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URDU TRANSLATION AND VALIDATION OF THE SHAME AND STIGMA SCALE FOR HEAD AND NECK CANCER PATIENTS

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Abstract

This study aimed to translate and validate the Shame and Stigma Scale (originally developed by Kissane, 2013) into Urdu for head and neck cancer patients. The Department of Urdu Studies at Quaid-i-Azam University Islamabad conducted forward and backward translations to ensure linguistic accuracy and conceptual integrity. The Urdu version was tested on 225 patients (mean age 43.33 ± 11.47), and confirmatory factor analysis confirmed the scale's original factor structure. Reliability was excellent, with Cronbach's alpha above 0.94, and validity was supported by strong convergent and discriminant correlations. The validated Urdu scale offers a reliable tool for assessing shame and stigma in Urdu-speaking populations, aiding psycho-oncology research and practice. Future studies are encouraged to use dyadic samples from multiple hospitals for broader insights.

INTRODUCTION

Shame is an experience that affects many individuals on a deeply personal level, especially when it comes to a head and neck cancer diagnosis (Neda, 2018). Patients often grapple with overwhelming feelings of self-blame and guilt tied to their past lifestyle choices, like smoking or chewing betel nut (Goyal et al., 2024). Stigma can lead to deep feelings of guilt and shame, and may even challenge a person's sense of identity (Tan et al., 2022). Patients with head and neck cancer frequently encounter stigma in various social and cultural settings, often independent of the specific risk factors that may have contributed to their diagnosis (Mangoulia et al., 2020; Tseng et al., 2022). The visibility of the head and neck areas can intensify these feelings, as individuals may feel personally accountable for their previous habits or connected to sexually transmitted HPV infections. It's important to recognize that the experience of stigma remains a significant reality for those with head and neck cancer, regardless of the behavioral risk factors involved (Tseng et al., 2019).

Individuals affected by head and neck cancer are especially vulnerable to both felt and enacted stigma, which can greatly affect their well-being and social interactions (Costa et al., 2014; Graboyes et al., 2019). The role of appearance and facial expressions in non-verbal communication and social interaction is profound (Kulkarni, 2013). For individuals receiving treatment for head and neck cancer, the end of their journey can lead to various degrees of facial deformities and functional impairments (Bakshi et al., 2021). The severity of these changes is influenced by the tumor's stage, location, and extent of spread. Such outcomes often invoke feelings of shame and stigma in patients (Kulkarni, 2013). Individuals with cancer often face significant stigma associated with their lifestyle choices, such as smoking (Threader & McCormack, 2016).

The stigma associated with head and cancer arises from various discursive practices that influence perceptions and experiences, due to this stigma becomes apparent through the vivid portrayals of treatment side effects, as reflected in participants' narratives, mirroring findings from previous research and the discourse linking head and neck cancer to behaviors like smoking, drinking, and sexually transmitted illnesses further perpetuates this stigma (McLaughlin & Mahon, 2014). Cancer fundamentally alters one's perception of self, fostering an identity tied to the disease, with patients often feeling "I am cancerous". The results further indicate that acknowledging oneself as a cancer patient brings a host of challenges: unpleasant symptoms, adverse treatment effects, emotional distress, and social isolation. These dilemmas arise from the interplay of physical and emotional transformations, coupled with social stigma and marginalization within communities (Suwankhong & Liamputtong, 2016).

Cancer survivors often encounter stigma when seeking help from relatives. Given their status as a high-risk group for COVID-19, family members may fear that cancer patients are more likely to be infected, leading them to distance themselves (Goyal et al., 2022ss). This is particularly concerning for those with H & NC, who already endure significant isolation and depression due to the physical consequences of their treatment, such as facial disfigurement and surgical scars. Recent studies indicate that these patients now face even greater levels of depression (Adjei et al., 2020). Furthermore, individuals with laryngeal cancer commonly experience a chronic cough, a symptom that overlaps with COVID-19. This similarity can lead to misconceptions, causing others to wrongly assume that cancer patients are COVID-19 positive, thereby intensifying the stigma they experience (Fayziev, 2020).

Head and neck cancer patients often suffer from psychological effects linked to stigma, including issues related to disfigurement, changes in body image, sexual dysfunction, and a diminished social identity (Manier et al., 2017). Cancer stigma has been identified as a significant factor contributing to a range of psychological issues, including loss of body image, self-blame, intrusive thoughts, and social isolation (Huang et al., 2021). The stigma associated with cancer serves as a major source of psychological distress (Amini-Tehrani et al., 2021), contributing to negative mental health outcomes such as depression and anxiety, as well as diminished self-esteem and self-efficacy (Sing et al., 2020). These factors collectively culminate in a significantly poorer quality of life for survivors (Zhang et al., 2020).

The purpose of the study was to translate the shame and stigma scale in Urdu for Head and neck cancer (HNC) patients often experience significant emotional distress, particularly shame and stigma due to visible physical changes, speech impairments, and societal perceptions. In Pakistan, cultural and religious beliefs further intensify these feelings, often leading to social withdrawal and psychological distress. A validated Urdu version of the Shame and Stigma Scale (SSS) is crucial for accurately assessing these emotional burdens and improving patient support. By localizing and validating this scale, researchers and healthcare professionals can better address the psychological challenges of head and neck cancer patients, ultimately improving their quality of life.

Method

Two phases were used in the present research study: the initial phase was focused on translating the scale in Urdu language. In the second stage, the study examined the factorial structure of the scale, which was confirmed in the culture of Indigenous people, and this factor structure validation through confirmatory factor analysis on an independent sample.

Objectives of the Study

1. To translate and cross-validate shame and stigma scale in Urdu language.
2. To establish the psychometric properties of the translated scale
3. To confirm the factor structure of shame and stigma scale by using confirmatory factor analysis

Phase I: Translation Procedure

The translation procedure of Shame and stigma scale developed by Kissane, (2013) is to translate and cross-validate into Urdu language. The Shame and stigma scale were translated from the source language (English) to the targeted language (Urdu). After getting permission from author (Kissane, 2013). The

translation was done by the Urdu language experts from the department of Urdu Studies, QAU Islamabad. For this purpose, the translators were well-versed in both the target and source language. They were instructed to translate the items accurately without bringing change to the core meaning of each item while keeping in the mind the Pakistani cultural context.

Step 1: Observing Cultural Relevance of Instruments.

Step I comprised of cultural relevance of instrument i.e. Shame and Stigma Scale (SSS) as this scale was first time used in Pakistani culture. Urdu version of the mentioned scales was not previously used so it is necessary to check its cultural relevance.

Step II: Obtaining Permission from the Authors.

Before translation and adaptation of shame and stigma scale permission was taken from the original authors as it was a matter of copyright for using this scale. Permission was obtained for translation, adaptation and cross language validation of instrument. It was obtained through e-mail and its copy was attached in the appendices. Urdu language translation was required to make scale comprehendible for illiterate and literate both type of patients. Adaptation were also made to make the items more appropriate on indigenous culture.

Step III: Forward Translation of the Scales into Urdu Language.

In this phase the translation from source language i.e. English into the Urdu was done. To achieve this goal four bilinguals were approached to translate the scale in Urdu language. As it was theoretically well supported that for translation of scale there should be more than one bilingual expert (International Test Commission, 2010). This process of translation was recommended to avoid theoretical, cultural and linguistic biases. A selection criterion of translators was that they should be fluent in both Urdu and English language, preferably holding Master's Degree in English literature. Two of bilingual's translators were PhD. students of Psychology, one was a practicing Psychologist and fourth one was teacher in English language. Purpose of the study and target population was explained to the translators. They were asked to translate the instrument as accurately as possible by keeping in view the target population. Careful instructions were given to translators so that the content and inherent meaning could be understandable for head and neck cancer patients.

Step IV: Committee Approach.

In this step committee of three members including the researcher himself were selected and all translations (English to Urdu) were evaluated. Committee was consisted of bilingual subject matter experts. Committee and selected the most appropriate translation by evaluating all the four translations in reference to their items. Main objective of the translation was to get most suitable translation that has semantic equivalence with original scale items. Response categories and instructions for completion of scale were also finalized in the committee approach.

Step V: Backward Translation.

Back translation was recommended as a supplementary measure to maintain the quality of translation (International Test Commission, 2010). After the selection of items in the committee approach those items were given for back translation into source language i.e. English. For this purpose, four bilingual experts were approached who had not seen the original English version and also had not participated in forward translation. Translators were also introduced with study variables and target population. Again, instructions were given to the translators to translate the items according to the understanding level of sample. For each scale four back translations were received. The translated items were written in a way that each item had four translated statements. After doing this a committee of subject matter experts was conducted to select the most appropriate translation according to understanding level of caregivers and semantic equivalence with original English version.

Step VI: Committee Approach.

To make comparison between back translated and original versions of the scales four back translations were reviewed by the similar committee approached previously to compare the back translated versions of scale with original scales to ensure equivalence and compatibility. All the back translations were giving the

same meaning (both literal and contextual) as that of the original versions and there were no major ambiguities except few minor alternations. After doing all these back translations were submitted to authors of original version scales.

Step VII: Try Out.

Translated versions of scales were administered on group of ten head and neck cancer patients and were reviewed by subject matter experts. Translated scales were given to the participants to give feedback on the comprehension, language difficulty, and statement clarity of the instruments. They were also requested to give input regarding the response format of questionnaire. Participants were asked to give their opinion if they found any item confusing or if they couldn't understand meaning of any statement. In try out translated Shame and Stigma Scale (SSS), was found understandable by the participants. Therefore, no major alterations were found except simplification of few ambiguous phrases.

Instrument

Shame and stigma scale (Kissane, 2013).

Shame and stigma scale is used to assess the Shame and stigma among head and neck cancer patients, the original scale is 20-item and 4 factors the nature of the shame with appearance, sense of stigma, regret and social/speech concerns was developed. The current investigation revealed that on cross validation of Shame and stigma scale (SSS) for use in our population. The 20 items on the final form are evaluated between "0 = never 1= seldom, 2 =sometime, 3=often and 4 = all the time" using a 5-point Likert scale. There are four reversal items on the scale

Item no 4. I am happy with how my face or neck looks.
Item no1. I like my appearance.
Item no 7. I enjoy going out in public.
Item no 21 I am able to join conversations.

The scale determines a final score. 20 is the lowest and 100 is the highest possible score. A person with a higher score has a higher level of Shame and stigma. The results of the validity analysis demonstrate that this scale can accurately gauge shame and stigma among head and neck cancer patients. Furthermore, two approaches were used to calculate the Shame and Stigma scale dependability. The split-half test technique was calculated (r =.74) after first calculating a Cronbach Alpha coefficient (a =.94). The Shame and stigma scale is a scale that can be used to quantify Shame and stigma, according to the reliability coefficients.

The first factor, known as the "shame with appearance," is made up of statements that represent the overall evaluation of the degree of shame among head and neck cancer patients, as well as appearance issues. "sense of stigma" is the name given to the second element, which consists of negative evaluation by society. The third factor is termed "regret" and is made up of statements that indicate a tendency to withhold, conceal and avoid talking about certain aspects of oneself past action.

Procedure

To conduct this study, a sample of N=225 head and neck cancer patients were taken. Purposive sampling technique (non-probability sampling technique) was used to collect data from participants was recruited from multiple hospitals in Rawalpindi and Islamabad. Prior to data collection, permission was obtained from the higher authorities of these hospitals. The participating hospitals were informed about the study's rationale, and informed consent was secured from all participants. Inclusion criteria of the present study, only confirmed diagnosis of Head and Neck Cancer by biopsy or pathology report. The patients under treatment i.e chemotherapy, surgery. Those patients who clearly read and understand the Urdu language. Patient stability to provide informed consent. Exclusion criteria was Patients with comorbidity psychological problems i.e. Neurocognitive, Intellectual Disability were not be part of study

They were assured that their responses would remain confidential and used solely for research purposes. Clear instructions were provided to participants to facilitate accurate responses, and any queries regarding the questionnaire items were addressed promptly. Upon completion of the questionnaires, head and neck cancer patients were thanked for their voluntary participation, emphasizing the importance of their contributions to the research.

Results

Confirmatory Factor Analysis was run to establish the construct validity by confirming the factor structure of the translated scales.

Table 1: Model fit Indices of Confirmatory Factor Analysis for Shame and Stigma Scale Urdu (N=225)

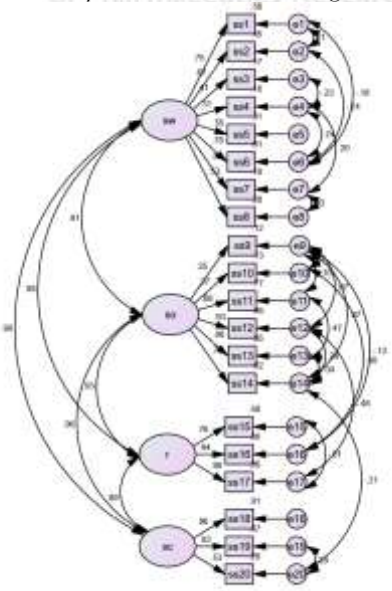
				Fit indices			
SSS	χ 2	χ 2/df	p	CFI	GFI	TLI	RMSEA
Model 1	934.63	7.25	.000	.82	.79	.78	.11
Model 2	521.63	3.26	.000	.94	.90	.92	.06

Note. χ 2=Chi-Square; df = Degree of Freedom; GFI = Goodness of Fit Index; CFI Comparative Fit Index; RMSEA Root Mean Square Error of Approximation; SSS = Shame and Stigma Scale

Table 1 demonstrates that Model 1 (without error covariance) is a poor fit. Model fit as evidenced by Model 2 is achieved by introducing error covariance thus reducing the error variance and improving the true one which helps to achieve the model fitness. The factor loading for each item underlying the respective factor.

The confirmatory factor analysis (CFA) obtained from 20 items of the shame and stigma scale and its sub-scales, which indicates that the regression weights of one item is below .35 item no 4. We retained this item in our scale with the opinion by subject matter expert. Error was removed after that model fit indices were in acceptable ranges. Confirmatory factor analysis of shame and stigma scale shows that the CFI (comparative fit index) value is .94, TLI (Tucker Lewis Index) = .92, GFI (Goodness of Fit Index) = .90, RMSEA = .06. In terms of the overall indices, it is evident that this model is acceptable. Lastly, shame and stigma scale final translated Scale consisted of 20 items with good model fit indices.

Figure I: Confirmatory Factor Analysis of Shame and Stigma Scale for Factor Structure (N= 225)



Note; SW= Shame with appearance, SO=sense of stigma, r= Regert, SC= Social/ speech concerns

Discussion

The aimed of the study was to translate and validate the shame and stigma scale for head and neck cancer patients in indigenous culture Pakistani population. Evidence of the validity and reliability of the shame and stigma scale was shown in the current study. The final version of the scale consists of four subscales and twenty items ("0 = never" and "4 = all the time"). The scale has four reverse-coded components. A total score is also provided by the scale. The scale's lowest possible score is 20, while the greatest possible score is 100. Higher shame and stigma scores are indicative of a higher degree of shame and stigma among head and neck cancer patients. In conclusion, the shame and stigma scale is a valid and reliable tool that can be used to assess shame and stigma among head and neck cancer patients. The findings of the validity and reliability studies are combined. Our study, as well as Kissane et al., (2013) original validation, showed that the items of the shame and stigma scale are targeted towards higher levels of shame and stigma severity. This means that the scale provides more accurate measures for people with high levels of shame and stigma in Pakistani culture. It may be concluded that this scale may be used in practice and study by psychologists, psychological counsellors, and practitioners in the field of psycho-oncology and family therapy.

Limitations and Future Directions

Despite its contributions, this study has certain limitations. The sample was drawn from a single hospital (CMH Rawalpindi), limiting the generalizability of the findings. Future research should validate the Urdu shame and stigma in a larger, more diverse sample, including patients from different regions, socioeconomic backgrounds, and rural communities.

Additionally, while the CFA results supported the factor structure of the SSS, longitudinal studies are needed to assess the scale's predictive validity over time. Future research should also explore the effectiveness of psychological interventions in reducing shame and stigma in Pakistani cancer patients.

Conclusion

The Urdu translation and validation of the Shame and Stigma Scale confirmed its psychometric robustness and cultural relevance in Pakistani head and neck cancer patients. The findings underscore the profound impact of cancer-related stigma on psychological well-being, particularly in collectivistic societies where social image and honor play a central role. By providing a validated tool to assess shame and stigma, this study contributes to enhancing psychosocial care, mental health research, and intervention strategies for Pakistani cancer patients.

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