

## Original Article

## Cancer stigma scale: Validity and reliability study of the Turkish version of the Cataldo Lung Cancer Stigma Scale for all cancer subtypes

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## ABSTRACT

**Aim:** Many people move away from society after being diagnosed with cancer. Most of the cancer-related studies are focused on lung cancer. The aim of the study is to establish the validity and reliability of the Turkish version of the Cataldo Lung Cancer Stigma Scale (CLCSS) Short Version for all cancer subtypes.

**Material and method:** The patients participating in the study consisted of individuals who were diagnosed with cancer either inpatient or outpatient treatment. In the evaluation of the structural validity, the compliance statistics were used to assess the adequacy of the model obtained in the confirmatory factor analysis. At the end of the validity evaluation, the Cronbach's alpha coefficient was calculated as an estimate of the internal consistency of each sub-dimension.

**Results:** The mean age of the participants was  $56,90 \pm 11,14$  years. According to the confirmatory Factor Analysis and Compliance statistics of the 21 items in the Turkish version of the scale, except for two items, it was determined that it is suitable for three sub-dimensional structures. In the factor analysis of Varimax rotation, the Keizer-Meyer-Olkin ratio of the sample is 0.884 and Barlett's test result is 3792.05 (0.001). The two items (most people are disturbed by someone with cancer, people with cancer lose jobs when they learn about employers) were below 0.40, they were not included in any factor. The Cronbach's alpha value was determined as 0.89 for the three-factor scale.

**Conclusion:** The Cataldo Lung Cancer Stigma Scale short version is a valid and reliable tool for all cancer patients, not just lung cancer.

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## 1. Introduction

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group.<sup>1</sup> Health-related stigma (HRS) refers to the stigmatization of a person or group by others because of an illness.<sup>2</sup> This is characterized by rejection, shame, or devaluation as a result of the expectation, perception or experience of negative social judgment about the person or group.<sup>1</sup> HRS is unstable, intercultural and affected by time.<sup>3</sup> HRS has been associated with less known, less understood, long-term, non-treated, fear-inducing diseases.<sup>4,5</sup>

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To date, most of the literature focuses on HRS and small numbers of diseases. For example, leprosy, epilepsy, HIV, and mental illnesses.<sup>6</sup> Although cancer was accepted as a stigmatized disease and cancer patients perceived stigmatization, it was less studied.

Cancer-related stigma is historically caused by fear of death and suffering.<sup>7,8</sup> Many people move away from society after being diagnosed with cancer.<sup>9–11</sup> The fear of stigmatization is an obstacle to explaining the cancer diagnosis.<sup>10,12</sup> Most of the cancer-related studies are focused on lung cancer.<sup>10,13</sup> Most of these patients are patients who smoke and think that they cause the disease because of the strong causation relationship between smoking and lung cancer. They feel stigma perception according to smoking status. Those currently drinking, older smokers and nonsmokers have reported a perception of stigmatization. They display symptoms such as smoking and self-embarrassment.

The current scales in the literature investigating stigmatization for cancer patients have been prepared for lung cancer.<sup>13,14</sup> Cataldo

et al. (2011) developed the Cataldo Lung Cancer Stigma Scale for lung cancer by using the HIV stigma scale.<sup>13,15</sup> Because both diseases are similar in terms of the course of the disease and the perceived problems. The scale was originally a likert-type scale consisting of 31 items. Then, to reduce the patient's burden, an abbreviated form of 21 items was developed.<sup>14</sup> Stigmatization is not only for lung cancer but for all cancer patients with negative consequences on health. It is a problem that prevents health-related help seeking behavior and increases the burden of disease, depression and low quality of life.<sup>16,17</sup>

In this study, it was planned to adapt the validity and reliability of the Turkish version of the Cataldo Lung Cancer Stigma Scale (CLCSS) Short Version for all cancer subtypes.

## 2. Material and methods

### 2.1. Translate procedure

Permission was obtained from the authors to develop and use the Turkish version of the scale.

The scale was translated by a psychiatrist and a public health professional. After this translation has been checked and agreed on, the patients and their relatives have been red to test the comprehensibility of the scale questions. Then, it was translated into English by a linguist again. This translation was checked by a psychiatrist independent of the translations of the scale and its appropriateness was tested and the scale text was established.

### 2.2. Sample

The study sample consisted of literate and volunteer individuals who were diagnosed with cancer in outpatient or inpatient clinic in Akdeniz University Hospital Oncology Department. The sample size was calculated as approximately 15 people for each item and the sample size calculated for 21 items was determined as 315 people. It was aimed to reach 350 people as sample size. In our study, 342 patients filled the scale completely and 342 patients were evaluated.

The criteria for inclusion in the study were to be older than 18 years of age, to have a cognitive competence to fill the cancer diagnosis research scales and to be literate.

All participants were informed about the study and volunteers were accepted from those who agreed to participate in the study. This research was deemed ethically appropriate by the Clinical Research Ethics Committee of Akdeniz University Faculty of Medicine.

### 2.3. Tools

#### 2.3.1. Sociodemographic and clinical data form prepared by the researchers was filled in the patients as evaluation tools

The form included questions about sex, marital status, education, work status and cancer types. Then, all the patients were filled in the Turkish version of CLCSS.

#### 2.3.2. Turkish version of Cataldo Lung Cancer Stigma Scale

This scale was developed and used by Cataldo et al. (2011) to measure the stigmatization perception of outpatient lung cancer patients.<sup>14</sup> Carter-Harris et al. used the scale in lung cancer patients with depression.<sup>17</sup> The short form of the scale was then prepared for ease of application. The dimensionality of the original form, the reliability of the internal consistency and the short form's explanatory factor analysis and reliability were shown.<sup>15</sup> The short form of the scale consists of 21 questions. The scale includes shame and guilt, social isolation and discrimination subscales. In this study, the term 'cancer' was used instead of 'lung cancer'.

### 2.4. Data collecting

Patients with illiteracy and cognitive competence who were inpatient or outpatient in Akdeniz University Hospital Oncology Department were informed and their sociodemographic data form and CLCSS were applied to the patients after their informed consent was obtained.

### 2.5. Statistical analysis

A total of 342 cancer patients were enrolled for validity analysis. Factor analysis was performed to determine the relationship between factors and variables for validity analysis (explanatory and confirmatory). Confirmatory factor analysis (CFA) was performed to evaluate the validity of the scale. Substances not loaded on any sub-dimension as a result of CFA (factor load > 40 of relevant size) were excluded from the analysis.

Compliance statistics were used to evaluate the adequacy of the model obtained as a result of CFA. At the end of the validity assessment, the Cronbach's alpha coefficient was calculated to estimate the internal consistency of each sub-dimension. The Cronbach's alpha coefficient is the smallest acceptable value of 0.70 for group-level evaluation.

In addition, the equivalent halves method was used from the single application-based methods used to determine the reliability of a test. In this method, the patients were coded as one and two respectively and Pearson correlation coefficient was examined.

## 3. Results

### 3.1. Sociodemographic and clinical features

The characteristics of the patients included in the study are presented in Table A. 62.6% of the patients were female, 83.3% were married, 59.4% were primary-middle school graduates, and 44.7% were employed. The mean age of the patients was  $56,90 \pm 11,14$ .

While 33.6% of the patients were diagnosed with breast cancer, the others were diagnosed with colo-rectal cancer, lung cancer, ovarian cancer, gastric cancer and other diagnoses, respectively (see Table B).

### 3.2. Validity reliability analysis

Within the scope of the study, 21 items were evaluated with CFA in terms of their suitability for three sub-dimensional structures in the reference article. According to compliance statistics, the Turkish version of the scale was found to be suitable for three sub-dimensional structures except two items. The items and factor loads are given in Table C.

In the factor analysis of Varimax rotation, the Keiser-Meyer-Olkin ratio of the sample was 0.884, and the Bartlett's test result was 3792.05 (0.001). Sample size is sufficient. As Bartlett's test result is 0.001, the data shows normal distribution and high correlation. The relationship between the scores obtained by the equivalent halves method and the scores of the participants was evaluated with Pearson correlation technique (see Table C). Correlation coefficients vary between 0.228 and 0.767. A strong correlation was obtained as a result of halving the matter. ( $P < 0.01$ ).

The communality distribution of the data was analyzed. The common variance of data is the amount of variance that a variable shares with other variables in the analysis.

During the analysis, those with a value of 0.40 were included in the analysis and the others were excluded from the analysis. As a result of the analysis, three factors (shame and guilt, social isolation and discrimination) were formed. The item load of three factors is

54.69%. The first factor was 23,243%, the second factor was 39,688%, and the third factor was 54,692. In factor analysis, after confirmatory factor analysis, the first factor included 7 items, the second factor 8 items and the third factor 4 items (Table D).

Two items (most people are disturbed by someone with cancer, people with cancer lose jobs when they learn about employers) were below the 0,40 value, they were not included in any factors. The internal consistency coefficient obtained for the whole scale was 0.89.

#### 4. Discussion

In this study, the reliability and validity of the Turkish version of CLCSS was demonstrated in all cancer patients. More than half of the patients were female, most of them were married and the mean age was  $56.90 \pm 11.14$ . These findings are similar to the original study by Carter-Harris and Hall, except that the average age is lower.<sup>14</sup> Unlike the original study, the sample size was determined to be larger because all types of cancer were targeted.

The internal consistency coefficient for the whole scale was 0.89. The internal consistency coefficient of the original scale was found to be 0.93.<sup>14</sup> For the Cronbach's alpha coefficient, the value of 0.70 is the smallest acceptable value for the group level.<sup>18</sup> Our study shows that Turkish version of CLCSS is a valid and reliable scale for all types of cancer.

In terms of confirmatory factor load, 0.813–0.426 for Factor 1, 0.848–0.434 for factor 2, and 0.833–0.624 for factor 3 were found compared to the original study. These values are similar to the original study (0.86–0.58, 0.85–0.37, 0.89–0.70).<sup>14</sup> Two items (most people are disturbed by someone with cancer, people with cancer lose jobs when they learn about employers) were not included in any factor since they were below the value of 0.40.<sup>18</sup> These two items were excluded from the scale and the Turkish version of CLCSS consisted of 19 questions. The fact that these two items are not included in any factors may be related to the socio-economic system and cultural structure of our society. For example, in our country, the social security system is carried out by the state and in the business sector, the disease is the less likely to be dismissed. In the period when the patients cannot work, there are options such as report use or disability pension. Another item (most people are disturbed by someone with cancer) is not included in any factors. However, there are other similar items on the scale that express the social distance. A striking detail is that although the expression in this item contains generalization, the perception of stigmatization towards people is more pronounced in other similar items in the factor related to social distance.

The relationship between the equivalent halves method and the scores of the scores of the participants was evaluated by Pearson correlation technique and a strong correlation was obtained. This shows that the scale has high reliability.

#### 5. Conclusion

As a result of the adaptation studies of the Turkish short form of CLCSS, it has been shown that it is valid and reliable not only in lung cancer but also in all cancer patients and it can be used to show the stigmatization of cancer patients for our country. As a result of the analysis, three areas similar to the original scale were found. The two items remained outside the model in terms of factor load. By the nature of stigmatization, more than one factor can arise from mixed, interactive and mutual influences. Shame and accusation, social loneliness, and discrimination are the elements involved in stigmatization. As a result of scale adaptation, these substances remain within the model and are similar to the original study.

#### Conflict of interest

The authors declare that this manuscript is an independent study, has no conflict of interest including any financial, personal or other relationship with other people or organizations within three years of beginning the submitted work.

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#### Appendices

**Table A**  
Sociodemographic characteristics of the patients

	Number	Percent (%)
<b>Sex</b>		
Male	128	37,4
Female	214	62,6
<b>Marital status</b>		
Married	285	83,3
Single	13	3,8
Divorced	20	5,8
Spouse is died	23	6,7
<b>Education</b>		
Literate	39	11,4
First-second school	203	59,4
High school	56	16,4
University	44	12,9
<b>Work status</b>		
Not working	153	44,7
Working	44	12,9
Other	145	42,4

**Table B**  
Diagnosis types of patients participating in the study

	N	Percent (%)
Breast CA	115	33,6
Colo- rectal CA	55	16,1
Lung CA	38	11,1
Ovarian CA	33	9,6
Gastric CA	18	5,3
Other	83	24,3

**Table C**  
Total statistics of scale items.

Items	Item total correlation	Without this substance $\alpha$
2	,640	,885
3	,677	,881
4	,718	,880
5	,648	,878
6	,637	,881
7	,526	,879

(continued on next page)

Table C (continued)

Items	Item total correlation	Without this substance $\alpha$
9	,584	,889
10	,564	,885
11	,622	,885
13	,697	,878
14	,641	,880
15	,707	0879
18	,729	0877
19	,767	,877
20	,721	,878
24	,228	,895
26	,436	,881
27	,537	,880
28	,766	,883
29	,726	,884
30	,666	,884

Pearson Correlation Analysis.

Table D

Distribution of substances as a result of confirmatory factor analysis

Items	Factor 1	Factor 2	Factor 3
1. I work hard to keep my cancer a secret.	,798		
2. Having cancer makes me feel like I'm a bad person.	,798		
3. I'm very careful whom I tell I have cancer.	,813		
4. I feel I'm not as good as others because I have cancer.	,700		
5. Having cancer makes me feel unclean.	,553		
6. I feel set apart, isolated from the rest of the world.	,426		
7. Smokers could be refused treatment for cancer.	,738		
8. Some told me cancer is what I deserved for smoking.		,594	
9. My cancer diagnosis was delayed because my healthcare provider did not take my smoker's cough seriously.		,434	
10. I stopped socializing with some because of their reactions.		,813	
11. People have physically backed away from me.		,772	
12. People I care about stopped calling after learning that I have cancer.		,778	
13. People avoid you because cancer is associated with death.		,755	
14. Some people who know have grown more distant.		,848	
15. I was hurt how people reacted to learning I have cancer.		,834	
16. Cancer is viewed as a self inflicted disease.			,624
17. Others assume that a patient's cancer was caused by smoking, even if he or she never smoked.			,833
18. Others assume that a patient's cancer was caused by smoking, even if he or she had stopped smoking years ago.			,827
19. Some people act as though it is my fault that I have cancer.			,755

Confirmatory Factor Analysis.

**Factor 1:** Shame and accusation.**Factor 2:** Social isolation.**Factor 3:** Discrimination.

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