



The Shame and Stigma Scale in Head and Neck Cancer (SSS): Translation and Validation in Greek

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Abstract

Head and neck cancer can be especially difficult for the patients, as affects the most visible areas of the body and usually have severe impact on patients' daily activities. The degree of disfigurement is a determinant of self-image, social contact and sexuality and introduces the concepts of shame and stigma. The aim of the study was to translate and validate the SSS into Greek. The SSS was translated into Greek and administered to 65 head and neck cancer patients who had surgery upto a year ago. Participants were also administered the General Health Questionnaire-28 (GHQ-28) and Life Satisfaction Inventory (LSI). The majority of participants were men (90.8%) and had larynx cancer (72.3%). The SSS consists of 20 questions and includes four subscales, Shame with Appearance, Sense of Stigma, Regret and Social/Speech Concerns. The SSS presented high internal consistency (Cronbach's $\alpha=0.93$, whereas the four subscales alpha ranged from 0.72 to 0.87), validity and reliability. Item to scale correlations ranged from 0.470 to 0.815. There is a strong positive correlation between SSS and GHQ score and a strong negative correlation between SSS and LSI score. Patients who had surgery more than 3 months ago have statistically significant higher SSS and GHQ score and lower LSI score. The Greek version of SSS showed good psychometric properties and could prove as a useful tool for health care professionals, helping them to identify problems and provide solutions in time, achieving the best possible functional level for the individual.

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Abbreviations: SSS: Shame and Stigma Scale in Head and Neck Cancer; GHQ-28: General Health Questionnaire-28; LSI: Life Satisfaction Inventory.

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Introduction

Head and neck cancer is the sixth leading cancer by incidence worldwide. Worldwide, almost 640,000 new cases of head and neck cancer emerge annually and more than 350,000 deaths are recorded. Cancers of the oral cavity, pharynx and larynx are the most common types of cancer [1]. Alcohol abuse and tobacco are risk factors [2]. Viruses such as HPV (condylomata acuminata virus) and EBV (infectious mononucleosis) as well as large periods of exposure to the sun, poor oral hygiene, candidiasis and dietary factors have also been implicated. Given the fact that, during the last years, survival rates have improved, the interest of studies is focused on patients' quality of life [3,4].

Head and neck cancer can be especially difficult for the patients, as the disease and the surgical removal of the tumor affects the most visible areas of the body and usually have severe impact on daily activities such as the patients' ability to eat, drink, breathe, speak, as well as their appearance. The degree of disfigurement is a determinant of self-image, social contact and sexuality [5,6] and introduces the concepts of shame and stigma [7].

Physical appearance impacts on self-esteem, and can lead to depression and social isolation [5,8]. Measures that document the nature and intensity of shame and stigma are pertinent to interventions seeking to modulate this outcome in survivors [9,10].

The long-term effects of shame on social, marital, and family relationships can be evident in deteriorating relationships despite improved physical functioning and general well-being [11]. Feelings of being stigmatized as a result of unsightly appearance have also been persistent over time and contribute to the social consequences of persistent shame [7,12].

Shame and Stigma Scale in Head and Neck Cancer-SSS [7] was developed in 2011 by an international team of experts. Until then, these concepts were identified by other studies as important implications for patients with head and neck cancer, but had not been thoroughly examined until then.

The results of this study will provide important information on the biopsychosocial well-being and overall quality of life of patients with head and neck cancer. Exploring the effects of the disease itself as well as the treatment is considered to be particularly useful [3,14,15] given the rapid increase observed in the number of cases during the last years and this becomes urgent by the fact that there are no similar studies in the Greek population, while there are huge gaps in the international literature.

Methods

The target population of the study was patients who had surgery for head and neck cancer upto a year ago, regardless of age, gender and site of the cancer. Three months is generally considered the time period in which any deformity from surgery has begun to develop [7].

The study was conducted in two NHS hospitals (General Hospital of Athens "Ippokrateio" and Special Cancer Hospital of Piraeus "Metaxa", upon written permission from the scientific and the administrative committee of the hospital and written patient consent for voluntary participation in the study. Completion of the questionnaires was anonymous and patients were individually interviewed by two researchers, either during hospitalization or visit to the outpatients ENT clinic.

Shame and Stigma Scale in Head and Neck Cancer [7] consists of 20 questions and the score is calculated according to five-point Likert scale, ranging from 0 (Never) to 4 (Constantly). It includes four subscales, Shame with Appearance, Sense of Stigma, Regret and Social/Speech Concerns. The total and subscales scores are calculated by summing the responses to the relevant items and then multiplying the sum by a scaling constant [$100 / (4 * \text{number of items on scale})$]. Scores range from 0 to 100.

In order to use the SSS Scale in the study, written permission was requested and given by the author Dr. Kissane. The translation of the SSS into Greek was carried out as follows: a) Translation into Greek by two people (a registered nurse, PhD University of Athens and a psychologist) who had excellent knowledge of the Greek and English language as well as of the concepts mentioned in the questionnaires. b) Reverse translation of the two Greek texts into English by an independent bilingual person (Associate Professor of Psychiatry, University of Athens). c) Discussion of the results and the alternative translations from the three persons translating, correction of the context where applicable and final agreement on a unified text.

A pilot study was conducted in 5 patients with head and neck cancer, in order to assess the clarity and understanding of the questions and the ability of patients to answer them. The time required for completing the questionnaires was also determined and reached up to 10-15 minutes. The results of the pilot study were positive because they established the adequacy of the scale as easy and understandable and therefore no further modifications were required.

The General Health Questionnaire (GHQ-28) [16,17] and Life Satisfaction Inventory (LSI) [18,19] were used to assess the validity of SSS. These scales have been already translated and validated in Greek and their use is widespread.

The statistical analysis was conducted using the Statistical Package for Social Sciences Analysis SPSS 20.0. Initially, all variables were described with methods of descriptive statistics and a reliability test of SSS was performed by calculating the coefficient Cronbach's alpha (acceptable values > 0.7). Kolmogorov-Smirnov test was used in order to allocate the variables with regard to normality. The level of significance was set to $p \leq 0.05$. The variables had normal distribution. To assess the differences between groups Student's t-test and One-way ANOVA were used. Pearson's correlation coefficient was used to assess the intensity of the linear correlation between two quantitative variables. Level of significance for the correlations was 0.05.

Results

Sample characteristics

The overall response rate was 81.25% (80 questionnaires were distributed of which 65 valid were returned), which may have increased the validity of the study. Sample's demographics, personal and professional characteristics are presented in Table 1. The study involved 65 patients aged 63.55 ± 10.22 . The majority of the participants were men (90.8%), married (76.9%), graduated elementary school (49.2%), were smokers (90.7%) and were drinking almost every day or several days during the week (46.1%), and had larynx cancer (72.3%), stage III (35.4%) or IV (33.8%).

Table 2 presents the scores of SSS, GHQ-28 and LSI. All SSS scores are extremely high, indicating a very important and seri-

ous burden on patients in the specified fields investigated. The mean total SSS score is 40.71 ± 20.22 , with the higher scores noted in Regret (46.79 ± 29.22) and in Social/Speech Concerns (41.66 ± 26.51). Scoring for Shame with Appearance is 35.24 ± 19.20 and for Sense of Stigma is 34.41 ± 24.16 . The scores of the group of patients recorded by Kissane et al. were much lower. Specifically, the total SSS score was 18.08 ± 14.67 , the score for Shame with Appearance 18.78 ± 19.17 , the score for Sense of Stigma 12.86 ± 17.03 , for Regret 29.49 ± 23.94 and for Social/Speech Concerns 15.22 ± 18.63 [7]. However, although ratings in absolute numbers are different than ours, the score for Regret remains higher in both groups.

The majority of the sample (50.8%, $n = 33$) have total GHQ score greater than or equal to 23 (median), suggesting that there is a psychological problem. In the subscales, higher scores indicating higher levels of specific disorders and are observed in Social Dysfunction, Anxiety and Insomnia, while Severe Depression presents lower scores.

The mean value of the total LSI score (39.43 ± 9.83) and the 13 dimensions of life satisfaction are lower than the mean value of the weighting group of LSI, but within normal limits. According to the weighting of the scale, good overall life satisfaction rating is found in the range 46.1 ± 7.69 [19].

Psychometric characteristics of SSS

Reliability

For the Greek version of SSS Scale, Cronbach's alpha coefficient is 0.93 for the total scale while for its subscales is as follows: Shame with Appearance alpha = 0.84, Sense of Stigma alpha = 0.87, Regret alpha = 0.86 and Social/Speech Concerns alpha = 0.72, indicating strong internal consistency. Item-scale correlations ranged from 0.470 to 0.815 ($p < .001$). The highest correlation for each item occurred between the item and the corresponding factor (Table 3). There were no corresponding questionnaires for SSS to use as templates ("gold standards"), in order to assess the external reliability.

Table 1: Demographic characteristics ($n=65$).

Demographic characteristics / Mean \pm SD / N (%)			
Sex		Drinks (at least one)	
Male	59 (90.8%)	Nearly everyday	16 (24.6%)
Female	6 (9.2%)	Several days/week	14 (21.5%)
Marital status		1-2 days/week	10 (15.4%)
Single	5 (11.7%)	1-3 days/month	4 (6.2%)
Married	50 (76.9%)	<1 day/month	7 (10.8%)
Widowed	3 (4.6%)	Never	14 (21.5%)
Live with partner	7 (10.8%)	Number of drinks/day	
Education		0	18 (27.7%)
Elementary school	32 (49.2%)	1-2 drinks	25 (38.5%)
Highschool	20 (16.8%)	3-4 drinks	15 (23.1%)
University	13 (20%)	5-10 drinks	4 (6.2%)
Age	63.55 \pm 10.22	>10 drinks	3 (4.6%)
Primary site of disease		Smoking	
Larynx	47 (72.3%)	Currently	19 (29.2%)
Pharynx	3 (4.6%)	Ex-smoker	40 (61.5%)
Oral-Tongue	15 (23.1%)	Only a few times	2 (3.1%)
Stage of disease		Never	4 (6.2%)
I	1 (1.5%)	Years smoking	34.28 \pm 15.11
II	19 (29.2%)	Cigarettes/day	40.95 \pm 21.71
III	23 (35.4%)		
IV	22 (33.8%)		

Validity

The content of the SSS questions reflects the characteristics of individuals with head and neck cancer. Since there are no corresponding questionnaires for SSS, GHQ and LSI was used for comparison, expecting positive correlation with GHQ and negative correlation with LSI, if SSS is valid. Indeed, Pearson's correlation for SSS were high: 0.61 with GHQ and -0.78 with LSI. The Pearson's correlation results between subscales are presented in Table 4. These support the validity of conceptual structure (convergent) as well as the validity based on criterion (predictive) In addition, in order for SSS to be valid, it should be graded differently for patients with head and neck cancer depending on the time elapsed since surgery. More specifically,

it is believed that in a three month period any disfigurement, due to surgery, has begun to develop [7]. The mean total and subscales score of SSS, GHQ and LSI for patients group operated more than 3 months ago is significantly higher than that of the group of patients operated up until 3 months (table 5). No statistically significant difference between the two groups were found for the mean score of social dysfunction (GHQ) and finances, hobbies, marital, sex and family life (LSI). These support the validity of conceptual structure (discriminant), as well as the validity based on criterion (concurrent).

Table 2: SSS, GHQ-28 and LSI scores of the sample (n=65).

	min-max	M ± SD
SSS Total score	0-81.25	40.71 ± 20.22
Shame with Appearance	0-87.50	35.24 ± 19.20
Sense of Stigma	0-99.98	34.41 ± 24.16
Regret	0-100	46.79 ± 29.22
Social/Speech Concerns	0-100	41.66 ± 6.51
GHQ Total score	0-81	26.34 ± 18.67
Somatic Symptoms	0-21	6.38 ± 5.42
Anxiety/Insomnia	0-21	7.65 ± 5.75
Social Dysfunction	0-21	8.69 ± 5.16
Severe Depression	0-18	3.62 ± 4.85
LSI Total score	13-65	39.43 ± 9.83
Physical Condition	1-5	2.78 ± 1.13
Cognitive Condition	1-5	3.49 ± 0.95
Mental Wellbeing	1-5	2.91 ± 1.14
Work	1-5	3.06 ± 0.96
Finances	1-5	2.62 ± 1.01
Marital Life	1-5	3.18 ± 0.95
Sex Life	1-5	2.82 ± 1.18
Family Life	1-5	3.35 ± 1.00
Role in the Family	1-5	3.46 ± 0.90
Number of Friends- acquaintances	1-5	3.25 ± 0.88
Hobbies	1-5	2.92 ± 1.16
Appearance	1-5	2.80 ± 1.12
General Quality of Life	1-5	2.78 ± 0.97

SSS: Shame and Stigma Scale in Head and Neck Cancer, GHQ: General Health Questionnaire, LSI: Life Satisfaction Inventory.

Table 3: Item-Scale correlations and Cronbach's.

SSS item	SSS	Shame	Stigma	Regret	Concerns	Cronbach's α forSSS (if item deleted)
1.	0.47*	0.55*	-	0.40**	0.41**	0.926
2.	0.54*	0.66*	0.35**	0.38**	0.34**	0.925
3.	0.73*	0.83*	0.53*	0.42*	0.66*	0.921
4.	0.27***	0.25***	-	-	-	0.931
5.	0.73*	0.77*	0.58*	0.31***	0.74*	0.921
6.	0.78*	0.82*	0.69*	-	0.84*	0.920
7.	0.61*	0.64*	0.52*	0.30***	0.55*	0.924
8.	0.79*	0.88*	0.58*	0.31***	0.76*	0.920
9.	0.55*	0.41**	0.66*	0.25***	0.49*	0.925
10.	0.67*	0.43*	0.79*	0.60*	0.49*	0.922
11.	0.69*	0.46*	0.83*	0.53*	0.51*	0.922
12.	0.79*	0.70*	0.81*	0.34**	0.76*	0.920
13.	0.68*	0.46*	0.83*	0.49*	0.51*	0.922
14.	0.76*	0.69*	0.77*	0.36**	0.74*	0.920
15.	0.68*	0.48*	0.61*	0.88*	0.42**	0.922
16.	0.43*	-	0.30**	0.87*	-	0.928
17.	0.65*	0.46*	0.52*	0.90*	0.40**	0.923
18.	0.81*	0.79*	0.67*	0.41**	0.85*	0.919
19.	0.79*	0.73*	0.75*	0.34**	0.88*	0.920
20.	0.47*	0.46*	0.36**	-	0.65*	0.927

* $p < 0.001$, ** $p < 0.01$, *** $p < 0.05$, SSS: Shame and Stigma Scale in Head and Neck Cancer.

Table 4: Pearson's Correlations for SSS.

	Shame with Appearance	Sense of Stigma	Regret	Social/Speech Concerns
GHQ Total Score	0.69*	0.44*	-	0.61*
Somatic Symptoms	0.65*	0.37**	-	0.51*
Anxiety/Insomnia	0.68*	0.34**	-	0.53*
Social Dysfunction	0.54*	0.40*	-	0.53*
Severe Depression	0.57*	0.45*	-	0.57*
LSI Total Score	-0.80*	-0.62*	-0.37**	-0.76*

* $p < 0.001$, ** $p < 0.01$, SSS: Shame and Stigma Scale in Head and Neck Cancer, GHQ: General Health Questionnaire, LSI: Life Satisfaction Inventory.

Table 5: T-test analysis results for SSS, GHQ and LSI.

	surgery≤ 3 months (n=31) Mean ± SD	surgery>3 months (n=34) Mean ± SD	t
SSS Total Score	30.36±18.93	50.14±16.59	4.48*
Shame with Appearance	27.52±19.88	42.27±15.77	3.33**
Sense of Stigma	22.57±17.79	45.21±24.33	4.30*
Regret	33.06±27.67	59.31±24.93	4.24*
Social/Speech Concerns	29.83±25.8	52.44±22.42	3.77*
GHQ Total Score	19.42±16.64	32.65±18.39	3.02**
Somatic Symptoms	4.48±4.17	8.12±5.90	2.88**
Anxiety/Insomnia	5.68±5.59	9.44±5.37	2.76**
Severe Depression	1.77±3.20	5.29±5.49	3.18**
LSI Total Score	43.26±9.82	35.94±8.56	-3.20**
Physical Condition	3.16±1.19	2.44±0.99	-2.66***
Cognitive Condition	3.97±0.71	3.06±.95	-4.33*
Mental Wellbeing	3.29±1.24	2.56±0.93	-2.70**
Work	3.42±0.92	2.74±0.90	-3.02**
Role in the Family	3.77±0.80	3.18±0.90	-2.80**
Number of Friends- acquaintances	3.58±0.62	2.94±0.98	-3.10**
Appearance	3.16±1.21	2.47±0.93	-2.59***
General Quality of Life	3.06±1.06	2.53±0.82	-3.20**

*p<0.001, **p<0.01, ***p<0.05, SSS: Shame and Stigma Scale in Head and Neck Cancer, GHQ: General Health Questionnaire, LSI: Life Satisfaction Inventory.

Discussion

In this study, SSS was translated and validated into Greek. The psychometric properties are found particularly good: there is high internal consistency (Chronbach's index $\alpha = 0.93$) and significant validity of conceptual structure (convergent and discriminant validity), as well as the validity based on criterion (predictive and concurrent validity). Thus, it can be assumed that the scale assesses four parameters independently.

As expected, the group of patients who had surgery more than three months ago is more compromised (higher SSS and GHQ score and lower LSI score). In a three month period, any disfigurement due to surgery has begun to develop [7] and over time changes in body image and functions such as speech, taste, swallowing, etc. are having a negative effect on the quality of life of patients. Patients' anger and anxiety increases and life satisfaction as well as quality of social and interpersonal relationships reduces, which correlates strongly with shame and stigma [7,20,21].

Anxiety disorders are more common in the process of diagnosis while depression during the treatment period [22]. During immediate post-surgery period patients are more concerned about practical issues and are anxious about treatment success and survival. Once physical function begins to recover at an extent, people start worrying about body appearance and quality of life. This change might be also associated with the progressive impact of the disease on daily life while encouragement that patients receive by the supportive and friendly environment may play a role.

In the study of Fingeret al [23]. More than 75% of patients reported concerns about their current and future appearance, mainly due to changes resulted from surgery and nearly 60% reported that they feel stigmatized because of this. It is a fact that patients experience tremendous changes in their functionality even when there are no significant changes in overall health [24].

SSS scores of patients group recorded by Kissane et al [7]. were much lower than those in this study because the current sample was more homogeneous (the majority of patients were men with laryngeal cancer, stage III or IV). The fact that the vast majority were men arises from the fact that men are more than twice likely to develop head and neck cancer than women [25].

According to the study of Kissane et al [7]. Chronbach's alpha for the entire SSS is 0.93 indicating strong internal consistency and for the subscales ranges from 0.78 to 0.92. Pearson's correlation coefficient presents an average of 0.28 for the entire scale while it ranges from 0.36 to 0.45 for the subscales. The correlations between the SSS and other Scales demonstrate the convergent and discriminant validity of SSS. Total score of SSS and all subscales have moderate to high negative correlation with the FACT-G and FACT-H&N scales for cancer and moderate to high positive correlation with Demoralization Scale and Patient Health Questionnaire (PHQ) Depression Scale. Total SSS score correlates with the assessments of performance in terms of public meal, diet and overall functionality rating, while social concerns and/or concerns for speech correlate with all performance ratings. None of the SSS subscales correlates significantly with Marlowe-Crowne Social Desirability Scale.

Since the choice of a particular study population and an observational period can affect the confounding and misclassification in epidemiological studies [26] people who lived permanently in the province also participated in the study, in order to reduce selection bias and increase validity of the study despite the selection of a sample from hospitals in Attica.

Data collection was completed in one (1) year period (January to December) in order to avoid the selection of a particular observational period which could probably lead to an overestimation or underestimation of the evaluation of the respondents in terms of total (mental and physical) health that may present differences due to the climatic conditions during summer and winter months. Study's limitations include the sample size and the fact that there were no other scales evaluating the exact same concepts to be used as "gold standards" for comparison.

Conclusion

The findings of this study indicate that the Greek translation of SSS is valid, reliable and easy to use. It can become an important tool for health professionals in general hospital, helping them to better recognize the patients' adaptation to therapeutic interventions and self image changes, in order to identify problems and provide solutions in time achieving the best possible functional level for the individual.

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