21.98
40–49	58	21.76	18.06–25.46
50–59	60	16.48	13.30–19.66
> 60	27	19.3	13.81–24.79
Education			
Illiterate/not finished ES	36	19.06	14.21–23.90
Finished Elementary School (ES)	217	20.36	18.60–22.12
Finished Secondary school/college	139	17.87	15.88–19.86
Occupation			
Paid work	137	19.15	17.05–21.24
Own business/farmer	115	18.58	16.15–21.01
Non paid work	59	19.64	16.56–22.73
No work	79	20.56	17.41–23.70
Disability grade			
Grade 0	163	15.73	13.99–17.47
Grade 1	188	21.77	19.85–23.67
Grade 2	41	22.78	18.69–26.87
Domain sub scale			
Experienced stigma			
Grade 0	163	1.87	1.34–2.4
Grade 1	188	2.77	2.14–3.39
Grade 2	41	4.93	3.14–6.71
Internalized stigma			
Grade 0	163	5.17	4.46–5.87
Grade 1	188	8.3	7.58–9.02
Grade 2	41	8.44	6.84–10.04
Disclosure concerns			
Grade 0	163	5.23	4.62–5.83
Grade 1	188	6.58	5.99–7.17
Grade 2	41	4.71	3.41–6.01
Anticipated stigma			
Grade 0	163	3.42	2.86–3.98
Grade 1	188	4.11	3.54–4.67
Grade 2	41	4.71	3.65–5.77

needed to ensure that a scale will produce valid data on what it intends to measure. Being able to assess the level of stigma is important to assess the effect of interventions.

This study showed that all the concepts of stigma and the four domains assessed in the original Berger scale are relevant in the target population, indicating that the conceptual validity (as we propose to call this) is good. Other studies in Indonesia have also identified the relevance of stigma in general,^{14,34–36} and more specifically, on the manifestation of public avoidance and expulsion³⁷ and the issue of concealment.³⁸ After omitting the HIV specific items, the item validity was good.

However, there were substantial issues with the semantic and operational equivalences. This study identified several challenges in developing a *Bahasa Indonesia* version with a level of language “appropriate to the needs of the target population”.³⁹ In some cases it was

difficult to find an appropriate translation for a certain word or phrase (e.g. 'public nuisance' or 'uncomfortable'), in other cases some phrases did not suit the day to day world of the target population (e.g. 'rest of this world'). To achieve a good semantic equivalence, the words and phrases were changed where necessary trying to preserve their original meaning. Furthermore the meaning of words was discussed amongst the interview team so that they could bring across the meaning to the interviewee. The latter was also done in the study of Sumari-de Boer *et al.*⁴⁰ They studied stigmatisation among immigrants and indigenous HIV-infected patients in the Netherlands and needed to give explanations about items relatively frequently when the scale was administered. For example, 38% of the respondents needed explanations for one or more items in Personalised stigma domain.

We found that the statement format and agreement response scales were very difficult for the interviewees. Reading out loud the statements in the first person was confusing for the respondent as it was not clear to whom the interviewer referred. Changing the format from statements to questions proved a good way to resolve this issue. Every statement was split into two direct questions. The first asks whether a certain situation/experience is relevant or not. If relevant, the second asks about the frequency with which this has occurred. After testing the new format in the field, we concluded that the semantic, item and operational validity were good.

The adapted scale had changed so much in the way of structure and format, we decided to rename it to SARI Stigma Scale (SSS) before the main data collection started. The final format of this scale has 21 items, with items grouped in 4 domains with a sub-score for each. The domains are: experienced stigma (8 items), internalised stigma (6 items), perceived stigma (4 items) and disclosure concerns (4 items). The minimum total score is 0 and maximum total score is 66.

Next, the measurement equivalence of the SSS was assessed. The proportion of missing values was low. This implies that the items are understood well by respondents, confirming the findings of Sumari-de Boer *et al.* who used the Berger Scale.⁴⁰ The missing value percentage is most likely also low because respondents were able to select 'not applicable' as an answer. The scale did have a relatively high number of respondents who replied 'don't know' to some items, e.g. 'Do people affected by leprosy lose their jobs when their employers find out?' We assumed this happened because many respondents were not working, e.g. housewives and students, and therefore had no experience with this issue.

The internal consistency of the scale was good. The Cronbach Alpha found in our study (0.88) is higher than the values found in the study of Wright *et al.* (0.72–0.84),³³ similar to the values of Lindberg *et al.* (0.87–0.96) and a bit lower than those in the study of Berger *et al.* (0.90–0.93)²³ The factor analysis showed that two items did not perform as expected; one in the domain 'Experienced stigma' and the other in the domain 'Internalized stigma'. Analysis of the first item ('*Do you regret having told some people that you have (had) leprosy?*') shows that this item fit better with internalised stigma rather than experienced stigma. We expect this is because we asked about 'regret', which is a feeling/emotion, therefore fitting best in the Internalized stigma domain. This item needs special attention in any future study to confirm its place in this domain. Analysis of the second item ('*Do you feel set apart and isolated from the community since learning you have (had) leprosy?*') shows that the item correlates poorly within the domain 'Internalized stigma' and that it would fit better in the domain 'Experienced stigma'. This may be because the respondents may not only have *felt* set apart and isolated, but may also have *experienced* being isolated by their neighbour and relatives in real life. We recommend including item 2 in the Internalized stigma domain and item 17 in

the Experienced stigma domain in which they fit best. We believe that a shorter scale is better, if it can be shortened without any substantial loss in internal consistency or content validity and therefore we dropped item 7 since it poor fit, it show low factor loadings to the rest correlation. All other items fit well in their respective sub-scales, with factor loadings ranging from 0.63–0.95.

The construct validity of the SSS was supported by the moderately positive correlation with the P-scale and the sub-scales, but less than expected by the weak negative correlation with the WHOQOL-BREF ($r = 0.37$). It would be interesting to investigate the relationship between stigma and QoL in more depth in future research. Current studies show mixed results; for instance, Brouwers et al.¹⁹ did not find a significant association in a multivariate analysis in their study in Nepal, but they used a very short stigma tool that only measures anticipated and experienced stigma. Tsutsumi *et al.* who a substantial effect of stigma on QoL in Bangladesh.¹⁸ Also in two studies on mental health-related stigma an association was found.^{41,42}

In repeated interviews, the SSS showed good inter-interviewer reliability. (The ICC 0.75) was above the threshold of 0.70 suggested by Terwee.²⁸ The ICCs for the individual domains ranged from inadequate to good. The ICC of the Disclosure concerns domain was the weakest (ICC 0.54), followed by the domain Anticipated stigma (ICC 0.65), Internalized stigma (ICC 0.69) and Experience stigma (ICC 0.75). Berger et al. found a good reliability of the sub-scales of their Berger scale with 40 items.²³ This may be due to the fact that the sub-scales contained more items. It is known that longer scales are more likely to have higher alpha values than short scales. Wiklander et al. also found the reliability of the Disclosure concerns sub-scale to be weaker than that of the other three sub-scales in Sweden.³¹ This weak association implies that these three sub-scales should be as standalone scales only with caution.

The measurement error of the SSS was small at group level, with a SDC of 1.37. This means that small changes in stigma group scores can be reliably detected. This does not automatically mean, of course, that small changes are also meaningful in terms of a change in stigma that matter to the persons concerned. This concept – clinically important change – has not been determined yet for the SSS.

This study found no floor or ceiling effects in the overall SSS using the criteria of Terwee.²⁸ Three sub-scales have floor effects, but no ceiling effects. Floor effects are due a lack of sensitivity at the lower end of the scale. This is not necessarily a problem in a stigma tool, since mild levels of stigma would not be acted on anyway. The high proportion of floor effects in the experienced stigma sub-scale might be due to the relatively high levels of concealment. If people successfully conceal their illness, enacted stigma will not occur. Berger et al. did not test the floor and ceiling effects in their original scale.²³ Future research should attempt to improve the properties of the sub-scales, although may mean adding items, which would make the overall scale longer again.

An interesting finding was the weak correlation between disclosure concerns and experienced stigma. This would fit with the notion that concerns about disclosure do not require actual experience of stigma or discrimination. High levels of concern about disclosure, even in the absence of actual stigma experiences, have been noted by others also.^{43,44} Second, the disclosure concern score was higher for persons with no visible signs, compared to those with visible signs (see Table 6). One might expect a higher score for the latter group, as was indeed the case for the other types of stigma. However, this finding can be understood considering that visible impairments often cannot be concealed anymore and thus concerns about disclosure may be reduced, while the anticipation of stigma, actual stigma experiences and internalized stigma are increased in this group.^{14,19,22}

Health-related stigma affects not only persons affected leprosy, but hundreds of millions of others also. People living with HIV,^{23–25} mental health conditions,¹⁸ and many of the NTDs,^{1–3,45} However, stigma and discrimination and its effects are invisible, because there are hardly any available data to visualise these problems. Such data is urgently needed for political advocacy, fundraising, needs assessments, to target interventions to areas with high stigma, programme planning and management, and monitoring and evaluation of programmes and interventions. One reason for this gap in data and evidence for effectiveness of interventions is the lack of agreed instruments to assess the various aspects of stigma and discrimination across health conditions. We believe the SARI Stigma Scale is suitable for use as a generic instrument to measure health-related stigma, not only related to leprosy, but also to other NTDs and health conditions.

Limitations

This study only validated the SSS in *Bahasa Indonesia*. A substantial group of people in Cirebon District do not speak *Bahasa Indonesia* sufficiently. To assess the level of social stigma in these groups; translation and validation in different languages will still be needed.

Conclusion

This is first time that a comprehensive stigma measure is available for use with persons affected by leprosy. Valid stigma scales can be used for different purposes such as the assessment of the effectiveness of stigma reduction interventions, to strategically target areas where there is a high level of stigma or to increase insight in which type of stigma is most prevalent. The SSS that was developed based on the Berger HIV stigma scale showed good cultural validity to measure various aspects of stigma among persons affected by leprosy in the context of Cirebon. Further research is needed to confirm whether this instrument has the same validity in different settings and cultures and for use with other NTDs. A cross cultural validation process as described in detail in this article could be followed to achieve this.

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Appendix 1: Framework for cross-cultural validation

Herdman’s framework comprises several types of equivalences: conceptual, item, semantic, operational, measurement and functional equivalence. To assess measurement equivalence the quality criteria for measurement properties by Terwee are used.²⁸ The last equivalence category is ‘functional equivalence’, which refers to the extent to which an instrument is capable of measuring concepts equally well in a different context and culture. It is not a separate category, but an umbrella term for the former five equivalences. Stevelink & van Brakel refer to this as ‘cultural equivalence’.¹¹ The validation process of instruments should follow a clear protocol to make sure that appropriate procedures are followed.^{11,46} A recent study of the Stevelink & van Brakel outlined the steps needed to execute a cross-cultural validation.⁴ (Figure 1)

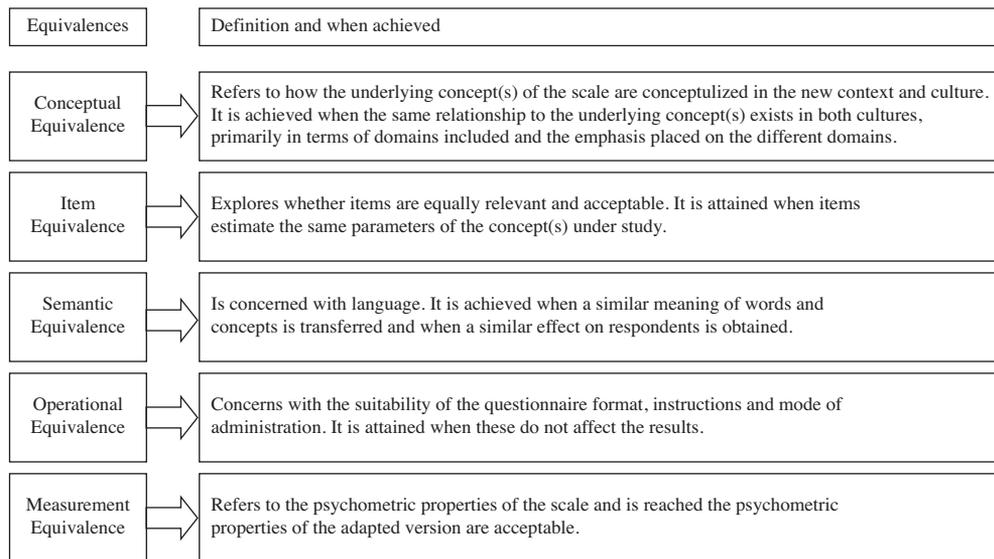


Figure 1. Framework for cross-cultural validation

Appendix 2: Details measurement properties

The following properties were assessed and are defined as follows:

- Internal consistency is the extent to which items in a (sub)-scale are inter-correlated, thus measuring the same construct.²⁸ Cronbach’s alpha is used as measure of internal consistency. A Cronbach’s alpha between 0.70 and 0.95 was classified as good. Factor analysis was used to reveal any pattern in the items, showing whether items all measure the same underlying construct or whether they are clustered in homogeneous sub-sets, thus measuring different constructs. Internal consistency was examined of the overall scale and for each of the sub-scales. The overall scale was expected to be multidimensional. The

scores of the subscales were expected to correlate. The analyses was done through a factor analysis using a polychoric correlation matrix, because of the categorical nature of the item scores.⁴⁷

- Construct validity is the extent to which scores of a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured.²⁸ Two instruments were used to assess the construct validity:

- The Participation Scale (P-scale) is an 18-item interview-based instrument which measures participation restrictions. It is developed based on the Participation domains of the International Classification of Functioning, Disability and Health (ICF).²¹
- The WHOQOL-BREF is a 26-item scale with four domains: 1 Physical health; 2 Psychological domain; 3 Social relations; and 4 Environment.⁴⁸ This scale has been validated in many countries in Asia such as India,⁴⁹ Malaysia,⁵⁰ Taiwan.⁵¹ It has also been validated in Indonesia among elderly people.⁵²

We hypothesised a moderately positive correlation of 0.4 and 0.8 (Spearman correlation coefficient) between the instruments total score and the P-Scale total score and between the sub-scores of the instrument. Similarly, we hypothesised a moderately negative correlation of 0.4 and 0.8 between the instruments total score and the WHOQOL-BREF score. The construct validity is considered good if 75% of prior hypotheses is confirmed.²⁸

- Reproducibility was assessed by calculating the inter-interviewer reliability and agreement. The interval between interviews was 10–14 days, this interval was considered long enough for respondents not to remember their answers during the previous visit and short enough for people's stigma situation not to have changed.
 - The intra-class correlation coefficient for reliability (ICC) assesses measurement error and was calculated to assess the test-retest reliability of the instrument. An ICC (individual) of at least 0.70 was considered evidence of good reliability.²⁸
 - Agreement was tested by calculating: i) the Standard Error of Measurement (SEM) using the formula $SEM_{\text{agreement}} = \sqrt{\sigma_{\text{error}}^2}$, ii) the Smallest Detectable Change individual (SDC_{individual}) by using the formula $1.96 * \sqrt{2} * SEM$ and iii) SDC_{group} by dividing the SDC_{individual} by \sqrt{n} .^{28,53}
- Floor and ceiling effects refer to the number of respondents who achieve the lowest or highest possible score. Floor and ceiling effect were considered to be present if 15% or more of the respondents had the lowest or highest possible score, respectively.²⁸
- Interpretability refers to reference values for different subgroups that help interpret whether a given score is high or low. The means and SD for four subgroups were calculated (sex, age groups, level of education and key person).

Appendix 3. SARI Stigma Scale

SARI Stigma Scale v.1.1 (based on the Berger HIV stigma scale)		No	Yes	Don't know	Not Relevant	Always/Often	Sometimes	Rarely/once	Score	
Experienced stigma										
1a	Do some people who know you have (had) leprosy keep more distance from you?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
2a	Do people you care about stop contacting you after learning you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
3a	Did you lose friends by telling them you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
4a	Do people avoid touching you once they know you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
5a	Have people physically backed away from you when they learn you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
6a	Do people seem afraid of you once they learn you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
7a	Do you feel set apart and isolated from the community since learning you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often has this happened?</i>					3	2	1		
		Subtotal								
Disclosure concerns										
8a	Are you careful who you tell that you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often are you careful?</i>					3	2	1		
9a	Do you feel the need to hide your leprosy	0		0	0					
b	<i>(If yes) How often do you feel the need to hide your status?</i>					3	2	1		
10a	Do you believe telling someone you have (had) leprosy is risky?	0		0	0					
b	<i>(If yes) How often do you believe it is risky?</i>					3	2	1		
11a	Do you worry that people may judge you when they hear you have (had) leprosy?	0		0	0					
b	<i>(If yes) How often do you worry about this?</i>					3	2	1		
		Subtotal								

SARI Stigma Scale v.1.1 (based on the Berger HIV stigma scale)		No	Yes	Don't know	Not Relevant	Always/Often	Sometimes	Rarely/once	Score
Internalised stigma									
12a	Do you feel guilty because you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
13a	Do you feel you are not as good a person as others because you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
14a	Are you embarrassed that you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
15a	Does having (had) leprosy make you feel unclean?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
16a	Do you regret having told some people that you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
17a	Does having (had) leprosy make you feel that you are a bad person?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
		Subtotal							
Anticipated stigma									
18a	Do people affected by leprosy lose their jobs when their employers find out?	0		0	0				
b	(If yes) How often does this happen?					3	2	1	
19a	Are people affected by leprosy treated like a public nuisance?	0		0	0				
b	(If yes) How often does this happen?					3	2	1	
20a	Do most people think that a person affected by leprosy is disgusting?	0		0	0				
b	(If yes) How often does this happen?					3	2	1	
21a	Do most people feel uncomfortable around someone affected by leprosy?	0		0	0				
b	(If yes) How often does this happen?					3	2	1	
		Subtotal							
		Total score							