RESEARCH ARTICLE

Editorial Process: Submission:07/08/2022 Acceptance:01/07/2023

Validation of the Cancer Stigma Scale in Nepalese Women

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Abstract

Background: Cancer stigma is known to have an adverse impact on cancer patients as well as vulnerable groups who are at risk of developing cancer. In Nepal, there is no validated instrument for assessing cancer stigma and there has been relatively little research examining the stigmatization of cancer among the Nepalese population. **Objective:** We aimed to validate the Cancer Stigma Scale (CASS) among apparently healthy Nepali women. **Methods:** We interviewed 426 Nepali women after the translation, back-translation, and cross-cultural adaptation of the CASS into Nepali. We assessed internal consistency using Cronbach's alpha and assessed model fit using confirmatory component analysis. **Results:** The Nepali CASS had satisfactory internal reliability, Cronbach's alpha of the overall scale and six components was 0.88 and 0.70–0.89, respectively. Confirmatory factor analysis confirmed the six-factor structure (RMSEA = 0.074, GFI = 0.864, AGFI = 0.825, CFI = 0.901, NFI = 0.866, $\chi 2/df=3.341$). Having no formal education was associated with higher levels of stigma related to avoiding cancer patients and attributing cancer to personal responsibility. **Conclusions:** The Nepali CASS demonstrated sufficient internal consistency, reliability, and model fit indices, making it suitable for assessing cancer stigma among Nepali people.

Keywords: CASS- cancer- Nepal- stigma

Asian Pac J Cancer Prev, **24 (1)**, 207-214

Introduction

With 19.3 million new cases and 10 million deaths in 2020, cancer is the second leading cause of mortality globally (Sung et al., 2021). The age-standardized cancer incidence and death rates in Nepal were 103.7 per 100,000 and 77.8 per 100,000, respectively, in 2018 (World Health Organization, 2020). In high-income countries, vaccination, early detection and treatment have dramatically reduced cancer prevalence and mortality (Kamaraju et al., 2020; Mitchell, 2020; Thun et al., 2010). However, both overall incidence and mortality from cancer are increasing in low- and middle-income countries (LMICs) due to social barriers, including unhelpful attitudes, stereotypes, discrimination and stigma (Shah et al., 2019). Cancer stigma – a social process of exclusion, rejection, blame, or devaluation due to cancer diagnosis (Link and Phelan, 2001) – is a barrier to successful cancer prevention care including, screening, and treatment interventions, that define the cancer care continuum (Chidyaonga-Maseko et al., 2015; Tripathi et al., 2017; Broom and Doron, 2012). Cancer stigma has a negative influence on cancer patients as well as vulnerable groups who are at risk of developing cancer. High-risk populations are hesitant to undergo cancer screening tests due to fear of being stigmatized, resulting in delayed optimal treatment outcomes (Friedman and Shepeard, 2007; Kwok et al., 2006; Lopez-McKee et al., 2008). A recent study in Nepal identified fear of cancer detection and social stigma as the two most prominent causes for lack of screening (Rademaker et al., 2021). There has been an upsurge of studies on cancer patients' perception of stigma in recent years, but less systematic research into the broader public's perspectives.

A valid and reliable tool to measure public stigma and attitude towards cancer in Nepal is necessary.

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Marlow and Wardle, (2014) developed a 25-item Cancer Stigma Scale (CASS) in the United Kingdom to examine several dimensions of cancer stigma in a non-patient population. The scale evaluates six dimensions of stigma: awkwardness, avoidance, perceived severity, policy opposition, personal responsibility, and financial discrimination. The CASS's psychometric properties have been examined, and the findings show good internal consistency and construct validity. The CASS was validated in China (Ye et al., 2019) and Japan (Takeuchi et al., 2021), with a comparable structure to the original and acceptable internal consistency, reliability, and model fit indices were obtained.

There are a few previous studies in Nepal that have assessed attitudes about cancer stigma (Thapa et al., 2018; Poudel and Sumi, 2019). CASS may be a suitable tool to measure cancer stigma in the general Nepali population. However, a locally validated tool is necessary to assess public cancer stigma assessment and develop strategies to address domains of cancer stigma in the community. This study translates the CASS into Nepalese and tests its psychometric properties in a Nepali population.

Materials and Methods

Translation

We translated the CASS into Nepali after obtaining approval from the original author following a standard guideline for translation and adaptation of instruments (World Health Organization, 2009). The first translator translated the scale from English to Nepali. An expert bilingual team identified and modified inadequate translation after discussing discrepancies between forward translation and the original version. A second independent translator back translated with no knowledge of the original scale. The bilingual expert panel reviewed the differences between the forward and back translations, and the principal bilingual author (AS) approved the back translation of the scale. All translators were graduates in public health, fluent in both English and Nepali, and familiar with the terminology of psychology. The Nepali CASS was pretested among 30 women, and vocabulary was revised as needed before finalizing.

Participants and setting

We recruited 426 apparently healthy women aged 30 to 60 years, residing in two municipalities (Banepa and Dhulikhel) of Kavrepalanchowk district, Nepal from March to June 2021. We used a snowball sampling technique for participant recruitment, after identifying the first few women through local community health volunteers. We excluded women with hearing impairments and mental disorders. We provided detailed information about the research to each participant by telephone. The participants received ample time to think and ask questions (if needed), and after satisfactorily answering all their queries, they all provided informed consent. We maintained confidentiality by keeping all data on password-protected computers. We conducted a telephone interview using a structured questionnaire and data was directly entered into an electronic form (Kobo toolbox). We avoided in-person contact due to COVID-19 risks.

Measurement

The CASS is a multidimensional instrument that has been demonstrated to have strong reliability (Cronbach's alpha 0.76– 0.91) and validity in assessing a person's attitudes toward cancer. The scale has six factors with 25 items (Marlow and Wardle, 2014). The items were chosen after a thorough examination of illness-related stigma among the general public and cancer patients, as well as among a panel of seven cancer researchers with different backgrounds in behavioral science and psychology. The six factors consist of: awkwardness (i.e., I would feel embarrassed discussing cancer with someone who had it), severity (i.e., Having cancer usually ruins a person's Career), avoidance (i.e., If a colleague had cancer I would try to avoid them), policy opposition (i.e., More government funding should be spent on the care and treatment of those with cancer), personal responsibility (i.e., If a person has cancer it's probably their fault) and financial discrimination (i.e., It is acceptable for insurance companies to reconsider a policy if someone has cancer). Each item has a six-point Likert scale (strongly disagree; disagree; slightly disagree; slightly agree; agree; strongly agree). The total scores range from 25 to 130, with higher scores reflecting higher stigma.

Socio-demographic Characteristics

We collected socio-demographic variables including age (in years), ethnicity (Brahmin/Chettri, Newar, Sherpa/Bhote, Other), religion (Hindu, Christian, Buddhist) education (years of formal education completed, occupation (farmer, homemaker, business, unemployed, other) and parity (0, 1-3, >3).

Data analysis

Descriptive statistics were used to summarize the demographic characteristics of the study participants. The mean of the CASS items (potential range 1–6) was used to compute the scores for each subscale (awkwardness, severity, avoidance, policy opposition and personal responsibilities). Cronbach's alpha coefficient was used to assess the CASS's internal consistency and validity. It is regarded as reliable if the cronbach's alpha is greater than 0.70 (Taber, 2018). Pearson correlation coefficient between subscales was also used to check for overlapping of factors. Overlapping of factors is indicated by a high correlation equal to or more than 0.85 (Henseler et al., 2015). The item-total correlation was used to assess each item's relevance to the instrument and to find items that had a significant impact on the overall scale score. Confirmatory factor analysis was used to assess whether the six-factor structure of original CASS fitted the data in Nepali women. Model fitness was assessed based on the maximum likelihood methods using the following criteria (Hu and Bentler, 1999): Root mean square error of approximation (RMSEA) < 0.08; Goodness-of-fit Index (GFI) > 0.80; Adjusted GFI>0.80; Comparative Fit Index (CFI) > 0.90; Normal Fit Index (NFI) >= 0.80 and; Chi-square / df ratio <5 (Ye et al., 2019). Construct

validity was determined using ANOVA test (p value <0.05). Differences in mean scores for each component by age (30-40 years, 41-50 years, 51-60 years) ethnicity (Brahmin/Chettri, Newar, Rai/Limbu, Sherpa/Bhote, Others), religion (Hindu, Christian, Buddhist) education (years of formal education completed, occupation (farmer, homemaker, business, unemployed, other) and parity (0, 1-3, >3) were determined. We analyzed all data using STATA 15.

Results

Participant characteristic

Table 1 summarizes the socio-demographic characteristics of the 426 participants. Mean age of the respondents was 42.4 ± 8.2 years. One-third of participants (31%) had no formal education and the majority (40%) were involved as farmers. Hindu was the predominant religion group (88%).

Mean and inter-factor correlation

The mean and standard deviation (SD) of the total Nepali CASS score was 15.5 (3.6). Table 2 shows the correlation of each item with the total score. Most items had moderate correlations with the total score on stigmatizing attitudes towards cancer (r ranging from 0.15–0.62). Items on policy opposition and personal responsibility had the weakest correlation coefficient less than <0.4.

Table 1. Socio-demographic Characteristics of the Study Participants (n=426)

Characteristics	Frequency (%)
Age(years), Mean(SD)	42.4 (8.2)
Ethnicity	
Brahmin/Chettri/Thakuri/Sanyasi	182 (42.7)
Newar	175 (41.1)
Sherpa/Bhote	27 (6.3)
Kami/Damai/Sarki/	24 (5.6)
Other	18 (4.2)
Religion	
Hindu	374 (87.8)
Buddhist	28 (6.6)
Christian	24 (5.6)
Educational status	
No formal education	132 (31.0)
Primary	49 (11.5)
Secondary	150 (35.2)
Above secondary	95 (22.3)
Occupation	
Farmer	168 (39.5)
Homemaker	106 (24.9)
Business	63 (14.8)
Unemployed	7 (1.6)
Others	82 (19.2)
Parity	
Zero	6 (1.4)
One to three	374 (87.8)
More than three	46 (10.8)

Correlation and internal consistency of each factor

There were moderate significant correlations between factors (Table 3). An exception was Policy Opposition, which was not correlated with Severity and Financial Discrimination. Internal consistency was satisfactory for the total scale and for each factor (Cronbach's alpha=0.73–0.83; Table 3).

Confirmatory factor analysis

The result of a six-component confirmatory factor analysis model suggested poor model fit: RMSEA=0.108, GFI=0.761, AGFI=0.701, CFI=0.769, NFI=0.737 and $\chi 2/df=5.981$. Therefore, as per modification indices, the model was adjusted. Item 5 was removed due low factor loading (<0.4). When the correlation between Item 3 and 4, Item 9 and 10, Item 12 and 15 and Item 21 and 22 were added, the model of fit improved remarkably, exceeding the proposed criteria: RMSEA = 0.074, GFI = 0.864, AGFI = 0.825, CFI = 0.901, NFI = 0.866, $\chi^2/df=3.341$ (Figure 1).

Construct Validity

Differences in mean scores for each component by age, ethnicity, religion, educational status, occupation, and parity were determined (Table 4). Occupation was not associated with stigmatizing attitudes towards cancer. Older women had higher mean scores for severity (p-value<0.001), avoidance (p-value=0.02) and financial discrimination (p-value = 0.02) compared to younger women. Kami/Damai (a low-caste group in Nepali society) had higher mean scores for personal responsibility compared to higher caste group (p-value <0.01). Participants with no formal education had higher avoidance scores (p-value =<0.01) and personal responsibility scores (p-value = <0.01). Women who had more than three children scored higher for severity compared to those who had fewer children (p-value = <0.01).

Discussion

This study reports the validated Nepali version of the cancer stigma scale (CASS) with 25 items assessing six aspects of stigma – awkwardness, avoidance, perceived severity, policy opposition, personal responsibility, and financial discrimination. The components were moderately correlated with one another, showed an adequate level of internal consistency, and demonstrated good fit with the Nepali data. As hypothesized, the Nepali CASS score was significantly associated with age, ethnicity, religion and education, supporting construct validity.

We translated and back translated the items, being true to the meaning of the original CASS. Specific adjustments were not necessary for the cultural adaptation. The Nepali CASS has a similar construct to the original CASS, but did not fit the original model. The similarity in the wording of items 3 and 4, items 20 and 21, items 9 and 10 and items 12 and 15 explained the possible correlation of

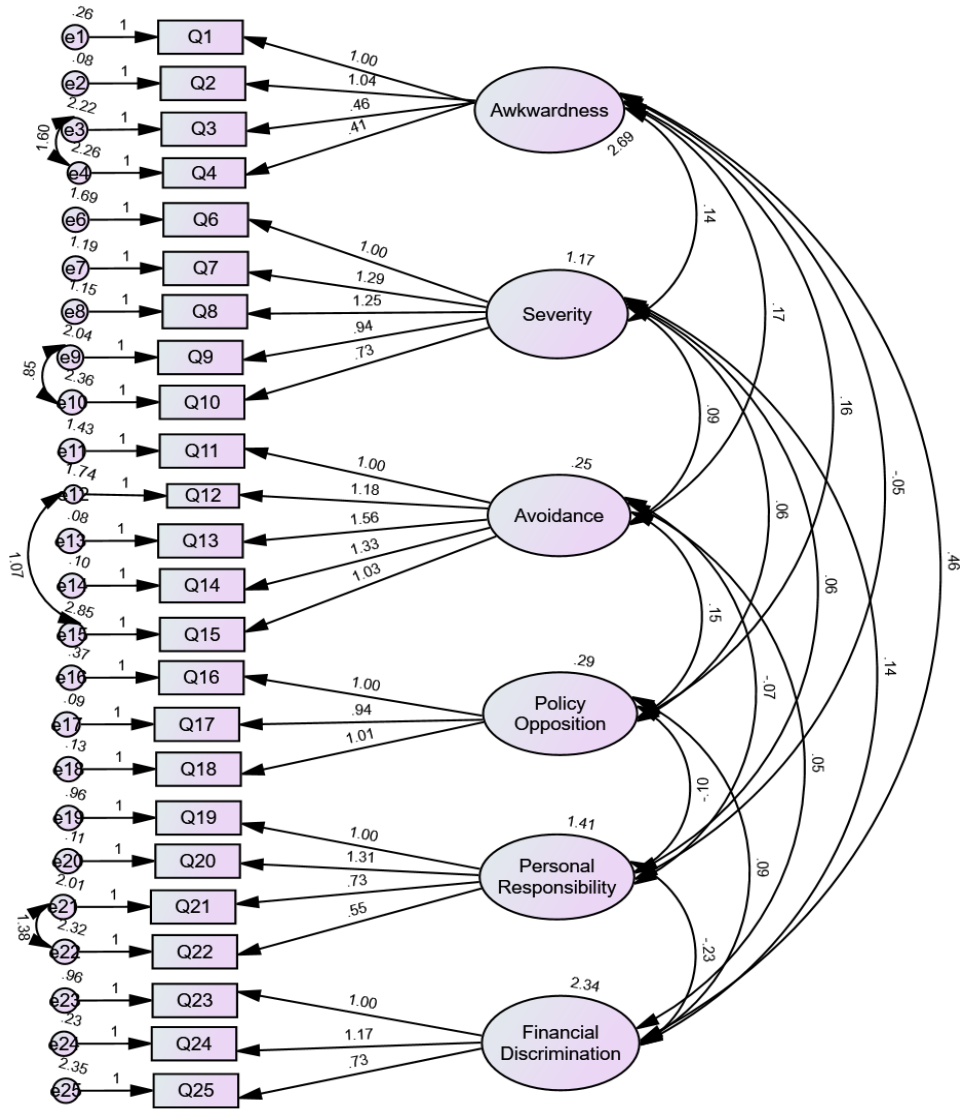

Figure 1. CFA of the New Six-factor Model of the Nepali version CASS with Standardized Parameter Estimates (the item numbers refer to question numbers in the original questionnaire).

residual errors. Experts agreed to delete item 5 and add the covariance between errors. The results of the CFA for the new 24-item six factor structure were satisfactory, and indicated a good fit to the Nepali data.

The CASS is a reliable measure for assessing cancer stigma across cultures. The mean of the total score of Nepali CASS was similar to those of CASS validation study in China (C-CASS) (Mean score: 15.1) (Ye et al., 2019) but lower than those of CASS validation study in Japan (J-CASS) (Mean score: 19.27) (Takeuchi et al., 2021). In the Nepali CASS, satisfactory internal consistency (0.78) was noted with a Cronbach's α value ranging from 0.73 to 0.83 for the social stigma domains. These results matched those of C-CASS (Cronbach's alpha 0.70–0.89) (Ye et al., 2019) and J-CASS (Cronbach's alpha=0.81–0.91) (Takeuchi et al., 2021). The findings were also comparable with Marlow's study where the alpha coefficient for the 25 items in the student sample and online panel sample ranged from 0.73–0.87 and 0.76–0.91, respectively (Marlow and Wardle, 2014).

In our study, each subscale of the CASS was associated with demographic characteristics, the same as the original CASS. As expected, older age was associated with a higher CASS score. Older aged groups perceived a high impact of cancer related stigma. This finding contrasts with the China study, which found higher cancer stigma among respondents aged less than 35 years (Ye et al., 2019). Compared with education status, women with no formal education had higher cancer stigma. This result is comparable with the study conducted in Ireland that found a negative association between education and cancer stigma (O'Connor et al., 2018). In Nepal, the number of elderly women who have completed a formal education degree is lower than that of younger women, and they have less access to social media and other educational activities that help to increase health literacy (Ministry of Health and Population, Nepal, New ERA and ICF, 2017). Lower education level is an indicator of lower socio-economic status in the Nepalese context, and it is associated with access to information on health-related matters (Raghupathi and Raghupathi, 2020). It is plausible that lower education levels may be a proxy

Table 2. Corrected Item-total Correlation and Response Trend for Each Item in the Nepali CASS

Scale		Item total correlation
Awkwardness		
Item 1	I would feel at ease around someone with cancer	0.49
Item 2	I would feel comfortable around someone with cancer	0.49
Item 3	I would find it difficult being around someone with cancer	0.57
Item 4	I would find it hard to talk to someone with cancer	0.62
Item 5	I would feel embarrassed discussing cancer with someone who had it	0.42
Severity		
Item 6	Once you've had cancer you're never 'normal' again	0.39
Item 7	Having cancer usually ruins a person's career	0.42
Item 8	Getting cancer means having to mentally prepare oneself for death	0.51
Item 9	Cancer usually ruins close personal relationships	0.53
Item 10	Cancer devastates the lives of those it touches	0.46
Avoidance		
Item 11	If a colleague had cancer I would try to avoid them	0.46
Item 12	I would distance myself physically from someone with cancer	0.51
Item 13	I would feel irritated by someone with cancer	0.4
Item 14	I would feel angered by someone with cancer	0.38
Item 15	I would try to avoid a person with cancer	0.55
Policy Opposition		
Item 16	More government funding should be spent on the care and treatment of those with cancer	0.21
Item 17	The needs of people with cancer should be given top priority	0.31
Item 18	We have a responsibility to provide the best possible care for people with cancer	0.31
Personal responsibility		
Item 19	A person with cancer is liable for their condition	0.19
Item 20	A person with cancer is accountable for their condition	0.19
Item 21	If a person has cancer it's probably their fault	0.19
Item 22	A person with cancer is to blame for their condition	0.15
Financial discrimination		
Item 23	It is acceptable for banks to refuse to make loans to people with cancer	0.48
Item 24	Banks should be allowed to refuse mortgage applications for cancer-related reasons	0.38
Item 25	It is acceptable for insurance companies to reconsider a policy if someone has cancer	0.51

for limited information about cancer leading to greater misconceptions and anticipated stigma.

As expected, higher stigma scores were observed among lower caste groups (Kammi/ Damai). This finding is comparable with the Marlow study that showed respondents with an ethnic minority background had higher cancer stigma (Marlow and Wardle, 2014). Previous studies on cancer stigma in ethnic minority populations in various nations have found that participants frequently identify cancer as a stigmatized disease, a "taboo," or something that isn't publicly addressed in their communities (Marlow and Wardle, 2014; Randhawa and Owens, 2004; Thomas et al., 2005). Christians and Buddhists had higher scores for personal responsibility compared to Hindu. This might be because of the fact that Hindu religion emphasizes the deeds of previous lives as the cause of diseases and accidents.

There are public health implications of a validated, Nepali CASS. The scale can be used to explore the association between cancer stigma and key clinical measures such as cancer screening uptake, cancer treatment, social support, and quality of life. The use of the scale can help compare cancer stigma between the general population and cancer patients and provide directions to support cancer patients in the community. Additionally, it can be used to measure effectiveness of cancer education programs in the general public. However, further studies to show the use of the Nepali CASS are warranted.

To the best of our knowledge, this is the first study to describe the psychometric properties of the CASS in the Nepali context and the first study to quantitatively estimate public cancer stigma in Nepal. However, our study has two main limitations. First, we choose to interview the female population because they were participating in a larger cervical cancer screening program, they may not be representative of males or the general population as a whole. Second, the stigma score may have been underestimated due to social desirability

Table 3. Correlation, Internal Consistency, and Test-retest Reliability of Each Factor

Factors	F1	F2	F3	F4	F5	F6	Total
Correlation							
F1: Awkwardness	1						
F2: Severity	0.20**	1					
F3: Avoidance	0.45**	0.17**	1				
F4: Policy opposition	0.27**	0.04	0.31**	1			
F5: Personal Responsibility	-0.13**	0.10*	-0.04	-0.13**	1		
F6: Financial Discrimination	0.28**	0.15**	0.34**	0.08	-0.19**	1	
Internal consistency[a]	0.8	0.79	0.73	0.81	0.8	0.83	0.78

[a]Cronbach alpha, *p < 0.05, **p < 0.01.

Table 4. Construct Validity of Nepali CASS

Characteristics	Awkwardness	Severity	Avoidance	Policy opposition	Personal responsibility	Financial discrimination	Total score
Age							
30-40 years	2.33	2.94	1.57	1.31	3.87	2.78	2.48
41-50 years	2.46	3.36	1.7	1.36	3.86	3.26	2.68
51-60 years	2.64	3.56	1.91	1.37	4.05	2.86	2.78
p-value	0.18	<0.01	0.02	0.59	0.53	0.02	<0.01
Ethnicity							
Brahmin/Chettri	2.37	3.23	1.78	1.38	4.04	2.75	2.6
Newar	2.55	3.18	1.66	1.28	3.51	3.42	2.6
Sherpa/Bhote	2.55	3.6	1.76	1.36	4.49	2.94	2.82
Kami/Damai	2.08	3.21	1.52	1.28	4.73	2.1	2.52
Others	2.24	2.5	1.6	1.42	4.28	1.92	2.35
p value	0.37	0.09	0.84	0.52	<0.01	<0.01	0.17
Religion							
Hindu	2.44	3.17	1.67	1.32	3.89	2.97	2.58
Christian	2.11	3.1	1.62	1.47	4.78	2.41	2.6
Buddhist	2.59	3.67	1.71	1.35	4.39	3.21	2.84
p-value	0.38	0.13	0.93	0.49	<0.01	0.18	0.1
Educational status							
No formal education	2.58	3.49	1.91	1.41	4.21	2.94	2.79
Primary	2.61	3.48	1.72	1.27	3.88	2.75	2.67
Secondary	2.32	2.99	1.49	1.26	3.72	3.03	2.47
Above secondary	2.29	2.97	1.58	1.37	3.75	2.99	2.49
p-value	0.15	<0.01	<0.01	0.13	<0.01	0.76	<0.01
Occupation							
Farmer	2.43	3.28	1.72	1.33	4.07	3	2.66
Homemaker	2.35	3.05	1.71	1.33	3.81	2.86	2.537
Business	2.45	3.08	1.6	1.28	3.81	3.23	2.58
Unemployed	2.74	2.88	1.37	1.71	3.89	3.14	2.6
Other	2.49	3.32	1.62	1.36	3.74	2.8	2.58
p-value	0.91	0.44	0.68	0.44	0.27	0.51	0.6
Parity							
Zero	1.97	2.07	1.53	1.05	4.08	2.17	2.15
One to three	2.45	3.15	1.67	1.34	3.88	3	2.6
More than three	2.38	3.7	1.7	1.3	4.05	2.77	2.69
p-value	0.63	<0.01	0.9	0.45	0.66	0.31	0.13

bias. We emphasized the importance of providing honest responses to the items asked before the interview.

In conclusion, we found the Nepalese version of the CASS to be valid and reliable, based on analysis of its psychometric properties. The scale's internal consistency was good, implying its reliability. The CFA findings indicated that the 24-item Nepalese version is compatible with the original English version's six-factor structure model. As a result, the CASS is a viable tool for evaluating public cancer stigma in Nepal. The study needs to be replicated in a representative sample of both male and female population in Nepal.

Author Contribution Statement

Archana Shrestha: conceptualization, methodology, validation, formal analysis, investigation, data curation, writing—original draft preparation, visualization, writing—review and editing, visualization; Anne Stangl: conceptualization, methodology, contributions to validation analysis, review and editing of manuscript; Bandana Paneru: Conceptualization, data curation, analysis, methodology, writing – original draft, writing – review & editing; Lisasha Poudel: Data curation, analysis, methodology, writing – original draft, writing – review & editing; Aerona Karmacharya: Data curation, analysis, writing – original draft, writing – review & editing; Soniya Makaju: Data curation, analysis, writing – original draft, writing – review & editing; Donna Spiegelman: Conceptualization, formal analysis, investigation, methodology, project administration, resources, supervision, writing – original draft, writing – review & editing; Sunila Shakya: Conceptualization, methodology, project administration, resources, supervision, writing – original draft, writing – review & editing; Aamod Dhoj Shrestha: Methodology, supervision, writing – original draft, writing – review & editing; Sangini Seth: Formal analysis, investigation, methodology, resources, supervision, writing – original draft, writing – review & editing.

Acknowledgements

Funding Statement

This study was funded by Yale University (Grant number: P30CA016359). This study was part of a bigger project aimed to study cancer stigma and its role in cervical cancer screening uptake in Nepal.

Ethical Declaration

The study was approved by the Ethical Review Board; Nepal Health Research Council (Ref no. 1533). Each participant was personally called and given comprehensive information about the study. The participants had enough of time to reflect and inquire (if necessary), and after receiving satisfactory responses to all of their inquiries, they all gave their informed consent. We upheld confidentiality by storing all information on computers with password protection.

Data Availability Statement

Dataset can be provided if required.

Conflict of Interest

The authors declare that they have no conflicts of interests.

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