Psychometric evaluation of the SARI stigma assessment scale and an understanding of stigma amongst people affected by leprosy in Iran

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Summary

Background: The SARI (Stigma Assessment and Reduction of Impact) project was designed to measure and then reduce the burden of the stigma of leprosy. Since there is no valid and reliable Persian version of this tool in Iran, this research aimed to translate this tool and study its psychometry.

Methods and materials: After determining the face and content validity, construct validity was determined using the confirmatory factor analysis (CFA) method. Cronbach's alpha coefficient was used in order to assess the reliability (internal consistency) of the tool, and the intra-class correlation coefficient (ICC) was used in order to verify the reliability of SARI over time.

Results: The results of this study show that the SARI tool has an acceptable content and construct validity. In terms of reliability, the value Cronbach's alpha overall was 0·897. The inter-class correlation coefficient was calculated based on the test-retest results. According to the obtained coefficients, the reliability of SARI tool was considered acceptable.

Conclusion: The results of the present study show that the reliability and validity of this tool are acceptable for use in related research in Iran.

Keywords: Leprosy, psychometric, stigma, SARI

Introduction

The chronic nature of many infectious diseases causes long-term physical and social effects on the lives of patients and their families.[1] Leprosy is one of the oldest chronic diseases[2] whose history goes back to the writings of an Egyptian papyrus in 1550 BC and manuscripts in Hindi 600 years before Christ.[3] Leprosy caused the horror from its earliest days due to its impact on the face and limbs, and despite effective treatment in recent decades, people's fear

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did not reduce. These patients live in camps outside the city and that can have a huge impact on their quality of life. Religious, cultural and social beliefs about leprosy, transformation and disability lead to stigma of the leprosy disease.

The existence of difficulties in finding work, education, marriage and deprivation of social amenities and facilities in the community and the status of the lower livelihood affect their quality of life.[4] These patients feel that they are not aligned with community needs due to the signs of the disease and then feel shame and frustration; they are marginalized in their community and deprived of citizenship and individual rights.[5] Leprosy is such an ugly word in people's minds that even in some cultures the word leprosy is used as a curse word in conversation.[6] In other words, the existence of a previously formed concept in the minds of individuals in society about the disease of leprosy causes a lack of understanding towards leprosy patients, and individuals easily judge them, so that even their families are considered unhealthy.[7]

Several studies in the literature have shown that leprosy stigma is still a global issue and it is common not only in endemic areas, but also in non-endemic areas and, despite cultural differences in different areas, the impact of stigma on people's lives is the same.[8] The stigma measurement tool was developed in the SARI project by a team of international researchers in Indonesia to help reduce the burden of the stigma of leprosy. The questionnaire can measure the various dimensions of leprosy stigma in a quantitative manner. It consists of 22 items and is scored based on the Likert scale (always, often, rarely and do not know). The SARI stigma questionnaire has four areas: Cronbach's alpha for each of these areas is 0·82 for experienced stigma, 0·79 for perceived stigma, 0·79 for internal stigma and 0·79 for expected stigma, while the kappa score of the scale in a test-retest setting was 0·75, which indicates good reliability of this instrument. It is thus seen as a comprehensive, reliable and valid instrument to assess different aspects of stigma in people affected by leprosy.[9] Since there was no available Persian version of this tool in Iran, this study was aimed to determine the validity and psychometric properties of a translation of the SARI tool, related to the perceived stigma in people affected by leprosy in Iran.

Brief Information about Leprosy in Iran

Leprosy is prevalent in the north and northwest of Iran compared to other parts of the country. The endemic area starts in Kermanshah city and passes through West Azerbaijan, Gilan and Mazandaran cities and finally ends in Mashhad city. The cause of prevalence in these areas is unknown. Although there are rare reports of leprosy from the south of Iran, there are only two centres to treat those with leprosy: Mehrab Khan in Mashhad in the east and Baba Baghi in Tabriz in the west. Approximately 700 people with leprosy are living in Mashhad because of the shrine of Imam Reza, the eighth Imam of the Shia religion, and people believe that this helps them to be cured. Not only Iranians move to Mashhad to for treatment of leprosy, but also those from different cities of Afghanistan. In 1881, the ruler of Mashhad decided to build a special area for these patients near to the Shrine of Imam Reza, called Mehrab Khan. In the 2016 report of the leprosy programme by the Ministry of Health of the Islamic Republic, it was stated that there were 11,813 registered patients with leprosy in Iran at the end of 2015, of whom 9,011 had completed treatment, 2,371 patients had died, 413 patients were missing and 18 patients were under multidrug therapy (MDT). There were 120 Afghans among the 413 missing patients. The accuracy of the statistics is questionable because of fear, the continued existence of social stigma associated with leprosy in public, traffic and entry of Afghans,

failure to provide timely statistics to the Department of Health and the lack of consistent follow-up of leprosy patients in treatment.[9]

Methods

This study is a methodological study that measures the perceived stigma of leprosy patients. The SARI (Stigma Assessment and Reduction of Impact) scale was used in this study.[10] This instrument is based on the Berger HIV Stigma Scale that was developed for patients with AIDS. The SARI project aimed to assess the effectiveness of three stigma reduction interventions for people affected by leprosy in Cirebon District, Indonesia. The Berger HIV Stigma Scale measures experienced, internal and perceived stigma, while the SARI scale examines additional aspects such as disclosure, contempt, shame, loss of self-confidence, and social and economic effects.[11] The translation, validity and reliability of the SARI scale were studied in Iran, with the permission of the lead author (Dr W. van Brakel); it was translated into Persian by two faculty members of the School of Nursing and Midwifery in Shahid Beheshti University of Medical Sciences. A back-translation was approved by Dr. van Brakel. Other steps to evaluate the validity and reliability were as follows:

FACE VALIDITY

Firstly, we asked five specialists in the field of nursing to assess the tool based on criteria such as being simple, understandable, having good written Persian and a good fit with the subject of interest. We asked them to give suggestions to enhance the face validity of the questionnaire.

CONTENT VALIDITY

The purpose of this study was to translate the SARI scale, carry out a psychometric evaluation, and then to examine the relationship between perceived stigma and the quality of life in patients with leprosy. After translation, face, content and constructive validity were confirmed, but we were not able to investigate convergent validity for two reasons: 1) Because of the high number of questions and the possibility of fatigue in the patients; 2) Given the content and structure validity which were confirmed, it was assumed that according to the original questionnaire, convergent validity was likely confirmed too.

The content validity of the questionnaire and its numerical value were determined using the minimum value of Lawshe's content validity ratio. The Lawshe method is a quantitative method to determine the content validity that is widely accepted.

For this purpose, 10 specialists were asked to categorize each question based on: 1) importance and relevance; 2) can be used but not necessary; 3) irrelevant and less significant.

A content validity ratio was calculated for each question based on the following formula:

$$CVR = \frac{n_E - \frac{N}{2}}{\frac{N}{2}}$$

n_E: The number of specialists who have voted the item as an essential question
N: Total number of specialists

Table 1. Minimum acceptable CVR in Lawshe method, based on the number of specialists

Acceptable value	Number of specialists
99%	5
99%	6
99%	7
78%	8
75%	9
62%	10
59%	11
56%	12
54%	13
51%	14
49%	15
42%	20
37%	25
33%	30
31%	35
29%	40

Results obtained after the calculation of the dimension according to the number of specialists are compared with the existing criteria in Table 1. In the study, the comments of 10 specialists were used and CVR according to the Lawshe table and number of specialists was calculated as 0·94.

In the next step, 10 specialists were asked to determine the degree of relevance and clarity of each of the items in the 4-point Likert scale based on the Waltz & Bausell content validity index (CVI).[12] If the calculated index is 0·79 or higher, it is acceptable. It should be noted that this method has high objectivity compared to other methods to determine the validity.[13]

The maximum and minimum value of the content validity index (based on the assessments of 10 specialists) were 1 and 0·85, respectively. None of the items was removed and the mean value of the content validity index (S-CVI/Ave) was 0·95.

CONSTRUCT VALIDITY

Confirmatory factor analysis was used to assess construct validity of the SARI scale. For this purpose, first and second order confirmatory factor analysis was used. Second order factor analysis was performed in order to determine whether it is possible to calculate the total score for the SARI scale or not.

The results of the first and second order factor analysis of SARI tool are provided in Figures 1 and 2 and Tables 2 to 4.

According to Table 2, it was found that there was a significant positive correlation between each of the four dimensions of the SARI scale.

According to the results presented in Table 3, it became clear that factor loading between each of the indicators is considerable and statistically significant. Also due to high factor loading between each of the four dimensions of stigma in the SARI scale (at least 0·55 to 0·77), It was determined that the construct validity of first and second order is acceptable. The indicators obtained from the model (Table 4) also showed that the first and second order of construct validity is at an acceptable level.
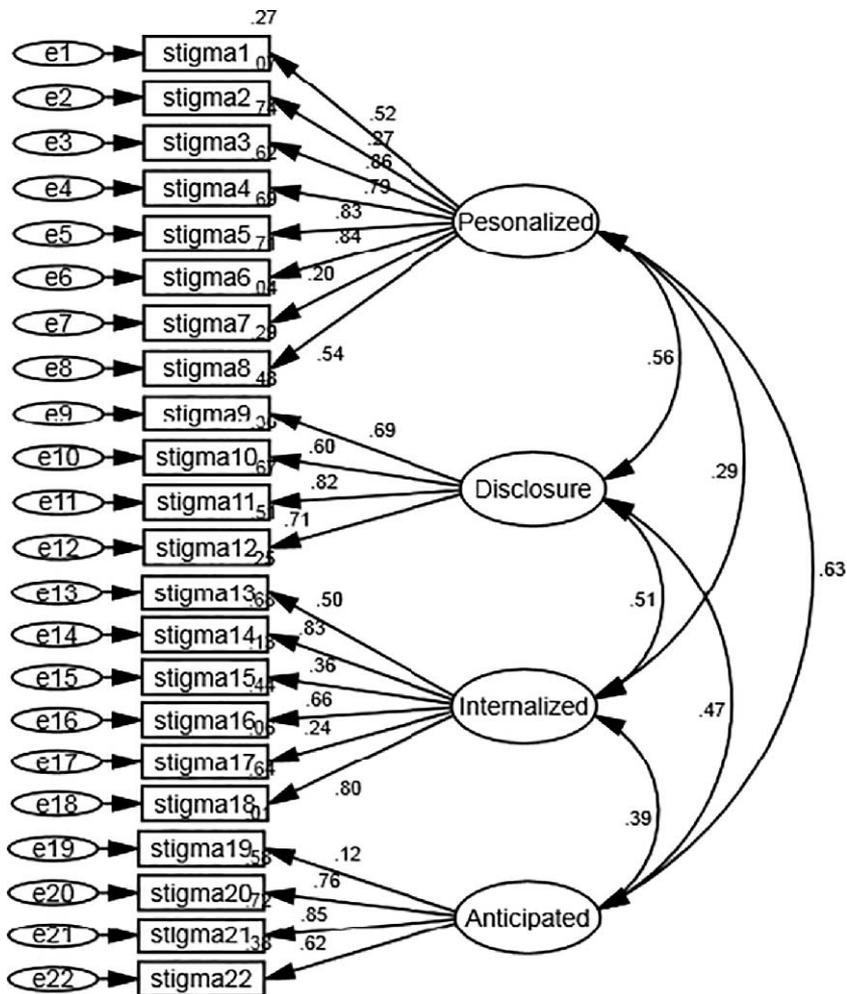
Figure 1. The results of the first order factorial analysis of the SARI scale.

RELIABILITY OF THE SARI SCALE

In a study of Luci *et al.* in 2015 the overall Cronbach's alpha of the Sari scale was 0·88 and in the dimensions of experienced stigma, revealed stigma, internal stigma and expected stigma, it was 0·82, 0·79, 0·79 and 0·79, respectively. Cronbach's alpha coefficient was used in order to investigate the reliability of the tool (internal consistency). According to the value of the coefficient of overall Cronbach's alpha and also the value of the coefficient for each dimension, it became clear that the tool has acceptable reliability. Given that the Cronbach's alpha coefficient of expected stigma was 0·625 (lower than the acceptable value), this value was accepted because the value of the coefficient of overall Cronbach's alpha was 0·897 (Table 5).

The intra-class correlation coefficient (ICC) was used in order to investigate the validity of the SARI scale. ICC was used to assess the reliability (stability) of the SARI scale over
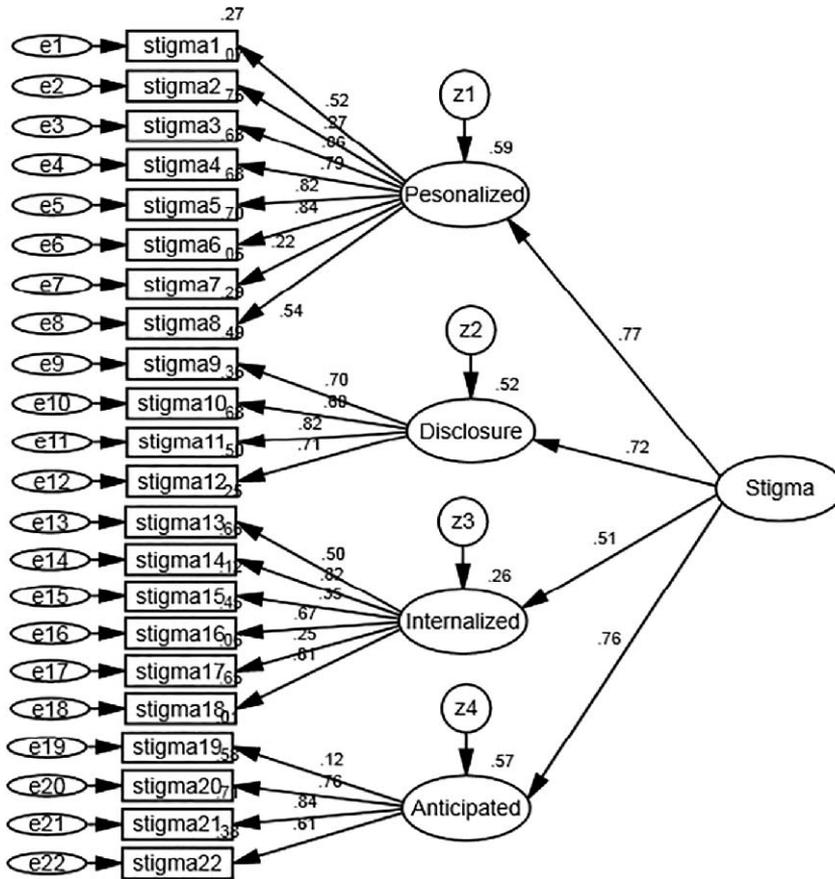
Figure 2. The results of the second order factor analysis for the SARI scale.

time. According to the intra-class correlation coefficient, the overall score was 0·892, which indicates that the SARI scale has acceptable reliability over time. For this purpose, after examining the construct validity, about 30 patients completed the SARI tool a second time. These 30 patients had announced their readiness to complete the SARI questionnaire during the previous stages and their phone numbers were given to researchers. Therefore, the

Table 2. The correlation between components of the SARI scale

P	β	SARI components		
***	0·625	Anticipated	< – >	Personalised
0·024	0·286	Internalised	< – >	Personalised
***	0·565	Disclosure	< – >	Personalised
0·002	0·472	Anticipated	< – >	Disclosure
***	0·512	Internalised	< – >	Disclosure
0·005	0·394	Anticipated	< – >	Internalised

Table 3. Beta coefficients and the significance of each coefficient obtained with respect to the second-order factor model of the SARI scale

P	β	C.R.	S.E.	Estimate	SARI components	
0·001	0·771	4·708	0·147	0·692	Stigma	<−- Personalised
0·001	0·723	5·303	0·154	0·814	Stigma	<−- Disclosure
0·001	0·513	4·155	0·176	0·731	Stigma	<−- Internalised
0·001	0·756	4·910	0·158	0·775	Stigma	<−- Anticipated
0·001	0·540	–	–	1·000	Personalised	<−- stigma8
0·044	0·215	2·011	0·205	0·411	Personalised	<−- stigma7
0·001	0·839	5·674	0·295	1·673	Personalised	<−- stigma6
0·001	0·824	5·625	0·297	1·673	Personalised	<−- stigma5
0·001	0·794	5·521	0·282	1·557	Personalised	<−- stigma4
0·001	0·863	5·747	0·272	1·563	Personalised	<−- stigma3
0·014	0·268	2·460	0·169	0·416	Personalised	<−- stigma2
0·001	0·520	4·248	0·231	0·980	Personalised	<−- stigma1
0·001	0·709	–	–	1·000	Disclosure	<−- stigma12
0·001	0·824	6·911	0·148	1·020	Disclosure	<−- stigma11
0·001	0·597	5·361	0·182	0·976	Disclosure	<−- stigma10
0·001	0·700	6·189	0·137	0·848	Disclosure	<−- stigma9
0·001	0·808	–	–	1·000	Internalised	<−- stigma18
0·019	0·250	2·341	0·097	0·228	Internalised	<−- stigma17
0·001	0·670	6·562	0·140	0·918	Internalised	<−- stigma16
0·001	0·348	3·284	0·083	0·272	Internalised	<−- stigma15
0·001	0·815	7·781	0·132	1·030	Internalised	<−- stigma14
0·001	0·504	4·842	0·112	0·541	Internalised	<−- stigma13
0·001	0·615			1·000	Anticipated	<−- stigma22
0·001	0·842	5·910	0·195	1·152	Anticipated	<−- stigma21
0·001	0·765	5·754	0·205	1·181	Anticipated	<−- stigma20
0·050	0·118	1·080	0·168	0·182	Anticipated	<−- stigma19

inter-class correlation coefficient was calculated based on the test-retest results. According to the coefficient, the reliability of the SARI scale was considered acceptable (Table 6).

Discussion and Conclusion

Stigma is a complex process that is defined as any unpleasant and undesirable attitude that is used to discredit individuals. The SARI scale is derived from the 40-item Berger questionnaire used for AIDS patients,[13] which has been approved in many countries, and its Cronbach's Alpha was 0·90 to 0·94 and in some subscales up to 0·96, which is very good and acceptable for a tool with so many items.[11]

The SARI scale was developed by international researchers in Indonesia, using collaborative methods. Counselors examined attitudes, personal qualities, skills, social and

Table 4. Fit indicators of second-order model for the SARI scale

Index	RMSEA	CFI	GFI	CMIN/DF
Obtained value	0·064	0·923	0·920	2·2
Acceptable value	0·08	0·90	0·90	3

Table 5. The results of the investigation of reliability of the SARI scale

Dimension	Item	Cronbach's alpha coefficient
Experienced Stigma	8	0·824
Revealed Stigma	4	0·784
Internal Stigma	6	0·747
Expected Stigma	4	0·625
Overall Stigma	22	0·897

Table 6. Intra-class correlation coefficient related to each component and the overall score of the SARI scale

Re-test Test	Test	ICC		Confidence Interval of 95%
		Lower Limit	Upper Limit	
Experienced Stigma	Experienced Stigma	0·819	0·935	0·778
Revealed Stigma	Revealed Stigma	0·823	0·912	0·795
Internal Stigma	Internal Stigma	0·864	0·945	0·771
Expected Stigma	Expected Stigma	0·844	0·910	0·798
Overall Stigma	Overall Stigma	0·892	0·949	0·773

*ICC: Interclass correlation Coefficient.

cultural life, knowledge and ethics, and key points were provided for the preparation of the questionnaire.[14]

In the study of the SARI scale's reliability and internal consistency (Cronbach's Alpha), the alpha coefficient was 0·88, and in the subscales was 0·79–0·89 which indicates good internal consistency.[11] This aspect was consistent with our study. However, in our study, the Cronbach's alpha coefficient for expected stigma was 0·625 (less than the acceptable limit), but it was approved because of an acceptable overall alpha (0·897). In the study of the reliability over time and intraclass correlation (ICC), the test-retest test was used, with a coefficient of 0·77, which was consistent with the Indonesian study (ICC = 0·75).[11]

This study aimed to determine the validity and psychometric properties of a Persian translation of the SARI scale, related to the perceived stigma in leprosy patients in Iran. The results of the present study showed that the reliability and validity of this tool is acceptable for use in related research in Iran, but it is requested that an appropriate tool is made with the native scenario of Iran which has spiritual and religious dimensions.

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