Stigma in Mexican patients with Lung Cancer: Psychometric Properties of the Cataldo Lung Cancer Stigma Scale (CLCSS) - Brief version

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Abstract

Introduction. Stigma in lung cancer patients may be associated with various negative outcomes such as increased psychosocial symptoms, severity of physical symptoms, and may act as a barrier to medical help-seeking behavior. The Cataldo Lung Cancer Stigma Scale (CLCSS) is one of the most widely used instruments for assessing health-related stigma in lung cancer patients.

Objectives. To determine the psychometric properties of the CLCSS in a Mexican sample of lung cancer patients.

Methods. A non-experimental, instrumental design was employed, using non-probabilistic sampling based on availability. The sample included 265 lung cancer patients. Confirmatory Factor Analysis (CFA) was conducted to assess construct validity, and Cronbach's alpha and McDonald's Omega were used for internal consistency and test-retest reliability, respectively, through Pearson correlation coefficient.

Results. The 17-item version yielded a model with 4 factors (stigma and shame, social isolation, discrimination, and smoking) explaining 50.74% of the variance, with adequate values of internal consistency and test-retest reliability.

Significance of results. The Mexican version of the CLCSS is culturally appropriate, brief, psychometrically valid, and reliable for assessing health-related stigma in Mexican lung cancer patients.

Introduction

Globally, lung cancer (LC) accounts for 2,206,771 cases and 1,796,144 deaths, with projections indicating an expected increase to 3,610,896 cases and 3,104,704 deaths by the year 2040 (International Agency for Research on Cancer 2021a). In Mexico, LC registers 7,588 new cases and 7,100 deaths (International Agency for Research on Cancer 2021b). Approximately 70% of cases are diagnosed at advanced stages (Hsu et al. 2020; Nooreldeen and Bach 2021). This may be attributed to various factors such as lack of access to healthcare services or knowledge of symptoms. However, another reason that may negatively impact help-seeking behavior is stigma. Stigma refers to the anticipation or fear of discrimination, and awareness of negative attitudes and actions related to a specific condition (Van Brakel 2006). Health-related stigma (HRS) is defined as a personal experience characterizing the feeling of exclusion or rejection, as well as guilt or devaluation resulting from the anticipation of adverse judgment. This judgment is based on an enduring trait of identity conferred by a health problem or health-related condition. The judgment is medically unjustified and can negatively affect health status (Weiss and Ramakrishna 2006).

For many patients with LC, HRS can negatively affect their willingness to participate in early detection, delay seeking medical evaluation for symptoms, limit their involvement in LC treatment and survivorship care (Hamann et al. 2018). Additionally, HRS is associated with the presence of anxiety symptoms (13%–43%), depression (25%–26%), emotional

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distress (38.6%–40.2%), low self-esteem, low treatment adherence, social isolation, limited living space, employment barriers, social exclusion, lack of social support, increased severity of physical symptoms, and consequently, leads to a decrease in quality of life (Brown Johnson et al. 2014; Carter-Harris et al. 2014; Cataldo et al. 2011; Cataldo and Brodsky 2013; Else-Quest et al. 2009; Ernst et al. 2017; Liu et al. 2016; Stergiou-Kita et al. 2016; Threader and McCormack 2016). Thus, identifying the presence and impact of HRS in this patient group will allow for the development of timely and effective psychosocial interventions (Cataldo et al. 2011) to prevent associated complications.

Tobacco consumption is one of the most significant risk factors; approximately 80% of LC cases are attributed to smoking habits (Sung et al. 2021). Although all LC patients are susceptible to stigma, those with a history of smoking may be perceived as responsible and even deserving of this illness (Hamann et al. 2013; Lobchuk et al. 2012). Therefore, stigma in LC is rooted in the belief that the patient's behavior was the cause of the cancer (Cataldo et al. 2011). It has been noted that approximately 95% of LC patients experience stigma (Hamann et al. 2014; Shen et al. 2016).

There are various instruments for assessing stigma in lung cancer patients (Webb et al. 2019), such as the Cancer Responsibility and Regret Scale (CRRS) (Criswell et al. 2016), the Explanatory Model Interview Catalog (EMIC) (Weiss et al. 1992), the Cancer-Related Perceived Stigma Scale (CRPSS) (LoConte et al. 2008), the Shame and Stigma Scale (SSS) (Kissane et al. 2013), and the Social Impact Scale (SIS) (Fife and Wright 2000). However, these instruments approach the construct from a perspective of "attitudes towards cancer" (Criswell et al. 2016; Kissane et al. 2013; LoConte et al. 2008) rather than health-related stigma. A current measure that has emerged for specifically evaluating HRS in lung cancer patients, with adequate psychometric properties, is the Cataldo Lung Cancer Stigma Scale (CLCSS) (Cataldo et al. 2011).

The original scale (Cataldo et al. 2011) consists of 31 items with 4 Likert-type response options measuring aspects of HRS, developed to assess perceived stigma among lung cancer patients. Subsequently, a shortened version of 21 items was developed (Carter-Harris and Hall 2014), as well as another version with 22 items (Lv et al. 2022), both demonstrating adequate psychometric properties.

The CLCSS has undergone various validations across different cancer diagnoses, including lung cancer (Carter-Harris and Hall 2014; Cataldo et al. 2011; Doganavsargil-Baysal et al. 2019; Lima 2015; So et al. 2017; Yang et al. 2014), demonstrating appropriate factorial structure, validity, and reliability. These studies have reported between 3 and 6 factors, with Cronbach's alphas ranging from 0.85 to 0.93 and explained variances from 54.69% to 68%, thus establishing it as a suitable instrument for assessing HRS in lung cancer patients.

Despite these efforts, a valid and reliable instrument is needed in Mexico for evaluating this construct in lung cancer patients. Therefore, the aim of the present research was to determine the psychometric properties of the Cataldo Lung Cancer Stigma Scale (CLCSS) in a Mexican sample of lung cancer patients.

Method

A total of 265 lung cancer patients of both sexes were included in the study. Table 1 describes the demographic and clinical characteristics of the sample. The study was cross-sectional, non-experimental, and instrumental (Carretero-Dios and Pérez 2005). This protocol was approved by the Ethics Committee of the National Cancer Institute in Mexico, with approval number (022/045/ICI) (CEI/027/22). Data collection took place between January and September 2023. Participants were recruited based on availability. Each participant agreed to take part in the study by signing an informed consent form.

Inclusion criteria

1. Participants with a diagnosis of lung cancer. 2. Aged 18 years and above. 3. Voluntary participation through understanding and acceptance of the informed consent letter. 4. Under active treatment. 5. Any clinical stage. 6. Karnofsky Performance Status Index $\geq$ 70 points.

Exclusion criteria

1. Participants with hearing or visual impairments preventing scale completion. 2. Those presenting severe psychiatric disorders and/or addiction to psychoactive substances. 3. Participants with cognitive impairments.

Elimination criteria

1. Participants deciding not to continue participating during the completion of the instruments. 2. Incomplete completion of the instruments.

Instrument

Identification Form: A participant identification form was designed, including sociodemographic and clinical data such as age, sex, education level, place of residence, smoking history, oncological diagnosis, clinical stage, medical treatment, and functional level (see Table 1).

Cataldo Lung Cancer Stigma Scale (CLCSS): Developed by Cataldo et al. (2011), this self-administered instrument utilizes a four-point Likert-type response scale ranging from 1 (strongly disagree) to 4 (strongly agree), with higher scores indicating a stronger perceived stigma by the patient. It consists of 31 items divided into 4 factors: Stigma and Shame (related to the patient's personal sense of stigma and shame and addresses the perceived consequences of others knowing about it) $\alpha = 0.96$, Social Isolation (addresses loss of social support) $\alpha = 0.95$, Discrimination (refers to feeling judged and discriminated against) $\alpha = 0.91$, and Smoking (refers to lung cancer being considered a disease caused by smoking, even if the patient has never smoked or quit smoking years ago) $\alpha = 0.74$. It has an overall internal consistency of $\alpha = 0.96$ and an explained variance of 57%.

Phase I: Cultural adaptation

Permission was obtained from the author to begin the translation process of the original English questionnaire into Mexican Spanish by an expert translator. Subsequently, a group of expert psychologists, pulmonologists, and oncologists conducted an assessment of content validity, difficulty, confusion, appropriate language of items, instructions, and response options. The Aiken's V index was then calculated for each item, with a critical value of .70 established as the lower limit of the confidence interval (Penfield and Giacobbi, 2004; Ventura-León 2019) for the 31 items. A pilot test

Table 1. Sociodemographic and clinical characteristics of the sample

	f	%		f	%
N	265	100	**Clinical stage**		
			I	7	2.6
Age (rank) 23–84 años	Me = 59.19		II	5	1.9
			III	23	8.7
Gender			IV	230	86.8
Male	162	61.1			
Female	103	38.9	**Treatment**		
			Chemotherapy	65	24.6
Civil status			Radiotherapy	8	3.0
Single (a)	48	18.1	Immunotherapy	21	7.9
Married (a)	145	54.7	Targeted therapy	152	57.4
Widower (a)	27	10.2	Follow-up period	21	7.9
Divorced (a)/separated (a)	27	10.2			
Free Union	18	6.8	**Karnofsky Index**		
			70	8	3.0
Paternity/maternity			80	41	15.5
Yes	238	89.8	90	196	73.9
No	27	10.2	100	20	7.6
Place of residence			**History of smoking**		
CDMX	81	30.6	Yes	103	38.9
Mexico state	78	29.4	No	162	61.1
Interior of the Republic	106	40.0			
			Exposure to wood smoke		
Scholarship			Yes	50	23.8
None	17	6.4	No	215	76.2
Primary	56	21.1			
Secondary	55	20.8	**Mutation (EGFR/ALK)**		
Preparatory	56	21.1	Yes	80	30.2
Degree	49	22.6	No	185	60.8
Postgraduate	21	7.9			
			Mental health history		
Occupation			Psychology	32	12.1
Home	146	55.1	Psychiatry	15	5.7
Employee	28	10.6	Psychology/psychiatry	11	4.2
Professional	20	7.5	None	207	78.1
Retired	23	8.7			
Businessman	22	8.3			
Unemployed	12	4.5			
Worker/technician	14	5.3			

was then conducted with a sample of 15 lung cancer patients to evaluate item difficulty, confusion, or offensive language in items, instructions, and response options (Ramada-Rodilla et al. 2013), and minor adjustments were made to items: "20. My lung cancer diagnosis was delayed because my doctor did not take my 'smoker's cough' seriously"; "26. People with lung cancer lose their jobs when

bosses know about lung cancer"; and "31. Medical staff does not take 'smoker's cough' seriously."

Statistical analysis

Construct validity

Confirmatory Factor Analysis (CFA)

Analyses were conducted with measures of central tendency and dispersion for sociodemographic and clinical data. The adequacy of the sample was determined using the Kaiser-Meyer-Olkin (KMO) coefficient and Bartlett's sphericity test. The construct validity of the CLCSS was analyzed using Confirmatory Factor Analysis (CFA) with the statistical program AMOS version 24, employing maximum likelihood estimation. The evaluation of fit was specified by observing appropriate limits of estimators, standardized parameters, and non-collinearity in measured variables. The following global fit indices were estimated: χ^2 and χ^2/df ratio, the goodness-of-fit index (GFI, NFI) and their complements (AGFI, TLI), as well as the comparative fit index (CFI), which is the best indicator for samples equal to or greater than 200, considering a value equal to or greater than .90 as acceptable. Lastly, the root mean square error of approximation (RMSEA) and the standardized root mean square residual (SRMR) were considered, with a value equal to or less than .06 considered acceptable. (Byrne 2010; Kline 2005; Ullman 2006).

To evaluate reliability, internal consistency was determined using Cronbach's alpha coefficient and McDonald's Omega, and test-retest reliability was assessed using the Pearson correlation coefficient. A significance level of $p < .05$ was adopted.

Results

Confirmatory Factor Analysis (CFA)

The KMO index was 0.91 (p < .001). The CFA of the CLCSS yielded a 4-factor model explaining 50.74% of the variance. The global fit χ^2/df ratio (1.848, p = .001) and fit indices NFI = 0.916; TLI = 0.950; CFI = 0.959; AGFI = 0.887; SRMR = 0.0673 and RMSEA = 0.057 demonstrate that the 4-factor model with 17 items is adequate and parsimonious. Factor loadings can be observed in Fig. 1.

The following items were removed from the dimensions: Stigma and Shame: "1. I feel guilty because I have lung cancer," "4. I am very careful about who I tell that I have lung cancer," "8. My lung cancer diagnosis was delayed because I missed the doctor's appointment," "9. Some people told me that lung cancer is what I deserve for smoking," "10. My lung cancer diagnosis was delayed because my doctor did not take my 'smoker's cough' seriously," "11. Smokers could be denied treatment for lung cancer." Social Isolation: "13. I stopped socializing with some people because of their reactions related to my lung cancer," "14. People have physically distanced themselves from me," "17. People avoid touching me if they know I have lung cancer," and "20. People's reaction to knowing I have lung cancer hurt me." Discrimination: "22. People with lung cancer are discriminated against," "23. Most people believe that a person with lung cancer is dirty," and "26. People with lung cancer lose their jobs when bosses or coworkers know about lung cancer." And Smoking: "31. Medical staff does not take 'smoker's cough' seriously."

Reliability indices

The internal consistency coefficient Cronbach's alpha obtained for the overall CLCSS was $\alpha = 0.85$. For the subscales, it was: Stigma and Shame (SS) $\alpha = 0.82$; Social Isolation (SI) $\alpha = 0.88$; Discrimination (D) $\alpha = 0.84$; and Smoking (S) $\alpha = 0.75$. Similarly, McDonald's Omega coefficients were calculated, yielding the following values: CLCSS overall: $\omega = 0.91$; SS: $\omega = 0.83$; SI: $\omega = 0.89$; D: $\omega = 0.84$; and S: $\omega = 0.77$.

For test-retest reliability, a 15-day interval was determined, as it was sufficient time to prevent patients from remembering their responses to the first administration, and it was considered that within this time frame, there would be no clinically significant changes in the patient's health (Ramada-Rodilla et al. 2013). The test-retest reliability obtained was 0.85. These results indicate an adequate level of consistency between repeated tests using the Mexican version of the CLCSS.

Proposal of cut-off points

For this study, the following cut-off points were proposed based on the values of the 25th, 50th, and 75th quartiles: Patients without stigma (0 to 20 points), mild stigma (21 to 23 points), moderate stigma (24 to 28 points), severe stigma (29 points and above). The percentage of stigma in the Mexican population was as follows: 28.3% had no stigma; 23.0% had mild stigma; 26.8% had moderate stigma; and 21.9% had severe stigma.

Discussion

The present study aimed to determine the psychometric properties of the CLCSS in a Mexican sample of lung cancer patients. Upon examining the dimensionality of the original CLCSS, it was identified that the instrument with 31 items did not adequately fit the Mexican population, thus suggesting the need for instrument reduction.

Regarding the identified dimensions, the CFA presented a 4-factor structure: Stigma and Shame (5 items); Social Isolation (5 items); Discrimination (3 items); and Smoking (4 items), which align with the original version (Cataldo et al. 2011) and subsequent studies in lung cancer patients (Lv et al. 2022; Yang et al. 2014). However, it differs from validations identified in heterogeneous samples of cancer patients (Doganavsargil-Baysal et al. 2019; So et al. 2017), where factorial structures range from 3 to 6 factors.

The items of the Stigma and Shame factor in lung cancer patients identified in this study align with what has been reported in the original version (Cataldo et al. 2011), the short version by Carter-Harris et al. (2014) named "shame and guilt," and the Chinese version (Yang et al. 2014). It was found that the items "3. Having lung cancer makes me feel like a bad person" and "6. Having lung cancer makes me feel dirty" are not included in this factor in the Chinese version.

Similarly, in the Korean version (So et al. 2017) in heterogeneous patient samples, a factor called "guilt" was identified, where the only item not found in our population is item "4. I am very careful about who I tell that I have cancer." Lastly, the version by Doganavsargil-Baysal et al. (2019), where the factor is "shame and guilt," the items align with what was identified in our study.

The items identified in the Social Isolation factor also align with what has been reported in the original version (Cataldo et al. 2011). However, items "12. I have lost friends by telling them I have lung cancer" and "16. People seem to be afraid of me because I have lung cancer" are not included in the short version (Carter-Harris et al. 2014)), the Chinese version, and in studies of heterogeneous patient samples (Doganavsargil-Baysal et al. 2019; So et al. 2017).
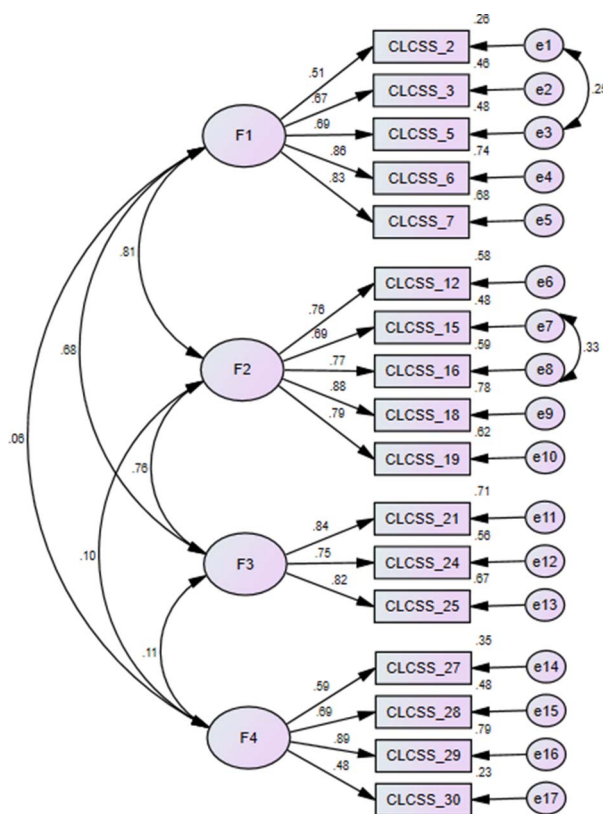
Models	χ^2 (gl)	CMIN/DF	NFI	TLI	CFI	GFI	AGFI	SRMR	RMSEA
Modelo original con 31 reactivos	1355.496	3.167	.738	.786	.803	.745	.704	.0965	.091
Proposed model with 17 items	205.144	1.848	.916	.950	.959	.918	.887	.0673	.057

Figure 1. Confirmatory factor structure with 17 CLCSS items in Mexican patients with lung cancer (n = 265).

Regarding the Discrimination and Smoking factors, it was found that they differ from what is reported in the studies (Carter-Harris 2015; Doganavsargil-Baysal et al. 2019; So et al. 2017) since in some validations there were between 3 and 6 factors that do not include the smoking and/or discrimination factor. Therefore, our results align with this factor from the original version (Cataldo et al. 2011).

The elimination of the 14 items was due to not meeting the established criterion of 0.40 in factor loadings. Regarding the items related to guilt and shame and social isolation, one possible explanation could be attributed to the variable social support. It has been noted that due to the characteristics of the disease and its treatment, lung cancer patients need a particularly high level of social support in all its dimensions (Porter et al. 2011), in addition to being considered a moderating variable of stigma (Maggio 2015). In Mexican oncological patients, Hernández (2019) identified that 52% of patients perceived high support; however, further evidence is required regarding the association between social support and stigma specifically in lung cancer patients.

Another possible explanation for the items related to discrimination and smoking may be the satisfaction with the healthcare team, composed of professionals specialized in cancer treatment who may have a sgreater knowledge of the disease's causes and may not convey negative attributions towards the patient. Stigma has

been noted as a barrier to seeking medical attention (Carter-Harris et al. 2014). In our country, Hernandez (2019) assessed satisfaction with the healthcare team in lung cancer patients, and it was found that 81% had moderate/high satisfaction.

Another possible explanation for the eliminated items may be the characteristics of the sample. It was identified that 30.2% of lung cancer diagnoses were due to a mutation (EGFR/ALK), which was treated with targeted therapy, and they had a Karnofsky performance status score of 90 points, indicating that, despite being in advanced stages, they were able to perform activities of daily living. In Mexico, it has been noted that patients with EGFR/ALK mutation tend to experience less stigmatization compared to other risk factors such as smoking (Arrieta et al. 2019; Cruz-Rico et al. 2017).

Regarding the levels of stigma identified in our study, they fall within what has been reported in previous studies, where lung cancer stigma has been reported at 95% (Hamann et al. 2014; Shen et al. 2016).

Regarding the reliability indices and explained variance, our findings indicate that Cronbach's Alpha and explained variance fall within acceptable ranges reported in previous studies (Carter-Harris and Hall 2014; Cataldo et al. 2011; Doganavsargil-Baysal et al. 2019; Lima 2015; So et al. 2017; Yang et al. 2014). Even though the number of items was reduced by almost half, the short version did not imply a decrease in consistency indices for the CFA. As

noted by Carter-Harris and Hall (2014), the shorter version will also reduce the burden on lung cancer patients when completing the instrument.

One of the main strengths of this research is the reporting of the CFA. Currently, only 2 studies have conducted the CFA of the CLCSS. The model fit indices are superior to the validation performed in a heterogeneous sample of cancer patients (So et al. 2017) but similar to the fit indices of the 22-item short version for lung cancer patients (Lv et al. 2022), and in these validations, it is concluded that the CLCSS is a suitable instrument for evaluating ERS. Therefore, this supports our findings to use the CLCSS as an instrument for this construct in our population.

Another strength of our study is the proposal of cutoff points, which have not been identified in validations conducted in both the original version and subsequent studies (Carter-Harris and Hall 2014; Cataldo et al. 2011; Doganavsargil-Baysal et al. 2019; Lima 2015; Lv et al. 2022; So et al. 2017; Yang et al. 2014). This allows us to have an overview of the impact of ERS on our population.

Limitations

Within the limitations of this study, the sample size and sampling type make it difficult to generalize the results of this research to the entire Mexican population with lung cancer, as well as the use of a specialized cancer treatment center. An additional limitation is the lack of concurrent and divergent validity. It is also recommended that future research pay attention to the floor-ceiling effect.

Conclusion

The Mexican version of the CLCSS is culturally appropriate, brief, psychometrically valid, and reliable for assessing health-related stigma in lung cancer patients. Its use in clinical care and research is recommended.

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