Brief Methodological Report

The Spanish Adaptation of the Palliative Performance Scale (Version 2) Among Cancer Patients at the End of Life: Psychometric Properties

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Abstract

Background. Palliative Performance Scale (PPS) is a reliable tool to assess performance status in cancer patients receiving palliative care (PC). Spanish validated and culturally adapted tools are needed.

Objectives. The objectives are to develop PPS translation and cross-cultural adaptation into Spanish and to assess its psychometric properties.

Design. Translation process with cross-cultural adaptation to produce Spanish Palliative Performance Scale (PPS-SPANISH).

Settings. PC Team at one University hospital in Spain.

Participants. Fifteen advanced cancer patients (60 assessments) were included for PPS translation and validation and 250 patients for cross-sectional analysis. All participants were recruited at oncology ward, emergency area, and outpatient clinic by PC team professionals. Informed consent was given. Average age was 66.4 ± 13 years (60% men).

Methods. The process is designed in three steps. In Step 1, PPS translation and reverse translation into Spanish (three bilingual speakers) and linguistic complexity measurement were performed. In Step 2, readability and intelligibility assessment was carried out. In Step 3, a pilot study was conducted to assess test-retest reliability followed by a cross-sectional study to measure internal consistency. Inclusion criteria were the same for two samples. Demographic data were also analyzed by descriptive statistics.

Results. Following cultural, linguistic, and grammatical adaptation, PPS-SPANISH was readable and reliable. The analysis of the test-retest reliability after 48 hours showed intraclass correlations >0.60. Cronbach's alpha coefficient was 0.99 (0.988−0.992). There was high agreement with other functional assessment tools (Barthel Index and Karnofsky Performance Status Index).

Conclusions. PPS-SPANISH showed reliability and validity, and it is suitable to assess performance status in cancer patients receiving PC. J Pain Symptom Manage 2017;54:570−577.

Key Words

Cancer, clinical tools, nursing practice, palliative care, palliative performance scale, spanish, validation studies

Introduction

Palliative care (PC) is not limited to the last days of life but applied progressively as the disease progresses, dependent on the needs of patients and families.[1,2]

Patient's experience of advanced disease is complex, covering a range of physical, psychosocial, and spiritual issues, requiring an interdisciplinary approach with the focus of care being patient and

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Accepted for publication: July 6, 2017.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2017.07.014

family rather than illness. A multidimensional bedside assessment is essential for symptom management, quality of life, and decision-making,[3] including the evaluation of the performance status (PS), in order to enable planning of accurate care and identify the impact of symptoms and patients activity; risk to cognitive impairment; psychological distress and coping resources; family structure and dynamics, community support, environment or financial situation; and spiritual concerns related to meaning, and values.[4]

In many of these areas, specific PC assessment tools have been developed and validated into Spanish, highlighting the role of functional assessment in care planning.[5,6] PS is a patient-oriented assessment with information related to individual daily functioning. It is also the most basic variable in functional outcome studies.[7,8] PS provides data to improve information about prognosis, physical deterioration, loss of autonomy, and place of care,[9] notably in cancer patients.[10]

Assessment can be difficult and influenced by different factors (disease evolution, symptoms, emotional status, personal assistance facilities, environment, and so on), and PS can change or deteriorate rapidly.[11]

Many tools have been developed to assess baseline PS and monitor changes, but most were developed for cancer, geriatric, and rehabilitation patients and adapted for use in PC settings.[12]

There is no clear consensus on the characteristics that functional assessment tool should have. There is consensus on the properties they should reach: they must be valid, reliable, sensitive to the change and with utility properties,[13] for example on patient's survival, and providing information for advanced care planning.

The Palliative Performance Scale, version 2 (PPSv2)[14] is a reliable functional assessment tool designed to measure the PS of patients receiving PC (Appendix A). It has been used for communication, admissions and discharges at hospice units, survival prognostication, and nursing care workload analyzes.[15,16]

The PPSv2 is an adaptation of the Karnofsky Performance Scale (KPS)[17] functional patient capacity divided into 11 categories measured in increments of 10%, from fully ambulatory and healthy patient (100%) to death (0%).[18,19] Factors that differentiate those levels are based on five dimensions (parameters): ambulation, activity and evidence of disease, self-care, intake, and conscious level (Appendices A and B).

A special feature of the test is that it does not take into account patient's place of care so has utility for hospitals, hospices, or home care.

PPSv2 has been translated into many languages but only validated in English and Thai.[20,21] Further, it is unclear if a translated but nonvalidated version of the PPSv2 into South American Spanish by Duarte has similar values in the Spanish culture for PC patients. The objectives of this study were to translate the PPSv2 into Spanish, to carry out the linguistic and cultural adaptation and to assess the reliability and validity.

Methods

The methods used were translation and cultural adaptation of PPSv2 into Spanish in hospitalized patients.

Translation

After written consent from PPSv2 authors was obtained, a three-step process was designed (Fig. 1).

First Step: Translation and Back Translation. Translation of PPSv2 into Spanish was carried out using a "forward-back-forward" translation procedure.

Three experts translated PPSv2 into Spanish, one with basic PC training and two with extensive experience. After consensus among researchers and translators, the first version was agreed.

A committee of expert linguists and reviewers assessed the second version to ensure consistent wording and meaning.

Two linguists and two clinicians performed back translation. Three linguists and three clinicians selected the best translation within the cultural context of the tool. They corrected grammar, linguistic, and semantic aspects, and the third version was obtained through consensus.

Second Step: Identification of Discrepancies. We assessed the linguistic validity of the tool by applying the cultural, linguistic, and grammatical adaptation to our environment (fourth version). We measured the readability of fourth version on the INFLESZ scale.[22] This provides five levels of difficulty: "very difficult" (<40), "a little difficult" (40−55), "normal" (55−65), "fairly easy" (65−80), and "easy" (>80). Three different linguistic experts assessed the scale intelligibility to finalize PPS-SPANISH. It was pretested and further reviewed by the multidisciplinary committee (five palliative clinicians, two doctors, and three nurses), before and after pretesting. The clinicians analyzed the Practicability of the test through consensus technique.

Third Step: Analysis of Psychometric Properties. We analyzed the interrater and intrarater reliability, external and internal validity, feasibility, and practicality. We analyzed data developing a pilot study (60 reviews) and a cross-sectional study ($n = 250$) corresponding to 250 reviews.

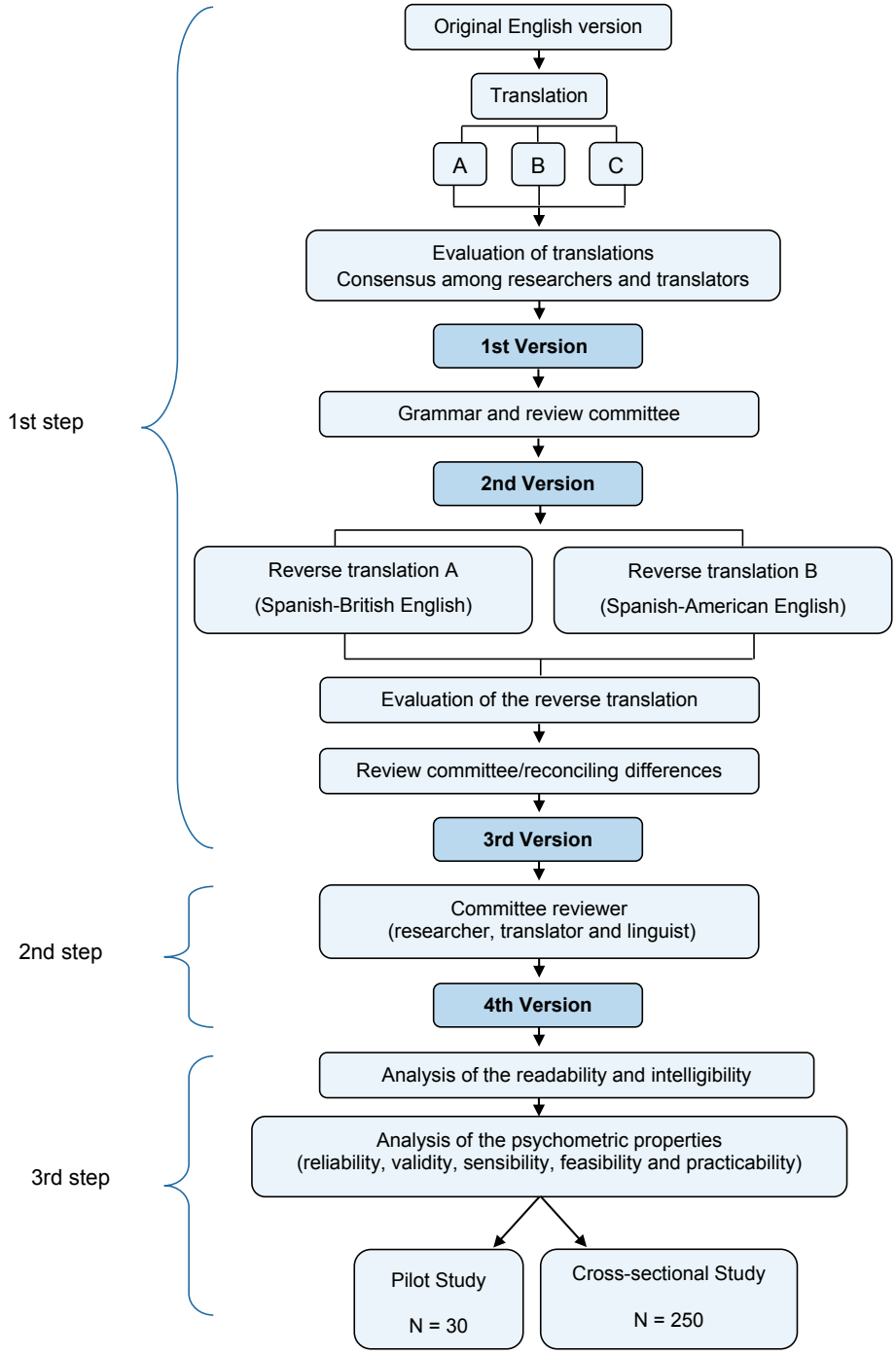

Fig. 1. Translation process.

Questionnaire

PPS-SPANISH (Appendix B) translated and culturally adapted was used in order to test its validation and psychometric properties.

Participants and Data Collection Procedure

The study took place at the University Hospital (Spain) from June 2011 to June 2012.

We held two training sessions with palliative clinician professionals (two doctors, three nurses, and postgraduate students) before starting recruitment to ensure that professionals fully understood the methodology of using PPS-SPANISH. This session gave us the opportunity to clarify understanding and to provide data collection tools.

The study population for PPS-SPANISH validation consisted of advanced cancer patients receiving PC.

Inclusion criteria were patients >18 on PC program (outpatients or inpatients) and agreement to participate was signed by patients or family.

In the pilot study, the sample ($n = 15$) comprised 60 assessments. Followed by the cross-sectional study ($n = 250$) who received one assessment each using PPS-SPANISH.

We also collected data related to cognitive and functional assessments. Cognitive evaluation was tested by Pfeiffer test,[23] which establishes the degree of cognitive impairment and adjusts the score by educational level, it was used as screening. Ramsay scale[24] used to report the conscious level is widely used in our hospital, although there is a specific scale in PC that has not been incorporated because it also does not allow us to establish the degree of comfort.[25] PS was assessed by validated Barthel test[26] and KPS.

Statistical Analysis

Pilot study. The internal consistency was measured by Cronbach's alpha coefficient, and the test-retest reliability was measured by intraclass correlation coefficient (ICC). We accepted ICC 0.9 (excellent), 0.8 (good), and >0.6 (moderate reliability).

Interobserver reliability was tested by pilot study with each participant by two different clinicians on two occasions, and test-retest reliability was assessed twice with a gap of 48 hours between assessments.

Cross-sectional study. We measured construct validity in order to check the ability of PPS-SPANISH to establish patients cluster according to patients' place of care (outpatient, inpatient, or emergency room). We used the Kruskal-Wallis nonparametric tool to analyze continues variables.

The relationship between PPS-SPANISH, KPS, and Barthel was measured using the Pearson correlation coefficient. Further, to establish correlation among the different categories of the PPS and place of care, Pearson correlation coefficients were also used. Data were analyzed using SPSS 18.0.

Ethical Considerations

Permission from PPSv2 copyright owner (Victoria Hospice, British Columbia, Canada) was given.

The hospital Research Ethics Committee approved the study.

All participants and family gave informed consent before being included. Anonymity and confidentiality were guaranteed.

Results

Table 1 shows the readability and intelligibility of PPS-SPANISH assessed through the INFLESZ scale (adapted to Spanish reading habits). The linguist analysis showed a readable and intelligible scale.

The psychometric properties in pilot study summarize the PPS-SPANISH properties: test-retest reliability was 0.89 (0.68−0.96) and interobserver reliability was 0.75 (0.26−0.92).

In a cross-sectional study ($n = 250$), the average age of the sample was 66.4 ± 13 years (men 60%). Demographic and epidemiological characteristics are included (Table 2). The internal consistency results of PPS-SPANISH are shown in Table 3. Reliability measured by the Cronbach α coefficient was 0.990 (0.988−0.992).

We provided construct validity by observing the test's capacity across patient groupings (outpatient, inpatient, and emergency department) according to the place of care and functional level. Statistical differences between these groups existed. By location of care, we found different groups (Fig. 2) with statistical differences using the Chi-squared test. We show the functional level between groups in Figure 3. We found higher scores in the group of outpatients measured by Kruskal-Wallis test (Figs. 2 and 3), Pearson's correlation coefficient between PPS-SPANISH and Barthel index, 0.854, and between PPS-SPANISH and KPS index, 0.927 ($P < 0.001$).

The practicability analysis was completed by consensus between five professionals during the training session where we resolved differences of the concepts that made them hesitate and solved hypothetical case reports.

The length of time to complete the functional assessment using the PPS-SPANISH varied depending on the PS, ranging from three to 10 minutes.

Discussion

This study reports the findings from translation, cross-cultural adaptation, and validation study of the valid PPSv2 in cancer patients in Spain. Even the process of producing translation questionnaires is complex and time consuming[27] but important to translate, adapt, and validate the tool into Spanish to be used in our clinical PC population.

As the Spanish spoken in Central America and South America is culturally different from Spanish spoken in Spain, and following the advice of linguists, we decided to initiate a new translation from the

Table 1
Readability Results From PPS-SPANISH (INFLESZ v1.0)

Syllables	708
Words	269
Phrases	85
Average syllables/words	2.63
Average words/phrase	3.16
Flesch-Szigriszt Index	39.70
Grade on the scale Inflesz	Very difficult

PPS-Spanish = Spanish Palliative Performance Scale.

Table 2
Sociodemographic and Clinical Characteristics of the Cancer Patients ($N = 250$)

Variable/Place of Care	Total	Outpatient	Inpatient	Emergency	*P*-value
Diagnòstic, *N* (%)					
Lung	76 (30.4)	45 (39.5)	25 (21.6)	6 (30)	<0.001
Uro-colon-rectum	36 (14.4)	12 (10.5)	20 (17.2)	4 (20)	
Nose, ear, and throat	32 (12.8)	21 (18.4)	7 (6)	4 (20)	
Upper digestive	35 (14.0)	10 (8.8)	23 (19.8)	2 (10)	
Lower digestive	36 (14.4)	20 (17.5)	15 (12.9)	1 (5)	
Other cancers	35 (14.0)	6 (5.3)	26 (22.4)	3 (15)	
Cognitive assessment (*n*)					
Pfeiffer	(227) 1.28 ± 1.98	(107) 0.94 ± 1.6	(102) 1.50 ± 2.26	(18) 2 ± 2.27	0.106
Level of awareness (*n*)					
Ramsay	(250) 2.05 ± 0.46	(114) 1.98 ± 0.18	(116) 2.1 ± 0.63	(20) 2.10 ± 0.30	0.218
Functional assessment (*n*); mean and SD					
Barthel	(250) 68.4 ± 32.49	(114) 91.3 ± 15.2	(116) 48.2 ± 30.94	(20) 55.5 ± 28.69	<0.001
KPS	(250) 55.32 ± 17.42	(114) 67.37 ± 10,22	(116) 44.74 ± 15.74	(20) 48 ± 15.76	<0.001
PPS	(250) 55.6 ± 19.11	(114) 70.4 ± 9.62	(116) 42.41 ± 15.8	(20) 47.5 ± 16.5	<0.001
Age					
Mean ± SD	66.4 ± 13	67.9 ± 11	64.1 ± 15	71.6 ± 11	0.105
Gender					
% of males	61.2	69.3	49.1	85.0	0.001

KPS, Karnofsky Performance Scale; PPS, Palliative Performance Scale.

original English test and not to use the official Spanish one from Guatemala.

During the consensus process, we had to agree on the comparability of some English terms as: "sickness, disease, and illness" or Spanish terms as: "muerto, fallecido" and especially adapt gender and verb tenses in Spanish. This consensus was necessary to ensure the readability and intelligibility of the text. The results of the readability of the test are "very difficult" corresponding to high-level studies (greater than bachelor degree) as all the health professionals have this level of literacy.

The validity rate of the scale was high for the Spanish population, and the results of the interrater and intrarater reliability testing indicate that PPS-SPANISH is a reliable tool with acceptable psychometric properties to be used among cancer patients aged over 18 years.

Interobserver reliability was tested in the pilot study using the PPS-SPANISH in each participant by two different professionals twice, and test-retest reliability was analyzed by using the tool two time points, the second 48 hours after the first one. We considered this period of time as important to ensure patients clinical and functional stability, due to patient frailty and unpredictable or rapid change in the clinical situation. To confirm patients' clinical and functional stability, we utilized additional scales; specifically the Barthel test and KPS scale at the same time to exclude patients who had undergone changes in functional health status.

The ICC of >0.80 demonstrates temporal stability and interobserver agreement. The results were consistent across different observers and remain consistent when measured at different time points. Our results are similar to those published by Chewaskulyong et al.,[20] in their validation in Thailand language.

From our results, we can see that PPS-SPANISH has applicability to the three different groups depending on where the patient is assessed (inpatient, outpatient, and emergency department). This scale discriminates between these groups of patients depending of place of care, and if we try to correlate with other functional status like KPS or Barthel, we find the same association. In our target, PPS and KPS correlate very well (Spearman 0.927; $P < 0.001$). Morita et al. found similar results (Spearman 0.94; $P < 0.001$). We equally found similar results if we compare Barthel and KPS in

Table 3
PPS-SPANISH Internal Consistency ($N = 250$)

	Ambulation	Activity and Evidence of Disease	Self-care	Intake
Ambulation				
Activity and evidence of disease	0.925			
Self-care	0.918	0.973		
Intake	0.906	0.967	0.977	
Conscious level	0.908	0.968	0.976	0.989

PPS-Spanish = Spanish Palliative Performance Scale.
All correlations were statistically significant ($P < 0.01$).

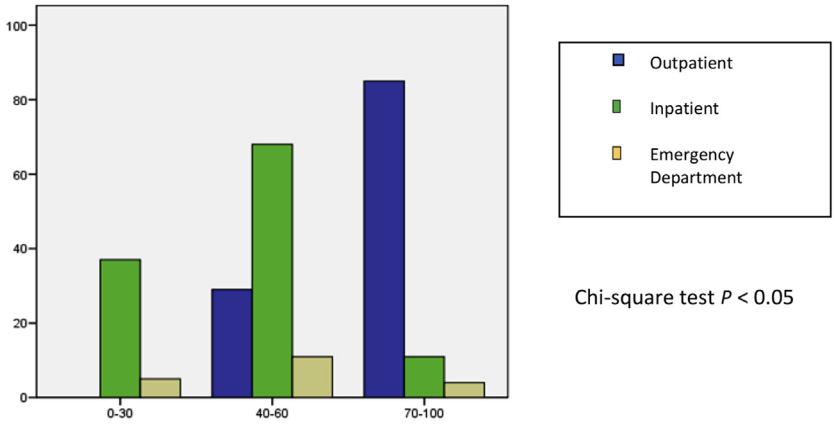

Fig. 2. PPS-SPANISH distribution according to the place of care. PPS-Spanish = Spanish Palliative Performance Scale.

the study of Nabal et al. Thus, we can confirm that KPS correlates very well with functional status.[28–30]

At the same time, PPS-SPANISH showed good correlation with KPS scale even though both scales are different. We postulate three different PPS-SPANISH stages according to their PS. We consider that a PPS range 10%–30% reflects patients receiving PC, from PPS 40% to 60%, transitional stage, and from PPS 70% to 100%, stable stage. Patients at the outpatient clinic were at the stable stage and none were deemed PC stage. On the other hand, patients treated as inpatient were identified as being at the transitional or PC stage. These data are similar to those published by Anderson et al.[14] who found that most of their hospitalized patients presented a PPS level between 30% and 50%; similar results were presented by Virik et al.[31] We did not find significance among patients in the emergency department or in oncology ward. This can be explained because the sample of patients assessed at emergency department was very low (20 patients) and those patients treated at emergency department share many characteristics with those treated as inpatients. In many cases, the emergency room is the gateway to the hospital.

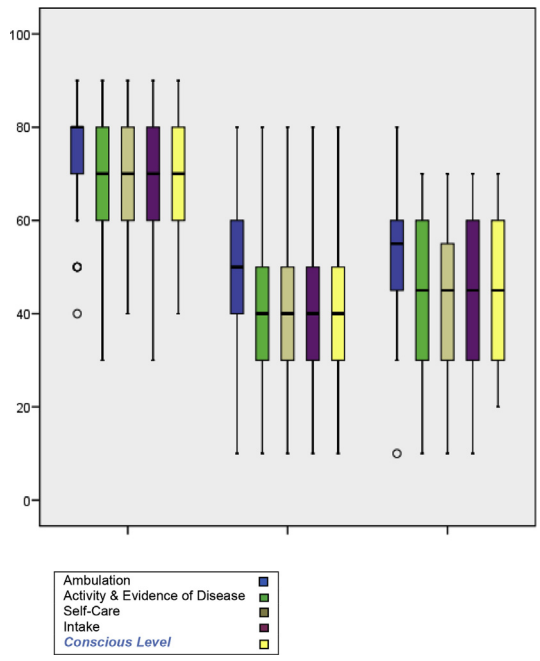

Fig. 3. PPS-SPANISH differences among categories according to the place of care. alfa-cronbach 0.990 (0.988-0.992), °$P < 0.001$. PPS-Spanish = Spanish Palliative Performance Scale.

Other PPS-SPANISH properties assessed were practicability and viability. This was undertaken by checking the time that it took to complete the PPS-SPANISH scale and by clinical team consensus. As this tool took three to ten minutes, similar in time as others like Barthel test, where the evaluation takes five minutes.[29] We note that readability results showed a "very difficult" for Spanish reading and correspond to high school level of literacy. As the PPS is not self-administered, we accept these results as all the clinicians have at least this level of literacy.

Limitations and Strengths of the Study

It is difficult to establish the most appropriate time range between assessments to confirm the test-retest reliability. Even if the tool is stable, the frail condition of many PC patients can vary quickly and change the capacity to engage with the assessment. We chose 48 hours between both assessments, and this can interfere with the second assessment, since professionals may remember the previous scores. This limitation can also be strength because it validates the test in real clinical conditions, which minimizes errors related to ambiguous situations when the validation method is based only on case reports. In the original

study and in the recent validation to Thai language, the period between both assessments was two weeks, but the assessment was performed based on case reports, not real patients. The best information that PPS scale gives to us is the evolution of the PPS in every patient, but it is not the goal of this study.

We consider that the shorter time period may be of benefit to future psychometric tool development.

The validation process was linked to hospital activity. As this tool can be used in a home setting, it will be very interesting to test it and to validate it with Spanish PC home care teams.

During the study, we also completed translation and validation into Catalan language, as all the people who live in Lleida are bilingual and we could test in both languages.

For the future, new research can be developed based on the PPS-SPANISH classification ability related to prognosis or according to different types of cancer.

Conclusions

The present study contributes to the use of PPS-SPANISH because the validation process ensures a valid and reliable tool to assess PS in advanced cancer patients receiving PC.

The study also demonstrated good equivalence to the original test developed in Canada.

In PC, PS assessment is essential when developing the interdisciplinary care plan. We consider that this tool will help native Spanish speakers to more easily assess PS, share this information across different health settings, and also compare the results to those published by English language.

Disclosures and Acknowledgments

This research received no specific funding/grant from any funding agency in the public, commercial, or not-for-profit sectors. There are no potential conflicts of interest known to any of the contributing authors.

The authors wish to thank PPSv2's authors for their permission to translate and use the PPSv2. We are especially grateful for the help received from Joan Arenas, Laia Pedra, Maria Pedra, Lorenzo von Hoffler, Jaume Barallat, Josep Maluquer, I.F. Trottman, Sarah Carlton, and Lesley Harvey for the translation and backtranslation. We would like to thank Conxita Palomar, Anna Jiménez, and Oriol Yuguero for collecting data by using the new version of the test. Finally, we want to acknowledge Ramon Rubinat, for his help with the intelligibility assessment process, Maria Macià for her help with the linguistic assessment, and Dr. Antonio Martin for his statistical support.

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Appendix A

Test PPSv2 Original

Victoria Hospice

Palliative Performance Scale, Version 2 (PPSv2)

PPS Level (%)	Ambulation	Activity and Evidence of Disease	Self-care	Intake	Conscious Level
100	Full	Normal activity and work, and no evidence of disease	Full	Normal	Full
90	Full	Normal activity and work, and some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, and some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable normal job/work, and significant disease	Full	Normal or reduced	Full
60	Reduced	Unable hobby/house work, and significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, and extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do most activity, and extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/− confusion
30	Totally bed bound	Unable to do any activity, and extensive disease	Total care	Normal or reduced	Full or drowsy +/− confusion
20	Totally bed bound	Unable to do any activity; extensive disease	Total care	Minimal to sips	Full or drowsy +/− confusion
10	Totally bed bound	Unable to do any activity, and extensive disease	Total care	Mouth care only	Drowsy or coma +/− confusion
0	Death	—	—	—	—

Instructions for use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a "best fit" for the patient, which is then assigned as the Palliative Performance Scale (PPS) percentage score.
2. Begin at the left column and read downward until the appropriate ambulation level is reached, then read across to the next column and downward again until the appropriate activity/evidence of disease level is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. It is important to note that "leftward" columns (columns to the left of any specific column) are "stronger" determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves; then, the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a "best fit" decision. Choosing a "half-fit" value of PPS 45%, for example, is not correct. The combination of clinical judgment and "leftward precedence" is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted in the following section, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall "best fit" using all five columns.

1. Ambulation
   The items "mainly sit/lie," "mainly in bed," and "totally bed bound" are clearly similar. The subtle differences are related to items in the self-care column. For example, "totally bed bound" at PPS 30% is due to either profound weakness or paralysis such that the patient not only can not get out of bed but is also unable to do any self-care. The difference between "sit/lie" and "bed" is proportionate to the amount of time the patient is able to sit up vs need to lie down.
   "Reduced ambulation" is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation, or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.
2. Activity and Extent of disease
   "Some," "significant," and "extensive" disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply "some" disease, one or two metastases in the lung or bone would imply "significant" disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia, or other major complications would be "extensive" disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, "some" may mean the shift from HIV to AIDS, "significant" implies progression in physical decline, new or difficult symptoms, and laboratory findings with low counts. "Extensive" refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, and so on.
   The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to nine holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (e.g., trying to walk the halls).
3. Self-Care
   "Occasional assistance" means that most of the time, patients are able to transfer out of bed, walk, wash, toilet, and eat by their own means but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.
   "Considerable assistance" means that regularly every day the patient needs help, usually by one person, to do some of the activities noted previously. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.
   "Mainly assistance" is a further extension of "considerable." Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.
   "Total care" means that the patient is completely unable to eat without help, toilet, or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.
4. Intake
   Changes in intake are quite obvious with "normal intake" referring to the person's usual eating habits while healthy.
   "Reduced" means any reduction from that and is highly variable according to the unique individual circumstances.
   "Minimal" refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.
5. Conscious Level
   "Full consciousness" implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, and so on. "Confusion" is used to denote the presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate, or severe with multiple possible etiologies. "Drowsiness" implies either fatigue, drug side effects, delirium, or closeness to death and is sometimes included in the term stupor. "Coma" in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hours period.

Appendix B

Test PPS-Spanish

Palliative Performance Scale (PPS-SPANISH)

Nivel PPS (%)	Deambular	Actividad y Evidencia de Enfermedad	Cuidado de sí Mismo	Ingesta	Nivel de Conciencia
100	Completo	Trabajo y actividad normal Sin evidencia de enfermedad	Completo	Normal	Alerta
90	Completo	Actividad normal y de trabajo Mínima evidencia de enfermedad	Completo	Normal	Alerta
80	Completo	Actividad normal/trabajo con esfuerzo Mínima evidencia de enfermedad	Completo	Normal o Reducida	Alerta
70	Reducido	Incapaz de trabajar y realizar actividad normal Enfermedad significativa	Completo	Normal o Reducida	Alerta
60	Reducido	Incapaz de realizar aficiones/ tareas del hogar Enfermedad significativa	Precisa asistencia ocasi onal	Normal o Reducida	Alerta o confuso
50	Principalmente sentado/tumbado	Incapaz de realizar cualquier trabajo Enfermedad severa	Precisa asistencia considerable	Normal o Reducida	Alerta o somnoliento ± confuso
40	Principalmente encamado	Incapaz de realizar la mayoría de actividades Enfermedad severa	Principalmente asistido	Normal o Reducida	Alerta o somnoliento ± confuso
30	Completamente encamado	Incapaz de realizar cualquier actividad Enfermedad severa	Totalmente dependiente	Reducida	Alerta o somnoliento ± confuso
20	Completamente encamado	Incapaz de realizar ninguna actividad Enfermedad severa	Totalmente dependiente	Pequeños sorbos	Alerta o somnoliento ± confuso
10	Completamente encamado	Incapaz de realizar ninguna actividad Enfermedad severa	Totalmente dependiente	Solo cuidados de la boca	Somnoliento o comatoso
0	Muerto	—	—	—	—

PPS-Spanish = Spanish Palliative Performance Scale.
Instrucciones: El Nivel de PPS se determina leyendo de izquierda a derecha para encontrar "la opción que encaja mejor con el paciente." Empezar en la columna izquierda, hacer la lectura hacia abajo hasta encontrar el nivel de deambular del paciente, a continuación, leer horizontalmente hasta la siguiente columna y después hacia abajo hasta encontrar la que corresponde. Así, las columnas de la izquierda tienen prioridad sobre las columnas de la derecha.

Instrucciones de uso del PPS (Ver definición de términos)

1. Las puntuaciones del PPS vienen determinadas leyendo horizontalmente cada nivel hasta encontrar la "opción que encaja mejor."
   - Empieza en la columna de la izquierda hasta encontrar el nivel de deambular adecuado.
   - Desplázate horizontalmente hacia la próxima columna y después hacia abajo hasta encontrar el nivel de actividad y evidencia de enfermedad. Si es necesario se puede escoger un nivel superior, teniendo en cuenta que las columnas de la izquierda tienen más potencia.
   - Desplázate horizontalmente hacia la columna de "Cuidado de sí mismo," "ingesta" y "nivel de conciencia," antes de asignar el nivel de PPS a la persona.

   Ejemplo 1: Una persona que está la mayor parte del día sentado o tumbado por la fatiga que le produce la enfermedad severa y requiere considerable asistencia para andar incluso en distancias cortas, pero por otro lado tiene un nivel de conciencia completo y buena ingesta. PPS 50%.

   Ejemplo 2: Una persona con tetraplejia que es totalmente dependiente, tendría un PPS 30%. Aunque pueda ser trasladado en silla de ruedas (inicialmente parecería tener un PPS de 50%), la puntuación sería 30% pues estaría completamente encamado por la enfermedad o por una complicación y los cuidadores necesitarían ayuda para las transferencias. La persona debe tener una ingesta normal y estar alerta.

   Ejemplo 3: Si la persona del anterior ejemplo es parapléjico y encamado pero aún es capaz de mantener el autocuidado en alguna ABVD como arreglarse o comer por sí mismo, entonces el PPS sería más alto que 40 o 50% hasta que necesite ser cuidado en todas las ABVD.
2. Las puntuaciones del PPS tienen incrementos del 10% solamente. Algunas veces hay columnas que se marcan fácilmente en un nivel concreto, pero otras veces parece mejor en un nivel superior o inferior. Entonces conviene utilizar el juicio clínico para escoger la mejor opción. Por ejemplo, marcar PPS 45% o 55% no es correcto, porque son valores intermedios. Los evaluadores tienen que poner qué es lo que el paciente puede hacer, más que centrarse únicamente en la observación.

3. El test PPS puede usarse con diferentes objetivos. Primero, es una herramienta de comunicación excelente para describir rápidamente el nivel funcional actual de un paciente. Segundo, tiene valor en su uso en valoraciones, comparaciones u otras medidas. Finalmente, parece tener valor pronóstico.

Definición de los términos del PPS

Como podemos ver más abajo, algunos términos tienen significados similares y las diferencias son más aparentes si se leen horizontalmente a través de cada fila hasta encontrar la "opción que se adapta mejor" haciendo uso de las 5 columnas.

Deambular

Los términos "principalmente sentado," "principalmente encamado" o "completamente encamado" son claramente similares. Las diferencias sutiles son relativas a los ítems de la columna "cuidado de sí mismo." Por ejemplo "completamente encamado" en el PPS 30% es debido a debilidad profunda o parálisis más que debido al hecho que el paciente no puede levantarse o es incapaz de tener cuidado de sí mismo. La diferencia entre "sentado/tumbado" y "principalmente encamado," se define por la cantidad de tiempo que el paciente es capaz de estar sentado *versus* la necesidad de estar tumbado.

"Deambular reducido" lo encontramos en un PPS 70% y en un PPS 60%. Si utilizamos la columna adyacente, la reducción en "deambular" se relaciona con la imposibilidad de llevar a término su trabajo normal en casa o fuera de casa, sus aficiones o las tareas del hogar. La persona aún es autónoma para andar y para hacer las transferencias, pero en el PPS 60% necesita asistencia ocasional.

Actividad y evidencia de enfermedad

"Mínima evidencia," "enfermedad significativa" y "enfermedad severa" se refiere a la parte física y a la evidencia científica y muestra ciertos grados de progresión de enfermedad. Se mide en términos de patología, sin tener en cuenta el impacto psicológico (tristeza, ansiedad …). Medimos qué es capaz de hacer, no qué hace realmente.

Ejemplo: "cáncer de mama":

- una recidiva implicaría "Mínima evidencia."
- 1 ó 2 mts en pulmón o en huesos implicaría "Enfermedad significativa"
- múltiples metástasis en pulmón, huesos, hígado, cerebro, hipercalcemia u otras complicaciones mayores implicaría "Enfermedad severa."

La extensión de la enfermedad es valorada también en el contexto de las habilidades que el paciente tiene para desarrollar su trabajo, las aficiones o las tareas del hogar. Por ejemplo: "Incapaz de trabajar y realizar actividad normal" significaría continuar con los paseos matinales pero con una distancia reducida, o no poder hacer absolutamente toda la actividad que hacía antes.

Ejemplo: Si el paciente tiene alguna evidencia de enfermedad, pero no puede trabajar por la quimioterapia, el PPS estaría entre 50 i 70%.

Cuidado de sí mismo

"Asistencia ocasional": La mayor parte del tiempo la persona puede hacer las transferencias, pasear, asearse, ir al WC, comer, pero ocasionalmente necesita ayuda (por ejemplo una vez al día o pocas veces a la semana).

"Asistencia considerable": De manera regular, cada día la persona necesita ayuda (por ejemplo para ir al WC, pero entonces puede lavarse los dientes solo, necesita ayuda para cortar la comida, pero puede comer solo).

"Principalmente asistido": Es una extensión asistencia considerable (necesita ayuda para ir al W.C. y para asearse).

"Totalmente dependiente": La persona es incapaz de comer, ir al W.C. o hacer cualquier cuidado de sí mismo sin ayuda.

Ejemplo: Paciente que tiene mínima evidencia de enfermedad, pero no puede trabajar porque no tiene buen soporte familiar o tiene depresión. PPS 70% o 80%.

Ejemplo: Un paciente tetrapléjico o parapléjico tendría un PPS 30%, ya que necesita ayuda para hacer las transferencias a una silla de ruedas. De ninguna manera podría hacerlo solo. Si solamente es parapléjico, y puede alimentarse de manera autónoma, podría tener un PPS 40% o 50%.

Ingesta

"Normal": se refiere a los mismos hábitos alimentarios que cuando estaba sano.

"Reducida": se refiere a una reducción de estos hábitos alimentarios.

"Pequeños sorbos": pequeñas cantidades, generalmente en puré o líquidos, que están muy por debajo de los requerimientos nutricionales.

Si lleva nutrición parenteral, si es nutricionalmente suficiente, se considera aproximadamente igual que si es capaz de comer solo.

Nivel de conciencia

"Alerta": Consciente, orientado y con buena capacidad cognitiva.

"Confuso": Presencia de delirium o demencia y un nivel de consciencia reducido, que puede ser poco, moderado o severo.

"Somnoliento": puede ser debido a la fatiga, a los efectos secundarios de los medicamentos, al delirium o porque se encuentra cerca de la muerte.

"Comatoso": No hay respuesta a los estímulos verbales o físicos. La profundidad de este coma puede fluctuar.

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