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Original Article

Validity and reliability of Turkish version of the Supportive Care Needs Survey for Partners and Caregivers of Patients Diagnosed with Cancer

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Abstract

Objectives: The aim of this study was to culturally adapt and test the psychometric properties of the Turkish version of the SCNS-P&C.

Methods: The sample of the study consisted of 228 cancer patients who were being treated at an oncology hospital. The data were evaluated using SPSS 22 (SPSS Inc., Chicago IL, USA) statistics software. The validity of the structure was determined using confirmatory factor analysis, which was performed with AMOS 21.0. Psychometric testing included internal consistency reliability (Cronbach's alpha coefficient), Spearman-Brown reliability, and validity analyses (confirmatory factor analysis and content validity).

Results: The Cronbach's alpha value of the survey was 0.96, and the Spearman-Brown value of the survey was 0.86. The model was validated by confirmatory factor analysis (χ^2/SD=2.53, GFI=0.73, IFI=0.87, CFI=0.87, RMSEA=0.08, and RMR=0.088).

Conclusion: The Turkish version of the SCNS-P&C was found to be reliable and valid for Turkish partners and caregivers of cancer patients, which means that its use can lead to a better understanding of needs. The SCNS-P&C can be used in future nursing research and practice as an assessment tool for partners and caregivers of cancer patients.

Keywords: Caregiver; oncology; partner; psychometric properties.

What is known on this subject?

- Meeting the supportive care needs of caregivers and partners of cancer patients positively affects the quality of life of the patients and relatives.

What is the contribution of this paper?

- To meet the supportive care needs of caregivers and partners, their needs should be evaluated using reliable measurement tools. Therefore, a Turkish culture-specific scale is necessary.

What is its contribution to the practice?

- The Supportive Care Needs Survey for Partners and Caregivers of cancer patients is a valid and reliable tool for use in the clinical and reserch environment in the evaluation of the needs of caregiving partners of cancer patients.

Despite developments in the diagnosis and treatment processes, cancer is still associated with death, pain, and uncertainty. Faced with a life-threatening disease like cancer is a crisis experience for both the patient and the patient's relatives.[1–3] This crisis experience may last for a long period of time due to the nature of the disease and its treatment process. Furthermore, the patient diagnosed with cancer may need care and treatment from the time of diagnosis to the end of the treatment, survival, recurrence or terminal phase. During this long-term struggle, the relatives of the patient are in a position where they on the one hand must try to cope with the threat of losing their loved ones, while on the other hand, they have to take on the responsibility of providing care and

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support to the patients. To cope with this tough period is not always easy for the relatives of the patient and can result in phsyical, psychological and social problems.[1,4,5]

The actions related to meeting the needs of patients diagnosed with cancer and their relatives that emerge in the cancer diagnosis, during the treatment process, and after the treatment are defined as "supportive care practices". The aim of supportive care is to help patients who are diagnosed with cancer and their relatives cope with this difficult/ stressful life event. Supportive care includes healthcare practices/ services that aim to bring the quality of life of the patients and their relatives and the benefits derived from the treatment to the maximum level possible. In this sense, the framework delimiting supportive care is quite broad, extending from the pre-diagnosis stage to the treatment process, recovery period or paliative care and terminal term all the way to the grief process.[6,7] While the fulfillment of supportive care needs increases the health status of the patients and their relatives,[8–10] the failure to meet these needs can decrease the patient's adaptation to the treatment process, cause physical and psychological issues, increase disability, and reduce the chance of survival, all of which would result in increased financial burden to the national healthcare system.[6,11–14]

Health systems are usually patient-centered and are organized to effectively address the diagnosis and maintain the treatment of the patient. This system, however, may neglect the needs of the relatives of the patient and thereby fail to meet the required needs.[4] Throughout the course of the cancer experience, the supportive care needs of the patients and their families should be addressed with a holistic approach, and their needs should be met in a multi-dimensional manner.[15,16] However, in almost all societies, obstacles to meeting these needs may emerge.[2,11,17,18] These problems regarding the relatives of the patient may manifest as failure to meet the information and support needs of the relatives, particularly in terms of providing for their psychological and social care.[4,8,18–21]

Supportive care needs, which can have critical effects on the health status of the patients diagnosed with cancer and their relatives, may differ based on the healthcare system, culture, technology, and time.[20,22] The fulfillment of these needs is done by developing applications specific to individuals and groups. In order to determine the existing supportive care needs and to evaluate and follow the effectiveness of the practices to fulfill these needs, a reliable, suitable and easily applicable measurement tool that is capable of measuring the supportive care needs without ignoring its multi-dimensional nature is required.[23] However, in the international literature, it can be quite clearly seen this subject, which has been a focus of interest since 2005, has not been sufficiently addressed in Turkey's body of literature. In Turkey, no measurement tool has been created based on the Turkish culture and language or adapted into Turkish to address the unmet supportive care needs of the relatives of the patients diagnosed with cancer, and there has been no study providing data in this area.

The literature shows that there are two commonly used measurement tools for determining the unmet psychosocial needs of the relatives of patients diagnosed with cancer. One of them is the Cancer Survivors' Partners Unmet Needs (CaSPUN), which is a 36-item multi-dimenstional tool that was developed by Hodgkinson et al.[24] (2007). However, this tool is specifically intended for the relatives of cancer-diagnosed patients who are at least one year post-diagnosis. The other most commonly used tool, as seen from the literature, is the Supportive Care Needs Survey—Partners and Caregivers (SCNS-P&C), developed by Girgis et al. in 2011. The SCNS-P&C is a multi-dimensional measurement tool consisting of 46 items.[25] Studies show that SCNS-P&C has many use areas.[5,19,20,26,27] As this measurement tool is more recent, better adapted to other languages and culture[2] and is able to be applied to the relatives of patients who were diagnosed with cancer for at least a six-month period,[25] it was found proper to adapt the SCNS-P&C to the Turkish language and culture. Therefore, this study aims to carry out the Turkish validity and reliability of the Supportive Care Needs Survey - Partners and Caregivers (SCNS-P&C) of patients diagnosed with cancer, which was originally developed to determine the supportive care needs of the relatives of patients diagnosed with cancer.

Materials and Method

Research Setting

The study was conducted in the Day Treatment Unit and inpatient treatment services of the oncology hospital of a university located in the province of Ankara using a cross-sectional methodological design.

Research Universe and Sample

The research universe was composed of caregiving relatives of inpatient or outpatient cancer patients presenting to the oncology hospital, where the study was conducted, between November 1, 2017 and January 1, 2018.

The sample size of the study was calculated based on the formula, "sample size = the number of items X the number of individuals", the standard method used in calculating the sample size for survey development studies. According to this calculation, the sample size was determined to be between 5-10 people for each survey item, and therefore, the study sample was calculated to be 225 people. Considering the possibility that participants may be excluded from the study due to various circumstances, such as failure to fill out all the information in data collection forms, once 235 people were reached, the data collection phase of the study was ended. A total of 7 participants were excluded from the study for failure to respond to all survey items, which resulted in the study being performed with 228 individuals.

The study inclusion criteria were that the participants be eighteen years of age and older, have been providing care for at least six months, be literate in order to read and answer the survey items, and voluntarily agree to participate in the study.

Data Collection Tools

The data for this study were collected using a socio-demographic data form that was prepared in accordance with the literature and the Turkish version of the SCNS-P&C.

The Participant Socio-demographic data form included questions on the particpants' age, sex, economic status, number of children, if any, employment status, and duration of caregiving period.

The SCNS-P&C Survey was developed by Girgis et al.[25] in 2011 in order to evaluate the supportive care needs of caregivers and partners of patients diagnosed with cancer in a multidimensional way. The survey evaluates the caregivers' needs through a five-point Likert-type scale featuring four sub-dimensions. Each item of the survey is scored between 1 and 5 points, with 1 indicating "I do not need any help" and 5 indicating "I need a high level of help". Evaluation of the responses is based on calculation of the mean score of the items arranged under each sub-dimension, where higher scores indicating higher supportive care needs. The survey sub-dimensions and their respective items were as follows: health care needs (7, 8, 9, 10, 11, 12, 13, 14, 16, 17) psychological and emotional support (31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44), work and social needs (21, 22, 26, 27, 28, 29, 30), and information need (1, 2, 3, 4, 5, 6, 23). Each of the survey items is independently evaluated. The Cronbach's alpha value of the original version of the survey ranges between 0.86-0.96 for each sub-dimension.

Research Application

The data were collected through the self-report method. The participants were left alone without their patients in a quiet environment while they completed the data collection forms. Each form took approximately 20 minutes to complete.

Ethical Considerations

This study was approved by the Ethical Commission of Hacettepe University (2016 / 35853172/431-2704 numbered). The standards of good clincal practice and ethical principles for human research, as specified in the Helsinki Declaration and its subsequent revisions, were always maintained throughout the course of the study.

Data Analysis

Statistical analyses of the data were conducted using the SPSS version 22.0 software program. Mean, frequency, and percentage were calculated as descriptive statistics in the evaluation of descriptive characteristics and survey scores.

Adaptation Phases of the SCNS-P&C Survey

To receive required permissions for the Turkish validity and reliability analysis of the survey, the original survey author was contacted via e-mail and his permission was granted. All study phases were carried out through the communication and exchange of ideas with the same person.

The SCNS-P&C Validity Study

Language Validity

The Turkish translation of the survey was conducted by three experts (one specialist in English language literature, two experts in psychiatric nursing). The three translations were evaluated together with an expert from the field to create the Turkish version of the survey. This Turkish version was sent to a faculty member from the Department of Turkish Language Literature of a university for evaluation of the Turkish language structure, and the final form of the Turkish version was completed in line with the suggestions made by this faculty member.

Content Validity

To confirm the content validity of the SCNS-P&C Survey, the expert opinions of 10 psychiatric nurses were taken. These experts evaluated the survey items using the four-type likert method to confirm whether they were relevent to the subject and understandable. Waltz and Bausell's content validity index[28] (1983) was used for content validity. After the content validity, the compatibility of the expert opinions was evaluated through the Content Validity Index.

Structure Validity

Confirmatory factor analysis (CFA) was used to determine whether the items and sub-dimensions explained the specific structure of the survey. At this phase, all survey questions were first included in the analysis before calculating the model goodness of fit values. The SPSS AMOS Graphics 16 program was used for the CFA.

The SCNS-P&C Reliability Study

At this phase, in order to determine the internal consistency reliability of the SCNS-P&C Survey, Cronbach's alpha internal consistency coefficient, item analyses, and split-half metholology were used.[29] The Cronbach's alpha coefficient was greater than or equal to 0.70 for the overall internal consistency of the survey and its sub-dimensions. In this study, the split-half process was applied as "the first half-the second half", and the "adjusted results with the Spearman-brown formula" were taken into consideration. A split-half reliability coefficient criteria of at least 0.70 was accepted for internal consistency. A p value <.05 was accepted as the significance level for all statistical tests.

Results

The mean age of the participants was 52.16 (SD=10.91), the mean caregiving period was 1.99 (SD=2.34) years, and the mean daily caregiving hours were 11.55 (SD=10.32) hours. Other variables related to the caregiving partners are presented in Table 1.

Table 1. Participant variables

	n	%
Sex		
Female	139	61.0
Male	89	39.0
Education		
Secondary education	62	27.2
High-school	106	46.5
University	60	26.3
Have children		
Yes	196	86.0
No	32	14.0
Employment status		
Employed	73	32.0
Unemployed	89	39.0
Retired	66	28.9
Income status		
Income is less than expenses	49	21.5
Income is equal to expenses	146	64.0
Income is greater than expenses	33	14.5
Have a physical disease		
Yes	79	34.6
No	149	65.4
Diagnosis of the patient cared for		
Gastrointestinal system cancer	85	37.3
Breast cancer	35	15.4
Genitourinary cancer	28	12.3
Hematological cancer	34	14.9
Brain cancer	11	4.8
Lung cancer	17	7.5
Skin cancer	9	3.9
Unanswered	9	3.9

Table 2. Test statistics used for the model fitness

Fit indices	Goodness-of-Fit Index	Values obtained in the model
CMIN/DF	$4<X^2/d<5$;	2.530
RMSEA	0.05<RMSEA<0.08	0.082
GFI	0.90≤GFI≤0.95	0.732
CFI	0.95≤CFI≤0.97	0.871
IFI	IFI is better the closer to 1	0.872
RFI	0.90≤ RFI ≤1	0.785
RMR	RMR is better the closer to 0	0.088

The Validity Findings of the SCNS-P&C Survey

In the content validity study of the survey, expert opinions were evaluated using the content validity index (CVI). The CVI value of the survey was found to be 0.80 at the α=0.05 significance level.

In the structure validity study of the survey, the confirmatory factor analysis (CFA) was used. At this phase, all survey questions were first included in the analysis before calculating the model goodness of fit values.[30] In examining the general values calculated for the first model, it was seen that the established model did not fit. In the first phase, the factor load values were checked to determine whether there was an item responsible for the incompatibility of the model. Since there were no value less than 0.5 that would have required it to be removed from the model, modification indices were examined to improve the goodness of the model. Here, the analyses were performed using the covariance values. Among the items included in the same sub-dimension, for those with higher covariances (greater than or equal to 10), two-way covariance marking was done, and the model was re-run. In the end, the model was improved without needing to exclude any items, and the values shown on Table 2 were obtained. The final model structure is given in Figure 1.

In examining the structural validity of the survey, it was found that the four-factor model showed acceptable fit (Chi-square/df=2.530. p=0.00; RMSEA=0.082; GFI=0.732; CFI=0.871;

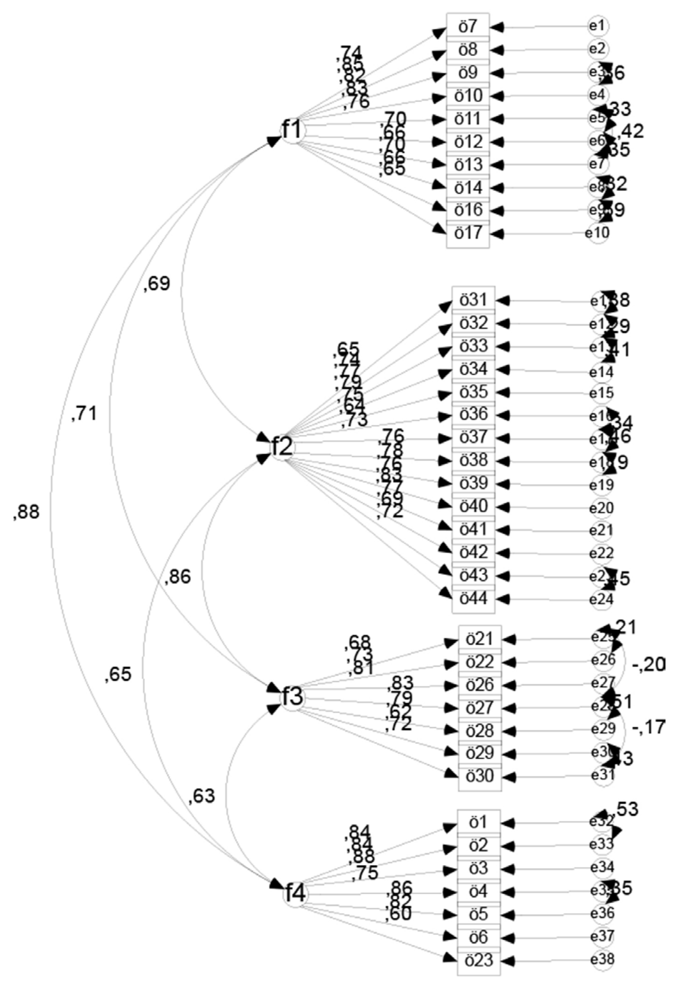

Figure 1. Factor structure of the scale of supportive care needs survey for spouses and caregivers of patients diagnosed with cancer and correlation of each item with total score.

Table 3. The findings of the reliability analysis for the Supportive Care Needs Survey for Partners and Caregivers of Patients Diagnosed with Cancer

Sub-dimension	Cronbach's alpha values	Spearman-Brown values	Guttman-split half values
Need of healthcare services	0.947	0.863	0.854
Psychological and emotional support	0.935	0.904	0.904
Work and social needs	0.908	0.912	0.809
Information need	0.872	0.853	0.825
Total	0.964	0.865	0.863

IFI=0.872; RFI=0.785; RMR=0.088). The study findings indicated that the fit values of the adapted survey were acceptable[30] (Table 2). The confirmatory factor analysis model factor loads of the Turkish version of the SCNS-P&C are presented in Figure 1.

The Reliability Findings of the SCNS-P&C

From the statistical analysis conducted, the Cronbach's alpha internal consistency coefficient of the survey was found to be 0.947; in other words, it was highly reliable.[31] The Cronbach's alpha coefficients calculated for each sub-factor are shown in Table 3. In examining the Cronbach's alpha values of the sub-dimensions, it can be seen that these values were all higher than 0.87. The correlation between the two halves of the SCNS-P&C was determined to be 0.86, with the Cronbach's alpha coefficient of the first-half (22 items) being 0.93 and 0.91 for the second-half (22 items). The Spearman-Brown coefficient was found to be 0.86, while the Gutmann Split-Half coefficient was found to be 0.86 (see Table 3). Taking these findings into consideration, it can be stated that the survey has high reliability. In looking at Table 4, it is observed that the item-total correlation of the SCNS-P&C ranges between 0.412 and 0.732. Considering that the items with item-total correlations higher than or equal to 0.30 differentiate individuals very well in terms of their measurable specifications,[32] the item-total correlation of the survey was determined to be sufficient.

Discussion

Supportive care needs, which have critically significant effects on the health status of patients diagnosed with cancer and their families, are multi-dimensional and variable. Identifying and monitoring these needs – the cornerstone in the fight against cancer – improving resources, and re-planning services are extremely important for planning and maintaining healthcare services. However, there is no measurement tool to evaluate the Turkish health system in this way. The Turkish adaptation of the SCNS-P&C will evaluate the supportive care needs of cancer patients and serve as an updated, reliable and acceptable measurement tool for meeting this requirement.

Since there is no other Turkish measurement tool that fulfills the objective of the SCNS-P&C, another measurement tool could not be used in the Turkish reliability study of the survey. The translations and analyses done to provide the language equivalence of the survey indicated that the Turkish version of the SCNS-P&C is understandable and applicable to the Turkish population. As a result of the analysis, the survey's four-factor structure was verified using the confirmatory factor analysis. The higher the value, the higher the fit of the model.[29,30,33] In the study conducted, the Chi-square test value for the model fitness was high (Chi-square/df=2.530. p=0.00). Furthermore, the value of the root mean square error of approximation (RMSEA) was found to be 0.082 and acceptable. The values of other fit indices were as follows: GFI=0.732. CFI=0.871. IFI=0.872. RFI=0.785. RMR=0.088. However, there is no consensus on which of the fit indices are accepted as the standard.[30] Results of the confirmatory factor analysis conducted using this information showed that the factor structure of the Turkish version of the SCNS-P&C fit with the structure of the original version. In the validity and reliability study conducted by Sklenarova et al.[27] (2015) for the German version of the survey, item 18 (Accessing information about possible fertility problems of the patient with cancer) was deleted after finding that it had a ceiling effect, and item 29 (Talking to other people who have cared for patients diagnosed with cancer) was excluded from the survey, because it was unable to be attributed to any factor. The items that were not loaded to the factor (15, 18, 19, 20, 24, 25, 45) in the original version were preserved; the factor loads of these items were high in the present study, and the author of the original survey also suggested that these items be retained; however, items 15, 18, 19, 20, 24, 25, 45 were not loaded to any factors in the Turkish version, as was the case for the original version of the survey, yet they were not excluded from the survey.

In the study, the Cronbach's alpha coefficients were found to be quite high, being 0.96 for the total survey, 0.94 for the sub-dimension of health care sevices, 0.93 for the sub-dimension of psychological and emotional support, 0.90 for the sub--dimension of work and social needs, and 0.87 for the sub--dimension of information need. Moreover, in the semi-test reliability analysis, the Spearman-Brown coefficient and the Guttman Split-Half coefficient were found to be at high levels. These results indicate that the survey has acceptable internal consistency and reliability.[32] These values were higher than those reported for the German validity and reliability values of the survey (0.76–0.95)[2] and similar to the those of the original version.[25] From the results of the item analysis con-

Table 4. The item-total correlation analysis for the Supportive Care Needs Survey for the Partners and Caregivers of Patients Diagnosed with Cancer

Items	Item-Total Correlation (n=228)
1. Access to information that suits your needs as a caregiver/partner	.706
2. Access to the information regarding the course or the possible outcomes of the disease of the individual diagnosed with cancer	.692
3. Access to the information regarding the supportive services available to the caregivers/partners of individuals diagnosed with cancer	.728
4. Access to the information on alternative therapies	.622
5. Access to the information about what may be the possible physical needs of the individual diagnosed with cancer	.690
6. Access to the information on side effects and benefits of the treatments	.661
7. Providing the best medical care to the individual diagnosed with cancer	.651
8. Access to local healthcare services when needed	.706
9. Being involved with the medical team responsible for the care of the individual diagnosed with cancer	.705
10. Having opportunities to discuss your concerns with the doctor	.723
11. Feeling confident that all the doctors are talking to each other to coordinate the care of the individual with cancer	.653
12. Ensuring the presence of a steady case manager to coordinate services for the individual with cancer	.638
13. Ensuring that complaints regarding the care of the individual diagnosed with cancer are addressed to the right person or party	.623
14. Reducing stress in the life of the individual diagnosed with cancer	.670
16. Provide sufficient pain control for the individual diagnosed with cancer	.704
17. Addressing fears about the physical or mental deterioration of the individual diagnosed with cancer	.730
18. Access to information about possible fertility problems of the individual diagnosed with cancer	.578
19. Practical care of the individual diagnosed with cancer, such as taking showers, changing clothes or giving medication	.614
20. Finding more hospital parking spaces reserved for the disabled	.412
21. Adaptation to the changes in the working life or in the daily life of an individual diagnosed with cancer	.673
22. The effect of providing care to the individual diagnosed with cancer on your own working life or daily life	.661
23. Obtaining information on the government support and financial support available for the individual diagnosed with cancer and for yourself	.683
24. Obtaining life and/ or travel insurance for the individual diagnosed with cancer	.641
25. Access to legal services	.730
26. Communication with the person for whom you provide care	.650
27. Communication with the family	.688
28. Receive more family support	.683
29. Talk to other people who provide care to an individual diagnosed with cancer	.579
30. Overcoming the issue of cancer at work or in social settings	.697
31. Managing the anxiety over cancer recurrence	.596
32. The effect of cancer in your relation with the individual diagnosed with cancer	.675
33. Understanding the cancer patient’s experience	.732
34. Balancing your own and patient's needs	.727
35. Adjusting to changes in the body of the cancer patient	.658
36. Addressing problems with sex life	.608
37. Receiving emotional support for yourself	.643
38. Receiving emotional support for loved ones	.667
39. Working through your feelings about death and dying	.697
40. Continuing the relationship with the people who do not understand the effect that providing care to an individual diagnosed with cancer has on your own life	.672
41. Dealing with cancer when the healing process of the individual is not what you expect	.724
42. Making decision about your own life in the context of uncertainty	.686
43. Discovering your own spiritual beliefs	.642
44. Finding meaning in the individual’s cancer illness	.661
45. Having opportunities to participate in decision making regarding the treatment of the individuals diagnosed with cancer	.568

ducted to determine the internal consistency of the survey, since there was no item with a total correlation lower than 0.30, no item was excluded from the survey, and the item-total correlations of the survey items were found to be at an acceptable level.

Conclusion

It was determined that the Turkish version of the Supportive Care Needs Survey for the Partners and Caregivers of Patients Diagnosed with Cancer is a valid and reliable survey for evaluating the needs of the partners who provide care for patients diagnosed with cancer, and thereby is a valid and reliable tool for use in the clinical and research environment. It is suggested that a broader sample group be used in future studies.

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