Original Article

The Turkish Validity and Reliability Study of Palliative Performance Scale

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Received: February 02, 2021; Accepted: March 31, 2021; Published: May 31, 2021

ABSTRACT

Objective: The Palliative Performance Scale version 2 (PPSv2) is a useful tool designed to assess the performance status of palliative care patients. The aim of this study was to translate the PPSv2 into Turkish and to test the validity and reliability of Turkish PPSv2 (PPS-TR) in cancer patients receiving palliative care. **Methods:** The translation of PPSv2 into Turkish was implemented using a forward–back forward procedure. The patients were allocated from inpatient palliative care unit, consultations from oncology services, palliative care polyclinic, and consultations from emergency unit. The inter-rater and intra-rater reliabilities were tested in a pilot study with 51 patients. The cross-sectional study consisted of 280 patients. The relationship between PPS-TR, Katz Index of Independence in Activities of Daily Living (Katz ADL), and Karnofsky Performance Scale (KPS) was also measured. Construct validity was assessed by observing the test capacity across patient groups based on the place of care. **Results:** Intraclass correlation coefficients (ICCs) at Time 1 and Time 2 were 0.982 (95% confidence interval [CI]: 0.972–0.989) and 0.991 (95% CI: 0.986–0.995). ICCs of intra-rater agreements were at least 0.956 (95% CI: 0.909–0.977) for three raters. KPS, Katz ADL, and PPS-TR scores of outpatients were significantly higher than those of inpatients and emergency. There was a perfect correlation between PPS-TR and KPS, while the correlation of PPS-TR with Katz ADL was almost perfect. **Conclusions:** The PPS-TR is a reliable and valid tool for assessment of performance status of cancer patients receiving palliative care.

Key words: Cancer, palliative care, Palliative Performance Scale, reliability, Turkish, validity

Introduction

Palliative care is the comprehensive and integrated care of patients and their families who are facing problems associated with life-threatening illness. It is an approach that focuses on optimal management of distressing symptoms while incorporating psychosocial and spiritual care according to their needs, values, beliefs, and cultures.[1,2]

The assessment of performance status is very important in palliative care in terms of prognostication, making treatment and care plan, informing the patient/family, appropriate use of health sources, and ensuring interdisciplinary communication between health professionals.[3-5] There is a strong association between performance status and survival in patients with life-limiting illnesses, and it may also be used individually as a prognostic tool.[6,7] Assessment of the performance status can be difficult and deteriorate rapidly with disease progress, symptom burden, emotional status,

Access this article online

Quick Response Code:

Website: www.apjon.org

DOI: 10.4103/apjon.apjon-2111

Cite this article as: Oğuz G, Şenel G, Koçak N, Karaca Ş. The Turkish Validity and Reliability Study of Palliative Performance Scale. Asia Pac J Oncol Nurs 2021;8:413-8.

or characteristics of the care facility.[8] Therefore, valid and reliable tests which are sensitive to change and with utility properties are essential for multidimensional evaluation of palliative care patients. Various palliative care assessment tools are being used in Turkey in different palliative care settings, but there is not any standardized consensus for the use of a clinical performance tool.

The Palliative Performance Scale (PPS) was first introduced by Anderson and Downing in 1996 as a new tool to measure the performance status in palliative care.[9] It is a modification of Karnofsky Performance Scale (KPS) and has been used for communication, profiling admissions and discharges to the hospice unit, survival prognostication, and nursing care workload analyzes.[5,10-12] PPS version 2 (PPSv2) includes five observer-rated domains: ambulation, activity and evidence of disease, self-care, intake, and conscious level, measured in 11 categories with 10% increments. Although initially designed for palliative adults with advanced illness, the PPSv2 has been utilized across various settings for others based on performance or functional status.[13] Since its development, it has been translated and validated in different languages.[14-16] PPSv2 is being increasingly used in studies or palliative care units in the country, but the Turkish reliability and validity study is not still performed.

The aim of the present study was to translate the PPSv2 into Turkish and to test the validity and reliability of Turkish PPSv2 (PPS-TR) in cancer patients receiving palliative care.

Methods

The study was conducted at a comprehensive cancer center in Ankara after receiving approval from the ethics committee of the hospital. The permission for translation of PPSv2 into Turkish and to perform a study to test the reliability and validity of the Turkish version was obtained from Dr. Michael Downing, one of the authors of original PPS and Victoria Hospice (British Columbia, Canada), the copyright owner. A training manual, instructions, and definitions for the use of PPSv2 and a set of case scenarios including facilitator training points were also obtained from Dr. Downing. All the participants or their families gave written informed consent for allocation to the study, and procedures were performed in accordance with the ethical standards of the institutional and/or national research committee and with the Helsinki Declaration.

The translation of the PPSv2 into Turkish was implemented as the first step using a "forward–back forward" procedure. The forward translation of the scale into Turkish was done by one physician experienced in palliative care, one linguist, and one nuclear medicine specialist interested in oncology. The physicians were speaking English fluently. After the translation was assessed with two other palliative care physicians, an agreement on the one that most adequately reflected the concept expressed by the English items was obtained. The final approved translation was back translated into English by another linguist, palliative care physician, and the chief nurse of palliative care unit. At the end of translation procedures, a committee involving all the professionals who participated in the translation reviewed the final version in terms of readability, intelligibility, and suitability, and corrected any discrepancies to maintain the original meaning. All translations were also checked by a freelance translator (notarized)/interpreter.

The professionals who were going to make the assessments underwent a training session about the use of PPSv2 and practiced with a set of 22 case scenarios received from the copyright owner.

The patients were allocated from inpatient palliative care unit, palliative care consultations from inpatient oncology services, outpatient palliative care polyclinic, and palliative care consultations from emergency unit. All the patients were above the age of 18 years and had a diagnosis of advanced cancer.

The study was designed similar to Barallat *et al*. including a pilot and a cross-sectional evaluation.[14] The inter-rater and intra-rater reliabilities were tested in a pilot study with repeating the measurement within a predetermined interval. A sample size of 51 patients (46 individuals +10%) for the pilot study with two assessments per patient was found enough to detect an intraclass correlation coefficient (ICC) of at least 0.8 (alpha = 0.05, beta = 0.20) for test–retest reliability.[14,17] Three observers were needed for an inter-observer ICC of at least 0.60.[17,18] Three palliative care professionals, two physicians and a nurse, rated the patients independently at 48-h intervals. A 48-h interval was chosen because of the possibility of rapid deterioration of patients, especially the inpatient ones with low-performance status. When the patient died after the first assessment, he/she was excluded from the study. The patients were also assessed by using the Karnofsky Performance Scale (KPS) and Katz Index of Independence in Activities of Daily Living (Katz ADL) at the same time. KPS is the origin of PPSv2 and has been widely used to measure the performance status of cancer and noncancer patients in various settings (0%–100%).[19] Katz ADL is a 6-point tool to assess the level of independency, especially in older adults (6 = patient independent and 0 = patient very dependent).[20] The Turkish validity studies of KPS and Katz ADL have been established by Yıldız Çeltek *et al*. and Arik *et al*., respectively.[21,22] All the ratings made by each observer were recorded, and they were blind to their first

assessment scores and the other raters. The palliative care consultations from emergency unit were not included in the pilot study as the second assessments were not available for all of them.

The cross-sectional study consisted of 280 patients which was calculated as 10 patients for different response categories of each domain in PPSv2. One observer performed all three tests to 50 patients to assess the criterion validity and PPSv2 to the rest. All the patients received only one assessment in the cross-sectional group.

Statistical analysis

The distribution of age and scale scores was examined by the Shapiro–Wilk test and normality plots. Age was reported as mean ± standard deviation in the pilot study and as median (minimum–maximum) in the cross-sectional study. Categorical variables were expressed by frequency (%). Median (minimum–maximum) values were given for scale scores.

Pilot study

Patient groups were compared by independent samples *t*-test for age and Fisher's exact test and Fisher-Freeman-Halton test for gender and diagnosis, respectively. The inter-rater reliability between three observers at Time 1 and at Time 2 and intra-rater reliability of each rater on two occasions (which also accounts for the test–retest reliability) were assessed by ICC estimates and their 95% confidence intervals (CIs) based on a single measurement, absolute agreement ICC and consistency ICC, two-way mixed-effects model. Values <0.5 are indicative of poor reliability, values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values > 0.90 indicate excellent reliability.[23] Inter-domain and final-domain correlations were measured by Spearman correlation coefficient (r_S).

Cross-sectional study

Patient groups were compared by Kruskal–Wallis test followed by stepwise step-down *post hoc* test for age and scale scores, and by Yates' Chi-square test and Fisher's exact test with Monte Carlo simulation based on 10,000 samples for gender and diagnosis, respectively. The relationship between PPS-TR, Katz ADL, and KPS was measured by r_S. Construct validity was assessed by observing the test capacity across patient groups based on the place of care. To establish association among the different categories of PPS-TR and the place of care, Chi-square analysis was performed.

$P < 0.05$ was considered statistically significant. All analyses were performed via IBM SPSS Statistics 22.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY, USA: IBM Corp.), and the graph was drawn by Microsoft Office Excel 2016.

Results

Pilot study

There were 51 patients in the pilot study; 71% of them (n = 36) were inpatient. The age of inpatients was significantly higher than the one of outpatients ($P < 0.001$). The gender and diagnosis were similar between inpatients and outpatients ($P > 0.05$). The demographic and clinical characteristics of the patients in the pilot study are given in Table 1.

ICCs at Time 1 and Time 2 were 0.982 (95% CI: 0.972–0.989) and 0.991 (95% CI: 0.986–0.995) indicating excellent inter-rater agreement [Table 2]. ICCs of intra-rater agreements were at least 0.956 (95% CI: 0.909–0.977) for three raters [Table 3].

Inter-domain correlations were very strong as given in Table 4. The final PPS score was also significantly and strongly correlated with domain scores.

Cross-sectional study

Out of 280 patients, 53.6% (n = 150) were inpatient, 35.7% were outpatient, and others were emergency cases. The age of inpatients was significantly higher than the

Table 1: Demographic and clinical characteristics of the patients in pilot study

Variable	Place of care			*P*
	Total (*n*=51)	Inpatient (*n*=36)	Outpatient (*n*=15)	
Age (year, Mean±SD)	63.25±14.06	67.67±11.91	52.67±13.48	<0.001*
Female [*n* (%)]	13 (25.5)	11 (30.6)	2 (13.3)	0.297§
Diagnosis [*n* (%)]				
Brain	2 (3.9)	2 (5.6)	0	0.073†
Head-neck	3 (5.9)	3 (8.3)	0	
Lung	6 (11.8)	3 (8.3)	3 (20.0)	
Breast	2 (3.9)	2 (5.6)	0	
Gastrointestinal	23 (45.1)	16 (44.4)	7 (46.7)	
Urogenital	10 (19.6)	9 (25.0)	1 (6.7)	
Other	5 (9.8)	1 (2.8)	4 (26.7)	

*Independent samples *t*-test; §Fisher's exact test; †Fisher-Freeman-Halton test.
SD: Standard deviation

Table 2: Inter-rater agreement of raters for Turkish Palliative Performance Scale version 2

Inter-rater agreement	ICC_A (95% CI)	ICC_C (95% CI)
Time 1	0.982 (0.972-0.989)	0.982 (0.972-0.989)
Time 2	0.991 (0.986-0.995)	0.991 (0.986-0.995)

CI: Confidence interval; ICC: Intraclass correlation coefficient; ICC_A: Absolute agreement ICC; ICC_C: Consistency ICC

one of outpatients [$P < 0.05$, Table 5]. The gender and diagnosis were similar across the place of care ($P > 0.05$). KPS, Katz ADL, and PPS-TR scores of outpatients were significantly higher than those of inpatients and emergency ($P < 0.05$).

The PPS-TR scores were divided into three groups as 0–30, 40–60, and 70–100. The distribution of these score categories was significantly different across patients' place of care [$P < 0.001$, Figure 1]. None of the outpatients had a PPS score between 0 and 30. The proportion of having a PPS score between 70 and 100 in outpatients was higher than those in the other two groups.

There was a perfect correlation between PPS-TR and KPS, while the correlation of PPS-TR with Katz ADL was almost perfect ($r_S = 0.967$, $P < 0.001$).

Table 3: Intra-rater agreement of raters for Turkish Palliative Performance Scale version 2

Intra-rater agreement	ICC_A (95% CI)	ICC_C (95% CI)
Rater 1	0.984 (0.968-0.991)	0.986 (0.975-0.992)
Rater 2	0.974 (0.940-0.987)	0.979 (0.964-0.988)
Rater 3	0.956 (0.909-0.977)	0.963 (0.935-0.979)

CI: Confidence interval; ICC: Intraclass correlation coefficients; ICC_A: Absolute agreement ICC; ICC_C: Consistency ICC

Discussion

In the present study, the Turkish translation of PPSv2 was found to be a reliable and valid tool for assessment of performance status of cancer patients receiving palliative care. The ICC of inter-rater and intra-rater agreements showed high reliability between the three observers at two different measurement points. The distribution of PPS-TR was different across patients' place of care, being significantly higher in outpatients. There was a perfect

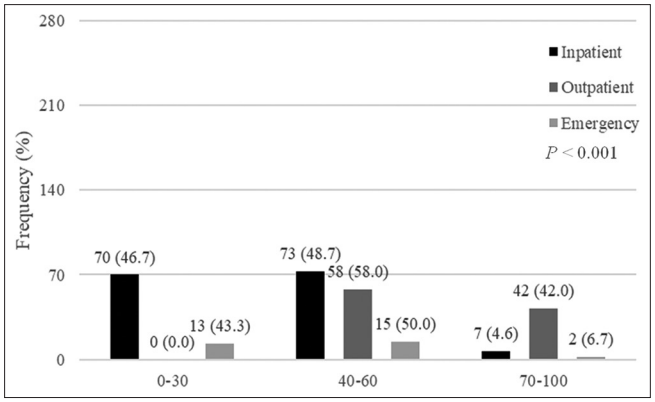

Figure 1: Turkish Palliative Performance Scale version 2 score distribution across the place of care

Table 4: Inter-domain and final-domain correlations of Palliative Performance Scale version 2

	Final PPS	Ambulation	Activity and evidence of disease	Self-care	Intake	Conscious level
Final PPS	1.000					
Ambulation	1.000	1.000				
Activity and Evidence of disease	0.983	0.983	1.000			
Self-Care	0.984	0.984	0.964	1.000		
Intake	0.971	0.971	0.939	0.968	1.000	
Conscious Level	0.968	0.968	0.946	0.948	0.943	1.000

All Spearman correlation coefficients are significant at <0.001 level. PPS: Palliative Performance Scale

Table 5: Demographic and clinical characteristics of the patients in cross-sectional study [Median (minimum-maximum)]

Variable	Place of care				*P*
	Total ($n=280$)	Inpatient ($n=150$)	Outpatient ($n=100$)	Emergency ($n=30$)	
Age (year)	57 (16-94)	59.5 (16-90)[a]	54 (17-81)[b]	57 (34-94)[a]	0.016*
Female [*n* (%)]	138 (49.3)	73 (48.7)	52 (52.0)	13 (43.3)	0.689§
Diagnosis [*n* (%)]					
Brain	8 (2.9)	8 (5.3)	0	0	0.077†
Head-neck	20 (7.1)	9 (6.0)	9 (9.0)	2 (6.7)	
Lung	30 (10.7)	12 (8.0)	15 (15.0)	3 (10.0)	
Breast	39 (13.9)	16 (10.7)	19 (19.0)	4 (13.3)	
Gastrointestinal	92 (32.9)	57 (38.0)	25 (25.0)	10 (33.3)	
Urogenital	47 (16.8)	25 (16.7)	14 (14.0)	8 (26.7)	
Other	44 (15.7)	23 (15.3)	18 (18.0)	3 (10.0)	
KPS ($n=50$)	40 (10-90)	30 (10-70)[a]	75 (50-90)[b]	30 (20-70)[a]	<0.001*
Katz ADL ($n=50$)	3 (0-6)	2 (0-6)[a]	6 (5-6)[b]	1 (0-5)[a]	<0.001*
PPS-TR	40 (10-90)	40 (10-80)[a]	60 (40-90)[b]	40 (10-70)[a]	<0.001*

*Kruskal-Wallis test; §Yates' Chi-square test, †Fisher's exact test with Monte Carlo simulation based on 10,000 samples; [a]Groups are similar with respect to the variable in the corresponding row ($P>0.05$); [b]Group is significantly different from the other groups with respect to the variable in the corresponding row ($P<0.05$). KPS: Karnofsky Performance Scale; Katz ADL: Katz Index of Independence in Activities of Daily Living; PPS-TR: Turkish Palliative Performance Scale version 2

correlation between PPS-TR and KPS, while it was almost perfect with Katz ADL.

PPSv2 is a communication tool for quickly describing a patient's functional status and allows following the changes or declining as the disease progresses. It offers a more common language than KPS, which it was derived by adding the evaluation of oral intake and level of consciousness. By more reflecting physical change, it is anticipated to be used for prognostication, research, and for program planning related to symptom control, drug costs, nursing and auxiliary requirements, and respite care needs.[9] Palliative care is an evolving concept of health care in Turkey, and the need is increasing along with the aging of the population and the rise in the incidences of chronic diseases. PPSv2 has been used in our palliative care unit since its establishment in 2007, but the validation study has not been performed. The design of our study was similar to Barallat *et al.*, including the inpatients in palliative care unit or oncology wards, outpatients in palliative care policlinic, and consultations from emergency department.[14] Three observers assessed the patients with 48-h intervals in the pilot study. Although longer periods are suggested for test–retest reliability, we preferred a shorter time scale because the cancer patients receiving palliative care are generally frail and their clinical status may rapidly change affecting the second evaluation. In the present study, the ICCs at Time 1 and Time 2 were 0.982 (95% CI: 0.972–0.989) and 0.991 (95% CI: 0.986–0.995) indicating excellent inter-rater agreement. Similarly, Ho *et al*. demonstrated a strong inter-rater reliability for the PPS among two groups with ICCs for absolute agreement of 0.959 and 0.964 for Group 1, at Time 1 and Time 2, and 0.951 and 0.931 for Group 2, at Time 1 and Time 2, respectively. They established its validity based on content validation through interviews of palliative care experts.[16] The findings of our study also show compatibility with the previously published other ones.[14,24] We have found the ICCs of intra-rater agreements at least 0.956 (95% CI: 0.909–0.977) for three raters. Test–retest reliability was found as 0.89 (0.68–0.96) and inter-observer reliability as 0.75 (0.26–0.92) in the Spanish study, which were a little lower than our results.[14] In the Arabic version, the intra-rater, test–retest, ICC was 0.935 (95% CI: 0.88–0.965, $P < 0.001$).[24]

The age of the inpatients was significantly higher than outpatients both in the pilot and cross-sectional study, while the distribution of gender and cancer diagnosis was similar across the place of care. In the cross-sectional study, the construct validity was assessed by observing the test capacity across patient groups based on the place of care. When the PPS-TR scores were divided into three groups as 0–30, 40–60, and 70–100, the score categories were significantly different among the care settings. The performance status of outpatients was better as expected; none of them had a PPS score lower than 40%, and the proportion of a PPS score between 70% and 100% was higher than the other two groups. Most of the inpatients in palliative care units and oncology wards or consultations from emergency department presented a PPS level below 60%. The patients in the emergency department are usually referred for hospitalization and have similar scores with inpatients, being somewhat a little lower. The results of the present study are in accordance with Barallat *et al*. although the number of patients is not the same.[14] In another study, Virik and Glare have reported the median PPS score on admission to palliative care unit as 30 (range: 10–70).[25] A validation study of PPS in an acute tertiary care hospital setting showed that 92% of inpatients at the time of palliative care consultation had a score between 10% and 40%. The PPS correlated well with length of survival and with selected symptom distress scores.[26]

In the present study, the participants were also assessed by two other functional capacity tests that are validated in Turkish population.[21,22] The KPS, Katz ADL, and PPS-TR scores of the outpatients were significantly higher than those of inpatients and emergency department. There was a perfect correlation between PPS-TR and KPS, while the correlation of PPS-TR with Katz ADL was almost perfect (r_S: 0.967, $P < 0.001$). The KPS correlation was similar in the study of Barallat *et al*. (Spearman: 0.927, $P < 0.001$).[14]

Limitations

There may be several limitations of this study. The time interval to determine the test–retest reliability was short as the observers may remember the patients and their scores in 48 h. This time scale was chosen because of the frailty and rapid interchangeability of the performance status of our study population. The observers assessed the patients without seeing their previous ratings and the results of the other two. The real patient and clinical conditions may also be a strength of our study. In recent reports, although the time intervals for assessments were 2 weeks, the cases were paper based, and it is unclear whether similar reliability would occur if clinicians had actually examined real patients.[15,16]

Conclusions

This study showed that PPS-TR is a reliable and valid clinical tool for the assessment of cancer patients receiving palliative care. It should be integrated into the current palliative care system to provide communication among the health professionals in assessing and following the functional status and disease progress of the patient,

determine prognosis, make care plans according to the performance and needs of the patient, and use the health-care sources effectively. Future studies can be carried out to test its practicability and usefulness in different patient populations and care settings.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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