

Reliability and Validity Study of a Tool to Measure Cancer Stigma: Patient Version

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ABSTRACT

Objective: The aim of this methodological study is to establish the validity and reliability of the Turkish version of “A Questionnaire for Measuring Attitudes toward Cancer (Cancer Stigma) - Patient version.” **Methods:** The sample comprised oncology patients who had active cancer treatment. The construct validity was assessed using the confirmatory and exploratory factor analysis. **Results:** The mean age of the participants was 54.9±12.3 years. In the confirmatory factor analysis, fit values were determined as comparative fit index=0.93, goodness of fit index=0.91, normed-fit index=0.91, and root mean square error of approximation RMSEA = 0.09 ($P<0.05$) (Kaiser–Meyer–Olkin = 0.88, $\chi^2 = 1084.41$,

$Df = 66$, and Barletta’s test $P<0.000$). The first factor was “impossibility of recovery and experience of social discrimination” and the second factor was “stereotypes of cancer patients.” The two-factor structure accounted for 56.74% of the variance. The Cronbach’s alpha value was determined as 0.88 for the two-factor scale. **Conclusions:** “A questionnaire for measuring attitudes toward cancer (cancer stigma) - Patient version” is a reliable and valid questionnaire to assess stigmatization of cancer in cancer patients.

Key words: Cancer, reliability, stigma, validity

Introduction

Stigma is a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception, and adverse social judgment regarding a person/group.^[1] Stigma

directly affects the stigmatized through mechanisms of discrimination, expectancy confirmation, and automatic stereotype activation, and indirectly through threats to personal and social identity.^[2] Stigma leads to the

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prolongation of the diagnosis process, discontinuation of the treatment, depression, limitation of the living area, a delay in the help-seeking behavior, and a reduction in the quality of life.^[1,3,4] Stigma may be more prevalent among people of certain ethnic origin, culture, or some diseases. Among the negative attitudes displayed by the society toward patients with AIDS, leprosy, epilepsy, tuberculosis, mental disorders, or schizophrenia are the prevention of the possibility of finding a job, exclusion from society, reduction of self-esteem, and loss of social status and support resources.^[5-10] Although considerable research has been devoted to stigma in patients with HIV/AIDS, mental illness, epilepsy, lung cancer, and physical disability,^[6-8,11,12] rather less attention has been paid to stigma in cancer patients.

Stigma has long been associated with cancer as a life-threatening condition. Cancer is a health issue which affects people not only physically but also psychosocially. Theories of stigma suggest that some cancers may be especially prone to stigmatization.^[13-15] Several studies indicate that patients with cancer feel stigmatized because of their disease.^[15,16] People with negative attitudes, stereotypes, and discriminatory attitudes toward cancer are more likely to be less willing to disclose the cancer diagnosis to neighbors or coworkers.^[17] Cancer-related stigma strains personal relationships and leads to the avoidance of people with cancer. There is no universally accepted definition or characterization of cancer-related stigma. According to Goffman, three conditions that cause stigma are physical deformities, blemishes of individual character (i.e., undesirable personal characteristics), and “tribal” stigma of race, nation, and religion.^[18] Figure 1 describes the conceptual framework of stigma.^[16] Stigma can arise from any characteristics that are perceived to be

different from the norm within a given society.^[17] Cancer patients are exposed to stigmatization due to their illness and changes in physical appearance due to alopecia and anemia, accompanies chemotherapy, radiotherapy, or the stoma.^[11,12,19] Patients with the opinion that they are exposed to stigmatization are more likely to suffer from depression.^[17] Fear of infection, fear of being perceived different from others by society because of alopecia, and fear of losing strength and becoming weak are among the main causes of stigmatization that people with cancer are exposed to isolation of cancer patients due to the suppression of the immune system which brings about the perception that the person is also isolated from society due to the disease.^[1]

There is no widely accepted measurement method. Qualitative research describes particular cases. In quantitative research, self-reported questionnaires are employed, but few psychometrically sound instruments currently exist. A literature review by Van Brakel^[8] revealed that in the literature, there were several studies in which stigma scales were used to assess stigma of different chronic diseases. Various tools are used to measure stigma felt by HIV/AIDS patients,^[10] patients with pulmonary tuberculosis,^[20] and patients with mental disorders.^[21] However, tools used to measure cancer stigma are very limited.^[17] The Social Impact Scale or the stigma scale of the Explanatory Model Interview Catalogue can be used.^[22,23] Cho *et al.*'s survey is preferred because it is simple and understandable and can be administered to patients with any type of cancer. The aim of this methodological study is to verify the reliability and validity of the Turkish version of “A questionnaire for measuring attitudes toward cancer (cancer stigma) - Patient version.”

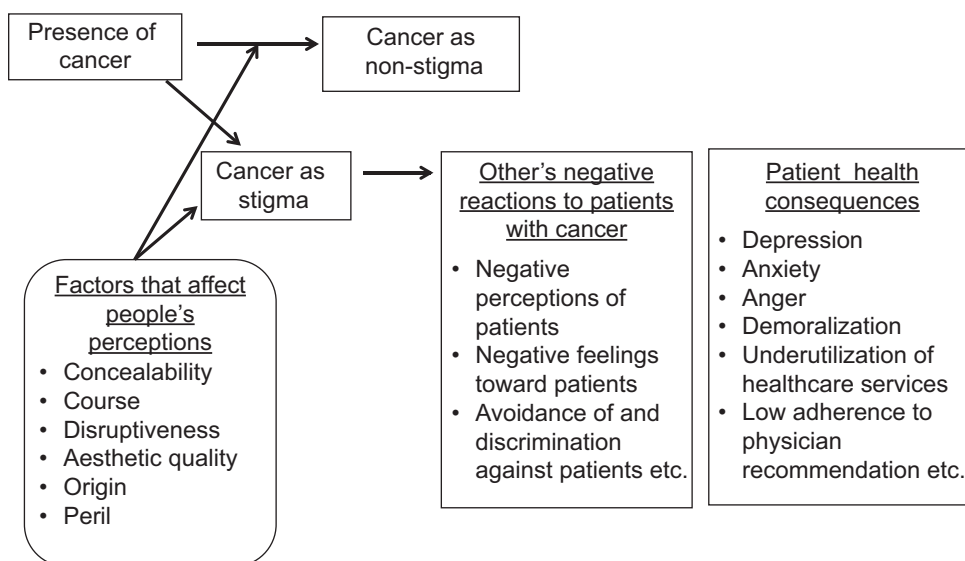


Figure 1: A conceptual framework of cancer stigma

Methods

Design

This study is a methodological study.

Participants and setting

The population comprised patients who were treated at the outpatient chemotherapy unit of a teaching and research hospital in the western part of Turkey. The study sample comprised oncology patients who had cancer treatment from January 15, 2016, to March 15, 2016, were not in remission, were willing to participate in the study, and were literate. Patients who had a psychiatric disease, had speech or hearing problems, were illiterate, or did not want to participate in the study were excluded from the study. In the study, because the size of the sample in validity and reliability studies should be a minimum of 5-fold^[24] or ideally 10-fold^[25] the number of the items in the scale, it was planned to include at least minimum 150 individuals in the study but at the end 199 patients were included in the study.

Instruments

The data collection tools used in the study were “the patient sociodemographic information form” and “a questionnaire for measuring attitudes toward cancer (cancer stigma) - Patient version.”

Patient sociodemographic information form

The form prepared by the researchers is in line with the relevant literature and similar studies comprised 14 items questioning the participants' sociodemographic characteristics, diagnosis, and treatment.

A questionnaire for measuring attitudes toward cancer (cancer stigma) - Patients version

The questionnaire was developed by Cho *et al.*^[17] to measure cancer patients' attitudes toward cancer. The patient version of the questionnaire has 12 items and three subscales: “Impossibility of recovery,” “stereotypes of cancer patients, and experience of social discrimination.” The items included in the survey are rated as (1) strongly disagree, (2) disagree, (3) agree, and (4) strongly agree. Mean scores ≥ 2.5 refer to negative attitudes toward cancer. The Cronbach's alpha value of the scale was 0.79. To conduct the validity and reliability study of the Turkish version of the questionnaire, permission was received from Juhee Cho through an E-mail.

Data collection

During the data collection process, the participants were informed about who the researchers were, and the purpose of the study, and then their written informed consent was obtained. Data collection was performed in the outpatient chemotherapy unit. The data were collected with the paper

and pencil method from the patients who were able to write. Patients who were not able to write due to vascular access were asked questions. Then, based on their responses, the form was filled out by the researchers. It took approximately 15 min to interview each patient.

Data analysis

The data were analyzed with the Statistical Package for the Social Sciences (SPSS- IBM®) Version 22.0. For the confirmatory factor analysis (CFA), the SPSS AMOS 22 (IBM®) was used. While arithmetic means and minimum and maximum values were used to determine the numerical data, numbers and percentages were used to determine the categorical data. For the reliability analysis, the internal consistency analysis methods were used. These methods were as follows: (1) item-total correlations (to determine the item reliability), (2) Cronbach's alpha (to determine the homogeneity), and (3) test-retest and Pearson product-moment correlation coefficient (to determine the stability of the scale over time). The value ≥ 0.30 was used as the criterion for the item-total correlation.^[26] While the content validity index was used for the content validity of the scale, the exploratory factor analysis (EFA) and CFA were used for the factor construct validity. To determine the suitability of the data for the factor analysis, Kaiser-Meyer-Olkin (KMO) value and Bartlett's test were used.^[20-22] For the calculation of the factor analysis, the Varimax rotation method was also used.

Ethical considerations

After the approval of the Noninterventional Clinical Research Ethics Committee (2016/25) and written permissions of the relevant authorities were obtained, the patients' written consent was obtained.

Results

Patients' sociodemographic characteristics

The mean age of the participants was 54.9 ± 12.3 years. Of them, 65.8% were female, 47.7% were primary school graduates, 73.5% were married, 14.6% were currently employed, 49.2% were residing in a city, 51.3% had an income less than the expenses, and 39.2% had received radiation therapy in addition to chemotherapy.

Validity of the scale

Language validity

After two translators with a good command of both English and Turkish translated the scale independently of each other from English to Turkish, the researchers checked the two translations in terms of understandability and clarity and gave the questionnaire its final form.

The resulting scale was back translated into English by an English teacher. The Turkish version and the original

English form were presented to the six experts of different areas dealing with the topic to evaluate the forms in terms of content validity. The mean score for all the 12 items of the scale given by the experts was 3.69 ± 0.19 out of four. The majority of the items (95%) were rated as “quite appropriate” and “very appropriate.” The content validity index was determined as 0.95. To determine whether the statements in the items were understandable, the questionnaire was administered to ten patients who were not in the sample group but had similar characteristics.

Construct validity

To examine the construct validity of the scale, factor analysis was conducted. In the analysis, KMO-sample adequacy was .88, $\chi^2 = 1084.41$, $df = 66$, and Bartlett's test value was $P < 0.000$. In the CFA performed to assess the construct validity of the scale, fit values were determined as comparative fit index (CFI) = 0.93, goodness of fit index (GFI) = 0.91, normed-fit index (NFI) = 0.91, and root mean square error of approximation = 0.09 ($P < 0.05$). The factor structure of the scale was checked with the EFA and principal component method, and the two factors were determined to have eigenvalues >1 . The eigenvalue of the first factor was 5.390, and it accounted for 44.91% of the variance. The eigenvalue of the second factor was 1.420, and it accounted for 11.83% of the variance. The two factors (“impossibility of recovery” and “experience of social

discrimination”) in the original scale were gathered under one single factor and included in the first factor. The second factor included “stereotypes of cancer patients.” The two-factor structure accounted for 56.74% of the variance. Eigenvalues of the items of the scale and factor loadings are given in Table 1. Loadings ranged between 0.55 and 0.79 [Table 2].^[17]

Reliability of the scale

Internal consistency analysis

The internal consistency of the 12-item scale used in this present study was tested. The internal consistency coefficient (Cronbach's alpha) was determined as 0.88 for the two-factor scale, 0.89 for the “impossibility of recover and experience of social discrimination” factor, and 0.59 for the “stereotypes of cancer patients” factor [Table 3]. After the data were obtained from 36 people who were contacted for the second time for the test-retest reliability of the scale, the Cronbach's alpha was calculated as 0.76. In addition, item-total correlations and Cronbach's alpha coefficients for each item of the scale were calculated using the item-elimination technique. As is seen in Table 4, item-total score correlations determined after the item and reliability analysis ranged between 0.31 and 0.72 and were considered significant ($P = 0.001$). The relationship between each subscale's score and the scale's overall score was examined. The reliability coefficients ranged between 0.63 and 0.96 ($P = 0.001$). The mean score for the overall scale was 2.20 ± 0.85 . While the mean score for the item 7 was the lowest (2.20 ± 0.85) that for the item 11 was the highest (3.05 ± 0.83) [Table 4].

External consistency analysis

Of all the participants, 36 people who were contacted for the second time were readministered the questionnaire after a 2-week interval. The participants were asked not to write their names but nicknames on the forms during the test-retest application. The scores and mean scores obtained at the two surveys were calculated with the Pearson product-moment correlation analysis. The Pearson product-moment correlation analysis revealed that the retest correlation value was $r = 0.76$, $P = 0.000$ [Table 2].

The Hotelling T^2 test was used to check whether the responses given to the items by the participants were similar. The results showed that the mean scores were different, that the Hotelling T^2 value was 43.95, $P = 0.000$, that the participants displayed different approaches to respond the items, and that the responses were reliable.

Discussion

Language validity of the scale

To evaluate the expert opinions on the language validity of the scale, the content validity index frequently used in

Table 1: Sample characteristics	
Variables	n (%)
Age	54.9 ± 12.3
Sex	
Female	131 (65.8)
Male	68 (34.2)
Marital status	
Married	146 (73.4)
Single	53 (26.6)
Education	
Illiterate	17 (8.5)
Elementary	95 (47.7)
Secondary	30 (15.1)
High school	37 (18.6)
University	20 (10.1)
Job	
Homemaker	87 (43.7)
Retired	54 (27.1)
Self-employment	29 (14.6)
Worker	17 (8.5)
Officer	7 (3.5)
Unemployed	5 (2.5)
Living area	
City	98 (49.2)
District	81 (40.7)
Village	20 (10.1)

Table 2: A questionnaire for measuring attitudes toward cancer - Patients version and item loadings for exploratory factor analysis

Question number	Factors and items (Cronbach's alpha)	Factor loading
Factor 1: Impossibility of recovery and experience of social discrimination		
Q9	Some friends avoid me because of cancer	0.790
Q2	I would not be socially active once diagnosed with cancer	0.785
Q10	Some neighbors tend to avoid interacting with me because of cancer	0.769
Q8	Cancer patients would not be able to make contributions to society	0.754
Q3	Job performance at the workplace may decrease even after successful cancer treatment	0.726
Q11	I have problems with my family/married life because of cancer	0.724
Q12	My employer/co-workers have discriminated against me	0.724
Q4	It is very difficult to be healthy again once a person is diagnosed with cancer	0.717
Q1	Cancer is impossible to treat regardless of highly developed medical science	0.607
	Percentage of variance	44.91
Factor 2: Stereotypes of cancer patients		
Q6	Cancer patients would have a difficult time having sexual intimacy	0.736
Q7	Cancer patients deserve to be protected in society	0.705
Q5	Cancer patients are easily recognized by their look	0.556
	Percentage of variance	11.83
	Total percentage of variance	56.74

*For calculation of all categories is assigned in each of the following value: "Strongly disagree: 1, disagree: 2, agree: 3, strongly agree: 4" thus higher mean, higher stigma

Table 3: Reliability values (n = 199)

Factors	Internal consistency coefficient (Cronbach's alpha)	Mean±SD	Correlations*
Factor 1 (1-4.and 8-12 items)	0.89	2.74±0.62	0.76
Factor 2 (5-7 items)	0.59	2.33±0.60	0.000
Total scale	0.88	2.64±0.55	
Test-retest value	0.76		

*Pearson's correlation. SD: Standard deviation

Table 4: A questionnaire for measuring attitudes toward cancer - Patients version item averages - standard deviations and factor analysis

Item number	Mean±SD	Corrected Item-total correlation coefficients	Cronbach's alpha
1	2.76±0.91	0.52	0.87
2	2.72±0.78	0.72	0.86
3	2.49±0.76	0.64	0.86
4	2.64±0.79	0.63	0.86
5	2.43±0.80	0.43	0.87
6	2.37±0.77	0.36	0.88
7	2.20±0.85	0.31	0.88
8	2.85±0.88	0.66	0.86
9	2.96±0.88	0.70	0.86
10	3.00±0.89	0.68	0.86
11	3.05±0.83	0.62	0.86
12	2.21±0.85	0.62	0.86

SD: Standard deviation

the validity studies was used.^[27] According to the expert opinions, the majority of the items (95%) were "quite appropriate" and "very appropriate." The content validity index was determined as 0.95.

Construct validity

To examine the construct validity of the scale, its suitability for the factor was checked. To have an adequate sample size, KMO value should be higher than 0.80, close to 1.^[28] According to the criteria determined, the KMO value in this present study was considered good.^[28] According to indices of CFAs values, the scale's compatibility was considered as good in terms of the CFI, NFI, and GFI values (a value ≥0.95 is considered as perfect fit, a value between 0.90 and 0.95 as good fit, and a value between 0.80 and 0.90 as fit).^[29] The higher the variance ratios obtained for EFA (which should be 50% and higher) are, the stronger the factor structure of the scale is. In this present study, the fact that the variance ratio was higher than 50% indicates that the scale's factor structure is strong.^[25] According to EFA, a two-factor structure was obtained in this present study although the original scale is a three-factor scale. That the items created a different factor structures suggest that cultural differences, social norms, and the perception of cancer reflect on the perception of stigma. To provide holistic and comprehensive cancer care, health team may need to do some changes to reduce or eliminate stigmatization against cancer patients. In addition, more efforts on cancer education, public awareness activities would be required to improve patients/public understanding of the disease.

Internal consistency analysis

Reliability indicates that the measuring procedure can be repeated and that the measuring procedure yields the

same results on repeated trials. Reliability which affects the validity of a test is the stability of the scale over time.^[25,28] Internal consistency of a measuring tool indicates that it can measure the variable related to all the items of the scale and that the scale is made up of independent subscales. The alpha coefficient is one of the methods used to test the reliability of the internal consistency.^[28] If the Cronbach's alpha coefficient is <0.40, the tool is not reliable; if between 0.40 and 0.59, its reliability is low; if between 0.60 and 0.79, it is quite reliable; and if between 0.80 and 1.00, is very reliable.^[25] In the present study, Cronbach's alpha value of this two-factor scale's reliability is very high.

In item-total correlations, a score ≥ 0.40 indicates very good discrimination, a score between 0.30 and 0.40 indicates good discrimination, and a score between 0.20 and 0.30 indicates poor discrimination, which suggests that the item should be revised.^[26,30] The mean scores of the items of the scale suggest that the participants displayed negative attitudes toward cancer.

External consistency analysis

The test-retest correlation in this study determined with the Pearson's correlation analysis was above .70, which indicates that the survey is consistent and is capable of providing similar measurement values in repeated measurements.^[31] The Hotelling T^2 test was used to check whether the responses given to the items by the participants were equal. The results of the analysis indicated that the participants displayed different approaches and that the responses they gave were reliable. The correlation coefficient is expected not to be lower than 0.70.^[24,32]

Strengths and limitations of study

The strength of this scale is that it consists of short and understandable statements, which suggests that it can be administered and evaluated easily. Thanks to this aspect of the questionnaire, it can provide great convenience for researchers. In the literature, it is recommended to test the reliability of the questionnaire using the parallel forms technique in the reliability analysis.^[25] The limitation of this study is that the parallel form reliability analysis was not performed because there is no other tool used to measure stigma regarding cancer patients.

Conclusion

To realize stigmatization in cancer patients, stigma perceived by the patient should be determined. Two important conclusions can be drawn from the results of this validity and reliability study of the Turkish version of the questionnaire conducted to determine the stigma perceived by cancer patients. The first one is that "a questionnaire for measuring attitudes toward cancer (cancer stigma) - Patients

version" is a valid and reliable tool and can be used to measure the attitudes of cancer patients with cancer. It is recommended to conduct validity and reliability studies of the questionnaire in different languages. The second one is that because it determines cancer patients' attitudes toward cancer, it can be used to help cancer patients cope with the disease and return to their normal social life. Future studies should also focus on more comprehensive characteristics of both felt and enacted stigma and their effects on all cancer populations. If our understanding of stigma in cancer patients is to be improved meaningfully, validated measures should be used.

Implications for practice and research

Patients with cancer are frequently stigmatized in many countries. Cancer stigma is an important psychosocial issue faced by patients and is associated with a variety of clinical outcomes, as well as social consequences. Clinicians should be sensitive to cancer stigma and consider potential implications on the quality of life of the cancer patients. Information about cancer-related stigma and attitudes displayed by health-care professionals is also urgently needed because evidence indicates the possibility of discrimination against people with cancer patients in clinics. For people experiencing stigma due to cancer, effective interventions such as education about the disease, building stigma-coping skills, counseling, and support are important for the promotion of quality of life.

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Conflicts of interest

There are no conflicts of interest.

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