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Article

Validation of the Malay version of the Shame and Stigma Scale among cancer patients in Malaysia

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Abstract: Assessment of stigma among cancer patients is of utmost importance as stigma may lead to various psychological sequelae and lower quality of life. This study aimed to translate the English version of the Shame and Stigma Scale (SSS) into Malay and validate the Malay version of the SSS (SSS-M) among cancer patients in Malaysia. Initially, concurrent translation and back translation of the SSS-M was performed, and face and content validity were assessed. Then, the SSS-M was administered to a total of 234 patients of mixed types of cancer to assess its reliability (internal consistency and test-retest reliability), construct validity (convergent and discriminant validity), exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). The SSS-M total score registered good internal consistency (Cronbach's α of 0.886) and test-retest reliability (intraclass correlation coefficient of 0.846, $p < 0.001$). EFA and CFA confirmed that the SSS-M consisted of 20 items in 5 domains. Its convergent and discriminant validity were achieved. Hence, the SSS-M demonstrated good psychometric properties and is available for use to assess stigma among cancer patients in Malaysia.

Keywords: stigma; cancer patients; Malaysia; Malay version of the Shame and Stigma Scale; reliability; validity

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1. Introduction

As the prevalence of cancer continue to rise across time, it has become a major public health concern globally. According to the World Cancer Report from International Agency for Research on Cancer (IARC), World Health Organization (WHO) in 2020, there was 19.29 million new cancer cases worldwide, and breast cancer has replaced lung cancer as the world's commonest cancer diagnosis [1]. Cancer is the fourth leading cause of death among adolescents and young adults worldwide [2]. Similarly, in Malaysia, the incidence of cancer is also in an increasing trend across time. The Malaysia National cancer registry report (MNCR) revealed that a total of 115,238 new cancer cases were diagnosed between 2012-2016 which represented a 11% increase in new cases and 30% more deaths compared to the 2007-2011 report, and the commonest cancer reported was breast cancer [3].

Cancer patients often suffer from psychological distress which not only affects the treatment of cancer and quality of life (QoL), but also being regarded as an independent risk factor for increased cancer mortality [4]. Stigma refers to an inner shame experience of patients due to disease which is regarded as a negative psychological stress response. Patients who suffer from public avoidance and exclusion in social interactions are prone for public stigma. In essence, patients who have been discriminated for a long time will develop self-doubt and shame leading to development of self-stigma [5].

A meta-analysis which included a total of 7114 cancer patients indicated that cancer- related stigma induced anxiety, depression, lower QoL and stressful life events [6]. High degree of stigma was reported among breast and cervical cancer patients [7]. Meacham et al (2016) showed stigma associated with breast cancer had an influence on treatment and care engagement [8]. While in head and neck cancer patients, stigma greatly affects psychological well-being [9], and it is significantly correlated to negative psychological consequences, especially in those who suffers from severe facial disfigurement [10]. In addition, medical help-seeking was found to be independently related to stigma in lung cancer patients [11].

Despite the importance of screening for stigma among cancer patients as stigma increases the risk of psychological sequelae and affects QoL, data on stigma among cancer patients in Malaysia is lacking. There are validated screening tools used to measure stigma against cancer. The Social Impact Scale is used to assess stigma in people with AIDS or cancer and its non-specific [12]. The Cataldo lung cancer stigma scale is a multidimensional measurement tool adapted from the HIV Stigma Scale to measure stigma among lung cancer patients, but it consists of 31 items which required a long duration of administration [13]. The Lung Cancer Stigma Inventory is developed by Hamann et al. (2018) to evaluate the lung cancer stigma and consists of 25 items [14]. While the Shame and Stigma Scale (SSS) measures the degree of stigma among head and neck cancer patients [15]. SSS contains four domains and twenty items: shame with appearance (8 items), sense of stigma (6 items), regrets (3 items) and social concerns (3 items). Therefore, it has a relatively shorter time of administration which is suitable for use to assess stigma among cancer patients as their concentration to answer questionnaire may be affected by symptoms of the illness and/or adverse effects of treatment. The Cronbach α of the SSS is 0.94, and the Cronbach α of each domain ranged from 0.78 to 0.90, indicating good to excellent internal consistency [15]. To date, the SSS have been translated and validated in Portuguese with the Cronbach α of 0.85 [16], in Chinese with the Cronbach α of 0.85 [17], and in Hindi with the Cronbach α of 0.85 [18]. However, the SSS has not been translated into the Malay language and validated for use to assess stigma among cancer patients in Malaysia. Hence, in this study, we translated the original English version of the SSS into Malay, assessed the psychometric properties of the Malay version of the SSS (SSS-M), such as internal consistency and test-retest reliability, face, content, and construct validity (convergent and discriminant validity), and performed exploratory and confirmatory factor analyses to confirm its domain structures.

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2. Materials and Methods

2.1. Study design

This study received approval from the Human Research Ethics Committee of Universiti Sains Malaysia (code: USM/JEPeM/21040321) and the Research Ethics Committee of Universiti Kebangsaan Malaysia (code: UKM/PPI/111/8/JEP-2021-753) and abide by the regulations of the 1964 Declaration of Helsinki and its amendments. This validation study was conducted between January 2022 to July 2022 whereby the source population was cancer patients who were registered at Advanced Medical and Dental Institute (AMDI), Universiti Sains Malaysia (USM) and Universiti Kebangsaan Malaysia Medical Centre (UKMMC). AMDI, USM is a tertiary referral center for cancer patients in the Northern region of Peninsular Malaysia, while UKMMC is a tertiary referral centre for cancer patients and a teaching hospital in the central region of Peninsular Malaysia. Hence, selection of these two medical centers will cover the cancer populations in the northern and central region of Peninsular Malaysia. The sample size calculation was performed as follows:

(a) Calculation of sample size for internal consistency was performed using the Statstodo Programme where probability of type I error = 0.05, power = 1 – β = 0.8, expected Cronbach's α = 0.95 [19], sample size required for each item = 4 subjects, total number of items = 20 items. Hence, the estimated sample size required was 80 subjects

(b) Calculation of sample size for test-retest reliability was performed using the G*Power 3.1.9.7 sample size calculator, whereby probability of type I error = 0.05, power = 1 – β = 0.8, H1 corr ϱ_ac = -0.2. Hence, the estimated sample size required was 192 subjects

(c) Calculation of sample size for exploratory and confirmatory factor analysis:

(i) For calculation of sample size for exploratory factor analysis of the SSS-M, we refer to the Rule of 5 which states that one's sample should be at least five times the number of observed variables to be studied [20]. Hence, the subjects-to-variables ratio should be 5 or greater. The total number of items in the two questionnaires are 20 items. Therefore, estimated sample size was 100 subjects.

(ii) For calculation of sample size for confirmatory factor analysis for SSS-M, we referred to the validation of SSS study by Kissane et al. (2013) [15] and calculated the estimated sample size using A-priori Sample Size calculator for Structural Equation Models. The effect size was 0.25, power at 0.8, number of latent variables was 4, number of observed variables was 20, probability of type I error = 0.05. Hence, the estimated sample size needed was 175.

Since based on all three calculations, the largest sample size required was 192 subjects. Hence, the sample size needed for the validation of Malay version of the SSS was 230 subjects (inclusive of 20% drop out).

The participants in this study were recruited via consecutive sampling. Initially, cancer patients who attended the oncology clinics of AMDI, USM and UKMMC were approached by the research assistant and screened for inclusion and exclusion criteria. The inclusion criteria included: (a) Those who were diagnosed with any types of cancer and at any stage of cancer, (b) able to read and write in Malay language, and (c) age 18 years and above. While the exclusion criterion was: (a) those with history of mental illness and other medical illness. Those who fulfilled all the inclusion criteria and without any exclusion criterion were approached by the research team and explained about the study, including the purpose and description of the study procedures, risks and benefits, the subject's right to withdrawn from the study, and assured anonymity of the data collected before they signed the informed consent to participate in the study.

2.2. Translation and back translation of the SSS-M and content validity

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Initially, the original English version of the SSS was translated into the Malay language by a bilingual language expert who is a native speaker of Malay and a bilingual native Malay speaker in the research team. Both translators were not in contact with each other. Then, the two translators discussed the translated copies of the questionnaires to construct a third joint-translated copy of the Malay versions of both the questionnaires. Similarly, a bilingual language expert who is a native speaker of English and had not seen the original English version of the questionnaires back translated the draft of the Malay version of the questionnaire into English. Then, all the translators discussed the translated and back translated copies of the questionnaires with the research project coordinator to construct the harmonized copies of the translated and back translated questionnaires.

Then, these translated and back translated harmonized copies of the questionnaire were examined by a team of content experts consist of an oncologist, a psychiatrist, two psychologists, and two community health specialists to construct the first draft of the Malay version of the Stigma and Shame Scale (SSS-M). Each expert was asked to assess the relevance of the questions and the response options for each item of the SSS-M. The rating options by the experts were as follows: "item is not relevant to the measured domains", "item is relevant to the measured domain" and "item is very relevant to the measured domain". Experts who rated the item as "item is not relevant to the measured domains" was given a score of 0, while experts who rated the item as "item is relevant to the measured domain" and "item is very relevant to the measured domain" were given a score of 1. The item-level content validity index (I-CVI) for each item was measured as the number of experts who gave a rating of "relevant" and "very relevant" for the item relative to their measured domain divided by the total number of experts. A value of ≥ 0.83 was considered as acceptable [21,22]. Scale-level content validity index according to the universal agreement (UA) among experts (S-CVI/UA) was evaluated as the sum of all the items in the SSS-M with UA of equal to 1, divided by the total number of items of the SSS-M. UA for an item was scored as 0 if not all the experts rated the item as "relevant" or "very relevant" to the measured domain, while UA was scored as 1 if all the experts rated the item as "relevant" or "very relevant" to the measured domain. The average scale-level CVI (S-CVI/Ave) was assessed as the sum of the I-CVI divided by the total number of items in the SSS-M. A S-CVI/UA score of > 0.8 and a S-CVI/Ave score of > 0.9 were considered as having a high CVI [23,24].

Then, the draft of the SSS-M was administered to 20 native Malay speaking cancer patients recruited from AMDI, USM to assess the semantic quality, comprehensibility, and appropriateness of administration duration. They were interviewed to pinpoint any redundant sentences, wordings and time taken to complete the questionnaires. They were asked to rate whether the words, sentences, and instructions of the SSS-M were "not appropriate", "appropriate", or "very appropriate" and to comment on any wording and sentences which need to be amended. In the pilot study, 65% of the respondents rated the semantic quality, comprehensibility and appropriateness of administration duration of all the wordings, sentences and instructions of the SSS-M as "appropriate" and another 35% rated the SSS-M as "very appropriate". There were no comments on any redundant wordings and sentences and no need to amend any wordings, sentences, and instructions. Hence, the SSS-M did not require further amendment from the panel of experts.

2.3. Measures

Initially, during baseline assessment, 234 cancer patients were recruited and were administered socio-demographic and clinical characteristics questionnaire and the SSS-M. Then, follow up assessment commence 3 weeks after the baseline assessment and the same participants

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were re-assessed with the SSS-M to evaluate the test-retest reliability. There were 117 participants who completed the follow-up assessment.

The socio-demographic and clinical characteristics questionnaire included data on age, gender, ethnicity, monthly household income, marital status, education level, types of cancer and stage of cancer. Each participant's age could be reported as "18-25 years old", "26-45 years old", "46-65 years old", and "more than 65 years". Gender could be registered as "male" and "female". Ethnicity could be recorded as "Malay", "Chinese" and "Indian". Monthly household income could be documented as "less than RM 4,500", "RM 4500-RM 11000", and "more than RM 11000". The marital status of the participants could be recorded as "married" and "single/divorcee/widow/widower". The education level of the participants could be reported as "up to primary education or below", "up to secondary education", and "up to tertiary education". As for types of cancer, it could be documented as "breast cancer", "head and neck cancer", "colorectal cancer", and other types of cancer". Finally, stage of cancer could be documented as "stage 1", "stage 2", "stage 3", and "stage 4". The data on the clinical characteristics of the participants were initially provided by the participants and the validity was confirmed by counterchecking the data with their medical files.

The Shame and Stigma Scale (SSS) is a self-administered instrument for evaluating the sense of shame and stigma reported by head and neck cancer patients. It is a self-reported instrument consists of 20 items, designated into four domains. Eight items are assigned to shame and appearance, three are assigned to social isolation, six to the feeling of stigma, and three items to regrets. Each item is scored in a 5-point Likert scale ranging from 0 to 4, where 0 corresponds to ''never'', 1 to ''seldom'', 2 to ''sometimes'', 3 to ''often'', and 4 to ''all the time''. Hence, its total score could range from 0 to 80, where higher score indicated higher degree of stigma due to cancer [15].

2.4. Statistical analysis

All the data was analyzed by the Statistical Package for Social Sciences version 26 (SPSS 26; SPSS Inc., Chicago, Illinois), except for confirmatory factor analysis which was performed using the SPSS Amos version 26 software (SPSS Amos 26). Descriptive statistics for the socio-demographic and clinical characteristics, and SSS-M scores at baseline and follow up were presented. All nominal data was presented as frequency and percentage, while all continuous data was presented as mean and standard deviation (SD). Internal consistency of all the domains and total score of SSS-M (in Cronbach's α) was assessed to measure the reliability of the SSS-M. Cronbach's α of > 0.7 was considered as acceptable. Test-retest reliability was also computed to further measure the reliability of the SSS-M which was presented as intraclass correlation coefficient (ICC). The ICC of > 0.5 indicated acceptable reliability, while a value of 0.75 to 0.90 depicted good reliability, and a value of > 0.90 indicated excellent reliability. Construct validity of the SSS-M was evaluated with exploratory factor analysis (EFA), confirmatory factor analysis (CFA), convergent and discriminant validity. In EFA assessment, initially factor extraction was performed for the SSS-M, whereby the Kaiser-Meyer-Olkin measure of sample adequacy value of > 0.6 was considered as acceptable, the Barlett's test of sphericity in which a p-value of < 0.05 indicated a valid EFA, and only factors with Eigenvalue of > 1 was retained. Factor extraction was then followed by Promax oblique rotation of variables, by which only items with factor loading of > 0.4 was considered acceptable. In CFA assessment, the best fitting factor model of the SSS-M was determined based on several variables: (a) standardized chi-square ($\chi 2/df$) of < 3.0 was considered acceptable, (b) Tucker-Lewis index (TLI) of ≥ 0.95 was considered acceptable, (c) comparative fit index (CFI) of ≥ 0.95 was considered acceptable, (d) goodness of fit index (GFI) of ≥ 0.90 was considered acceptable, and (e) root mean square error of approximation (RMSEA) of < 0.06 was taken as acceptable. The convergent validity of the SSS-M was evaluated by

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referring to the best fitting factor model of SSS-M confirmed by CFA, by which the average variance extracted (AVE) was calculated as (sum of the squared factor loadings of the items designated to the measured domain) / (sum of the total number of indicators). The AVE of > 0.5 was taken as acceptable indicating that the SSS-M had achieved convergent validity. As for discriminant validity, it was again assessed based on the CFA's best fitting factor model of SSS-M, whereby if the square root of AVE of the measured domain was higher than all the inter-construct correlation between domains of the SSS-M, then discriminant validity was considered achieve.

3. Results

3.1. Participants

The socio-demographic and clinical characteristics, and total SSS-M scores of all the participants are presented in Table 1. More than half of the participants were females (n = 153, 65.4%) and slightly more than half of them were within the middle age group that was between 46 to 65 years old (n = 120, 52.3%). Majority of the participants were within the low-income group, earning less than RM 4,500 per month (n = 193, 82.5%). In the context of clinical characteristics, slightly more than two fifth of the participants were diagnosed with breast cancer (n = 100, 42.7%) and more than half of the participants were in more advanced stage of cancer (stage 3 and 4, n = 144, 61.5%). The mean total SSS-M score at baseline was 17.37 (SD = 11.03), whereas the mean total SSS-M score at follow up was 18.19 (SD = 12.68).

Table 1. Socio-demographic and clinical characteristics of the participants

Variables	Number of participants (n)	Percentage (%)
Age:		
18-25 years old	2	0.9
26-45 years	63	26.9
46-65 years	120	51.3
> 65 years	49	20.9
Gender:		
Male	81	34.6
Female	153	65.4
Ethnicity:		
Malays	182	77.8
Chinese	37	15.8
Indians	15	6.4
Monthly household income:		
< RM 4,500	193	82.5
RM 4500-RM 11000	35	15.0
> RM 11000	6	2.5
Marital status:		
Married	197	84.2
Single/divorcee/widow/widower	37	15.8
Education status:		
Primary education or below	31	13.2
Up to secondary education	130	55.6
Tertiary education and above	73	31.2

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Types of cancer:		
Breast cancer	100	42.7
Head and neck cancer	72	30.8
Colorectal carcinoma	28	12.0
Others	34	14.5
Stage of cancer:		
Stage 1	26	11.1
Stage 2	64	27.4
Stage 3	78	33.3
Stage 4	66	28.2
Total SSS score (baseline)	17.37[a]	11.03[b]
Total SSS score (follow up)	18.19[a]	12.68[b]

[a] Mean, [b] standard deviation

3.2. Content validity index of the SSS-M

The content validity index of the SSS-M is summarized in Table 2. The I-CVI of all the items in SSS-M ranged from 0.83 to 1.0. The S-CVI/Ave of the SSS-M was 0.97. Finally, the S-CVI/UA of the SSS-M was 0.85.

Table 2. Content validity index (CVI) of the SSS-M by six experts

Items	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Experts in agreement	I-CVI	UA
Item 1	1	1	1	1	1	1	6	1	1
Item 2	1	1	1	1	1	1	6	1	1
Item 3	1	1	1	1	1	1	6	1	1
Item 4	1	1	0	1	1	1	5	0.83	0
Item 5	1	1	1	1	1	1	6	1	1
Item 6	1	1	1	1	1	1	6	1	1
Item 7	1	1	1	1	1	1	6	1	1
Item 8	1	1	1	1	1	1	6	1	1
Item 9	1	1	1	1	1	1	6	1	1
Item 10	1	1	1	1	1	1	6	1	1
Item 11	1	1	1	1	1	1	6	1	1
Item 12	1	1	1	1	1	1	6	1	1
Item 13	1	1	1	1	1	1	6	1	1
Item 14	1	1	1	0	1	1	5	0.83	0
Item 15	1	1	1	1	1	1	6	1	1
Item 16	1	1	1	1	1	1	6	1	1
Item 17	1	1	1	0	1	1	5	0.83	0
Item 18	1	1	1	1	1	1	6	1	1
Item 19	1	1	1	1	1	1	6	1	1
Item 20	1	1	1	1	1	1	6	1	1
Proportion relevance	1.00	1.00	0.95	0.90	1.00	1.00			
Average proportion							**S-CVI/Ave:**	**0.97**	

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of items judged as relevant across the six experts	**S-CVI/UA**	**0.85**
	0.98	

I-CVI = item-level content validity index, UA = universal agreement, S-CVI/Ave = average of the scale-level content validity index, S-CVI/UA = average of the scale-level content validity index across universal agreement among experts

3.3. Exploratory and confirmatory factor analyses of the SSS-M

The exploratory factor analysis of the SSS-M with Promax oblique rotation and Kaiser normalization are summarized in Table 3. A total of five factors were extracted (five factors with Eigenvalue of > 1.0) with the Kaiser-Meyer-Olkin measure of sample adequacy value of 0.892 and the Barlett's test of sphericity was significant ($p < 0.001$). Promax oblique rotation of the variables revealed that the shame of appearance domain consisted of 5 items with factor loadings ranged between 0.590 to 0.801 (items 2, 3, 5, 6 and 8), while the sense of stigma domain had 7 items with factor loadings ranged between 0.669 to 0.861 (items 10, 11, 12, 13, 14, 18, and 19). The regrets domain was made up of 3 items with factor loadings ranged from 0.723 to 0.886 (items 15, 16, and 17). We discovered a new domain for SSS-M i.e. positive perception domain which consisted of 4 items with factor loadings ranged from 0.534 to 0.773 (items 1R, 4R, 7R, and 20R). Finally, item 9 was the only item in the fifth factor extracted. Since item 9 evaluated one of the components of stigma, which was self-discrimination [25], the domain which item 9 was designated to was named as self-discrimination. All five factors contributed to a total variance of 61.218% of the SSS-M.

Table 3. Exploratory factor analysis with Promax rotation and Kaiser normalization for the SSS-M

Items	Shame with appearance	Sense of stigma	Positive perception	Regret	Self-discrimination
Item 2	0.739				
Item 3	0.777				
Item 5	0.517				
Item 6	0.801				
Item 8	0.590				
Item 10		0.827			
Item 11		0.861			
Item 12		0.669			
Item 13		0.726			
Item 14		0.725			
Item 18		0.829			
Item 19		0.730			
Item 1R			0.773		
Item 4R			0.674		
Item 7R			0.534		
Item 20R			0.621		
Item 15				0.726	
Item 16				0.723	
Item 17				0.886	
Item 9					0.727

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Eigenvalue	6.798	1.880	1.258	1.238	1.070
Variance (%)	33.988	9.399	6.289	6.191	5.350
Total variance (%)					61.218

As for CFA assessment of the SSS-M, a 4-factor model of the SSS-M whereby the items were allocated to domains similar to that of the original English version of the SSS was not fitting (χ^2/df = 1.986, TLI = 0.889, CFI = 0.906, GFI = 0.874, and RMSEA = 0.065). Then, a 4-factor model of the SSS-M with item 9 omitted was also not fitting (χ^2/df = 1.968, TLI = 0.898, CFI = 0.913, GFI = 0.880, and RMSEA = 0.064). Another 4-factor model of the SSS-M (whereby items 8, 10, 11, 12, 13, 14, 18, and 19 were allocated to the sense of stigma domain, items 2, 3, 5, 6, and 9 were allocated to the shame of appearance domain, items 1(R), 4(R), 7(R), and 20(R) were allocated to the positive perception domain, and items 15, 16, and 17 were allocated to regrets domain) were also not fitting (χ^2/df = 1.779, TLI = 0.912, CFI = 0.925, GFI = 0.887, and RMSEA = 0.058). Finally, a 5-factor model with items allocation to domain similar to the EFA findings (whereby items 2, 3, 5, 6 and 8 were designated to shame of appearance domain, items 10, 11, 12, 13, 14, 18, and 19 were designated to sense of stigma domain, items 1(R), 4(R), 7(R), and 20(R) were designated to positive perception domain, items 15, 16, and 17 were designated to regrets domain, and item 9 was designated to self-discrimination domain) was the best-fitting model of the SSS-M (χ^2/df = 1.563, TLI = 0.954, CFI = 0.958, GFI = 0.907, and RMSEA = 0.051). The CFA findings of the SSS-M are summarized in Table 4.

Table 4. Confirmatory factor analysis of three different models of the Malay version of the Shame and Stigma Scale (SSS-M)

Variables	5-factor model (according to EFA)	4-factor model (according to EFA but omit item 9)	4-factor model (including item 9)	4-factor model (according to original English version of the SSS)
Chi-square (χ2/df)	1.563	1.968	1.779	1.986
Comparative fit index (CFI)	0.958	0.913	0.925	0.906
Goodness of fit index (GFI)	0.907	0.880	0.887	0.874
Tucker-Lewis index (TLI)	0.954	0.898	0.912	0.889
Root mean square error of approximation (RMSEA)	0.051	0.064	0.058	0.065

3.4. The convergent and discriminant validity of the SSS-M

The evaluation of the convergent and discriminant validity of the SSS-M which was based on the best-fitting 5-factor model of the SSS-M are presented in Table 5. The average variance extracted (AVE) of all the 5 factors confirmed for the SSS-M ranged from 0.510 to 1.000. The square root of AVE

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for the shame with appearance (SWA) domain was 0.727 which was higher than the inter-construct correlations of SWA domain with all other domains of the SSS-M (correlations ranged from 0.387 to 0.704). The square root of AVE for the sense of stigma (SS) domain was 0.729 which was higher than the inter-construct correlations of SS domain with all other domains of the SSS-M (correlations ranged from 0.375 to 0.704). Similarly, the square root of AVE for the positive perception (PP) domain was 0.714 which was higher than the inter-construct correlations of PP domain with all other domains of the SSS-M (correlations ranged from 0.194 to 0.516). The square root of AVE for the regrets (R) domain was 0.721 which was higher than the inter-construct correlations of R domain with all other domains of the SSS-M (correlations ranged from 0.275 to 0.567). Finally, the square root of AVE for the self-discrimination (S-D) domain was 1.000 which was higher than the inter-construct correlations of B domain with all other domains of the SSS-M (correlations ranged from 0.194 to 0.387).

Table 5. Convergent and discriminant validity of the Malay version of the Shame and Stigma Scale (SSS-M)

Indicator variables	Latent variables	Standardized loading	Square of standardized loading	Sum of squared of standardized loading	Number of indicators	AVE	Square root of AVE	Inter-construct correlation
Item 2	SWA	0.725	0.526	2.640	5	0.528	0.727	SWA<-->R = 0.567, SWA<-->PP = 0.516, SWA<-->SS = 0.704, SWA<-->S-D = 0.387
Item 3	SWA	0.679	0.461					
Item 5	SWA	0.729	0.531					
Item 6	SWA	0.838	0.702					
Item 8	SWA	0.648	0.420					
Item 10	SS	0.736	0.542	3.726	7	0.532	0.729	SS<-->SWA = 0.704, SS<-->R = 0.638, SS<-->PP = 0.431, SS<-->S-D = 0.375
Item 11	SS	0.793	0.629					
Item 12	SS	0.676	0.457					
Item 13	SS	0.609	0.371					
Item 14	SS	0.739	0.546					
Item 18	SS	0.782	0.612					
Item 19	SS	0.754	0.569					
Item 1R	PP	0.704	0.496	2.038	4	0.510	0.714	PP<-->SWA = 0.516, PP<-->SS = 0.431, PP<-->R = 0.195, PP<-->S-D = 0.194
Item 4R	PP	0.792	0.627					
Item 7R	PP	0.695	0.483					

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Item 20R	PP	0.657	0.432					
Item 15	R	0.874	0.764	1.559	3	0.520	0.721	R<-->SWA = 0.567, R<-->SS = 0.538, R<-->PP = 0.195, R<-->S-D = 0.275
Item 16	R	0.632	0.399					
Item 17	R	0.629	0.396					
Item 9	S-D	1.000	1.000	1.000	1	1.000	1.000	S-D<-->SWA = 0.387, S-D<-->SS = 0.375, S-D<-->PP = 0.194, S-D<-->R = 0.275

AVE = average variance extracted, SWA= shame with appearance, SS = sense of stigma, PP = positive perception, R = regrets, S-D = self-discrimination

3.5. Reliability of the SSS-M (internal consistency and test-retest reliability)

The internal consistency of the domains of SSS-M exhibited Cronbach's α ranged from 0.570 to 1.000, whereas the internal consistency of the total SSS-M score registered a Cronbach's α of 0.886. In the context of the test-retest reliability, the intraclass correlation coefficient (ICC) of the domains of the SSS-M ranged from 0.714 to 0.933 and all were statistically significant ($p < 0.001$). While the intraclass correlation coefficient of the total SSS-M score was 0.846 and statistically significant ($p < 0.001$). The internal consistency and test-retest reliability of the SSS-M are summarized in Table 6.

Table 6. Internal consistency and test-retest reliability of the SSS-M

Domains	Internal consistency (Cronbach's α)	Test-retest reliability (intraclass correlation coefficient)
Shame with appearance	0.747	0.789, $p < 0.001$*
Sense of stigma	0.886	0.788, $p < 0.001$*
Positive perception	0.570	0.714, $p < 0.001$*
Regret	0.685	0.843, $p < 0.001$*
Self-discrimination	1.000	0.933, $p < 0.001$*
Total SSS	0.869	0.846, $p < 0.001$*

* statistical significance at $p < 0.05$

4. Discussion

This study translated the original English version of the SSS into Malay and validated and adapted the SSS-M for assessing shame and stigma among cancer patients in Malaysia by evaluating the reliability and validity of the SSS-M among Malaysian patients with various types of cancer. In term of reliability, the SSS-M and its domains exhibited acceptable to good internal consistency except

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for positive perception (Cronbach's α of 0.570) and the regrets (Cronbach's α of 0.685) domains. It is common that too few items designated to the measured a domain may result in low Cronbach's α value of the measured domain [26]- positive perception has only 4 items and regrets has 3 items. Otherwise, the internal consistency of the SSS-M total score (Cronbach's α of 0.886) was similar to that of the Chinese version of the SSS (Cronbach's α of 0.85) [17] and the Hindi version of the SSS (Cronbach's α of 0.85) [18] as well as almost comparable to the internal consistency of the original English version of the SSS (Cronbach's α of 0.94) [15]. As for the test-retest reliability, the domains (ICC ranged from 0.714 to 0.933, $p < 0.001$) and the total SSS-M (ICC = 0.846, $p < 0.001$) registered good to excellent test-retest reliability as compared to the domains (ICC ranged from 0.295 to 0.680, $p < 0.05$) and total score (ICC = 0.655, $p < 0.05$) of the Chinese version of the SSS [17].

The translation and back translation of the SSS-M followed the standard procedures of translation of questionnaires by the World Health Organization [27]. In the context of content validity index, the I-CVI of all the items in the SSS-M ranged from 0.83 to 1.00, indicating acceptable I-CVI, whereas the S-CVI/Ave was above 0.9 and the S-CVI/UA of the SSS-M was above 0.8, denoting that the content validity index was good. In the pilot study to test the semantic quality, comprehensibility, and appropriateness of administration duration of the SSS-M, the native Malay speaking cancer respondents commented that all the wordings, sentences and instructions as well as duration of administration were either "appropriate" and "very appropriate", with no redundant structures and no need for amendment. These findings revealed that the SSS-M had achieved good face and content validity.

The EFA performed in this study extracted 5 factors with the factor loadings of all the items designated to their respective domains were above 0.4. The Chinese version of the SSS also extracted 5 factors [17], unlike the English version of the SSS [15]. However, in the SSS-M, we could not extract items which are representative of the social concern domain. Instead, we extracted a factor representing positive perception which consisted of items 1R, 4R, 7R and 20R. The other factors extracted were similar to that of the Chinese version of SSS, such as shame of appearance, sense of stigma, self-discrimination, and regrets [17]. Moreover, CFA of the SSS-M confirmed that the factor structures and model extracted by EFA was indeed the best fitting model of the SSS-M: consists of 5 domains, in which items 2, 3, 5, 6 and 8 were designated to shame of appearance domain, items 10, 11, 12, 13, 14, 18, and 19 were designated to sense of stigma domain, items 1(R), 4(R), 7(R), and 20(R) were designated to positive perception domain, items 15, 16, and 17 were designated to regrets domain, and item 9 was designated to self-discrimination domain. The discrepancy in the item's allocation and factor structures of the SSS-M as compared to the original English version of the SSS may be due to differences in the language used and cultural difference. The wordings available in both languages to describe the meaning of the items of SSS may differ which may results in this discrepancy. However, the similarity in the factor structure of the SSS-M and the Chinese version of the SSS, may be contributed by some similarity in cultural background between both countries. The explanation of how the positive perception domain was extracted may be due to differences in the understanding of the reverse scoring items of the SSS between the participants in this study and that of the validation study of the original English version of the SSS, as pinpointed by Goyal et al. (2021) [18].

In term of the convergent validity of the SSS-M, based on the best fitting 5-factor model of the SSS-M confirmed by CFA, the AVE of all the 5 domains of the SSS-M were more than 0.5 (Table 5), indicating that convergent validity was achieved. As for the discriminant validity of the SSS-M, since all the square root of AVE of all the domains of SSS-M were higher than the inter-construct correlations of all the domains (Table 5), discriminant validity of the SSS-M was achieved.

This validation study had a few limitations. First, concurrent validity was not assessed in this study as there is no gold standard instrument in translated Malay version which evaluate stigma

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among cancer patients in Malaysia. Second, the gender and ethnicity distribution of the study sample were not representative of the cancer population in Malaysia. Hence, this will affect the generalizability of our research findings.

Despite these limitations, this study successfully translated the original English version of the SSS into Malay and validated the Malay version of the SSS among cancer patients in Malaysia. Clinically, it is pivotal to screen for stigma among cancer patients which could contribute to several psychological sequelae and lower the quality of life of cancer patients and provide important data to guide development of psychosocial interventions to reduce stigma among cancer patients in Malaysia. Hence, a validated screening tool for stigma among Malaysian cancer patients, such as the SSS-M, is of utmost importance for clinical use.

5. Conclusion

The SSS-M was successfully translated from the original English version of the SSS and exhibited good psychometric properties, such as internal consistency and test-retest reliability (reliability), face, content, and construct validity (validity). EFA and CFA confirmed that the SSS-M was made up of 20 items allocated to 5 domains (shame with appearance, sense of stigma, regrets, positive perception, and self-discrimination). The SSS-M can now use to assess perception of shame and stigma among cancer population in Malaysia.

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References:

1. World Health Organization (WHO). World cancer report 2020. 2020. Available online: https://www.iarc.fr/cards_page/world-cancer-report/. (accessed 15 August 2022).
2. GBD 2019 Adolescent and Young Adult Cancer Collaborators. The global burden of adolescent and young adult cancer in 2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Oncol.* **2022**, 23, 27-52.
3. Ministry of Health Malaysia. Malaysia National Cancer Registry Report (MNCR) 2012-2016. Available online: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.moh.gov.my/moh/resources/Penerbitan/Laporan/Umum/2012-2016%20(MNCRR)/MNCR_2012-2016_FINAL_(PUBLISHED_2019).pdf (accessed 17 August 2022).
4. Yang, Y. L., Liu, L., Wang, Y., Wu, H., Yang, X. S., Wang, J. N., Wang, L. The prevalence of depression and anxiety among Chinese adults with cancer: a systematic review and meta-analysis. *BMC Cancer*. **2013**, 13, 1-15.
5. Corrigan, P. W., Kerr, A., Knudsen, L. The stigma of mental illness: explanatory models and methods for change. *Appl Prev Psychol*. **2005**, 11, 179-190.
6. Huang, Z., Yu, T., Wu, S., Hu, A. Correlates of stigma for patients with cancer: a systematic review and meta-analysis. *Supportive Care Cancer*. **2021**, 29, 1195–1203.
7. Nyblade, L., Stockton, M., Travasso, S., Krishnan, S. A qualitative exploration of cervical and breast cancer stigma in Karnataka, India. *BMC Womens Health*. **2017**, 17, 1-15.
8. Meacham, E., Orem, J., Nakigudde, G., Zujewski, J.A., Rao, D. Exploring stigma as a barrier to cancer service engagement with breast cancer survivors in Kampala, Uganda. *Psychooncology*. **2016**, 25, 1206–1211.
9. Goyal, A. K., Bakshi, J., Panda, N. K., Kapoor, R., Vir, D., Kumar, K., Aneja, P. Assessment of Shame and Stigma in Head and Neck Cancer: A Meta-Analysis. *J. Maxillofac. Oral Surg.* **2021**, 102, 1-7.
10. Lebel, S., Castonguay, M., Mackness, G., Irish, J., Bezjak, A., Devins, G. M. The psychosocial impact of stigma in people with head and neck or lung cancer. *Psychooncology*, **2013**, 22, 140-152.
11. Carter-Harris, L., Hermann, C.P., Schreiber, J., Weaver, M.T., Rawl, S.M. Lung cancer stigma predicts timing of medical help-seeking behavior. *Oncol Nurs Forum*. **2014**, 41, E203–E210.
12. Fife, B. L., Wright, E. R. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav*. **2000**, 41, 50-67.
13. Cataldo, J.K., Slaughter, R., Jahan, T.M., Pongquan, V.L., Hwang, W.J. Measuring stigma in people with lung cancer: psychometric testing of the cataldo lung cancer stigma scale. *Oncol Nurs Forum.* **2011**, 38, E46-54.
14. Hamann, H. A., Shen, M. J., Thomas, A. J., Lee, S. J. C., Ostroff, J. S. Development and preliminary psychometric evaluation of a patient-reported outcome measure for lung cancer stigma: The Lung Cancer Stigma Inventory (LCSI). *Stigma Health*. **2018**, 3, 195-203.
15. Kissane, D. W., Patel, S. G., Baser, R. E., Bell, R., Farberov, M., Ostroff, J. S., Li, Y., Singh, B., Kraus, D.H., Shah, J.P. (2013). Preliminary evaluation of the reliability and validity of the Shame and Stigma Scale in head and neck cancer. *Head Neck.* **2013**, 35, 172-183.
16. Pirola, W. E., Paiva, B. S. R., Barroso, E. M., Kissane, D. W., Serrano, C. V. M. P., Paiva, C. E. Translation and cultural adaptation of the Shame and Stigma Scale (SSS) into Portuguese (Brazil) to evaluate patients with head and neck cancer. *Braz J Otorhinolaryngol*. **2017**, 83, 697-704.

Preprints (www.preprints.org) | NOT PEER-REVIEWED | Posted: 31 August 2022 doi:10.20944/preprints202208.0550.v1

17. Tseng, W.T., Lee, Y., Hung, C.F., Lin, P.Y., Chien, C.Y., Chuang, H.C., Fang, F.M., Li, S.H., Huang, T.L., Chong, M.Y., Wang, L.J. Validation of the Chinese Version of the Shame and Stigma Scale in Patients with Head and Neck Cancer. *Cancer Manag Res.* **2019**, 11, 10297-10305.
18. Goyal, A.K., Bakshi, J., Panda, N.K., Kapoor, R., Vir, D., Kumar, K., Aneja, P., Singh, B., Gupta, M., Singh Walia, S. Translation and Validation of Shame and Stigma Scale for Head and Neck Cancer into the Hindi Language. *J. Maxillofac. Oral Surg.* **2021**, 100, 1-15.
19. Ramli, M., Mohd Ariff, F., Khalid, Y., Rosnani, S. Validation of the Bahasa Malaysia version of the Coping Inventory for Stressful Situation. *Malaysian Journal of Psychiatry Online.* **2008**, 17, 1-8.
20. Bryant, F. B., Yarnold, P. R. Principal-components analysis and exploratory and confirmatory factor analysis. In *Reading and understanding multivariate statistics*, (Eds.); Grimm, L. G., Yarnold, P. R., Eds. American Psychological Association: Washington, DC., 1995; pp. 99-136.
21. Polit, D.F., Beck, C.T. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health.* **2006**, 29, 489–497.
22. Polit, D.F., Beck, C.T., Owen, S.V. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health.* **2007**, 30, 459–467.
23. Shi, J., Mo, X., Sun, Z. Content validity index in scale development. *Zhong Na Da Xue Xue Bao Yi Xue Ban*. **2012**, 37, 152–155.
24. Zamanzadeh, V., Ghahramanian, A., Rassouli, M., Abbaszadeh, A., Alavi-Majd, H., Nikanfar, A.R. Design and implementation content validity study: development of an instrument for measuring patient-centered communication. *J Caring Sci.* **2015**, 4, 165–178.
25. Murray, C.E., Crowe, A., Overstreet, N.M. Sources and components of stigma experienced by survivors of intimate partner violence. *J Interpers Violence.* **2018**, 33, 515-536.
26. Tavakol, M., Dennick, R. Making sense of Cronbach's alpha. *Int J Med Educ*. **2011**, 2, 53-55.
27. World Health Organization. Process of translation and adaptation of instruments. 2019 [Online]. Available at: https://www.who.int/substance_abuse/research_tools/translation/en/. (accessed 21 August 2022).