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Cross-cultural adaptation of the Paediatric Palliative Screening Scale for the early referral of pediatric patients to palliative care teams

José M. Vera García[1], Julieta Pontoriero Daroni[1], María C. Malzone[2]

ABSTRACT

Introduction. The Paediatric Palliative Screening Scale (PaPaS Scale) is a tool designed to help identify children aged 1 to 18 who would benefit from pediatric palliative care (PPC) and to facilitate early referral. No similar tool exists in Spanish. The objective was to translate and cross-culturally adapt the PaPaS Scale into Spanish for screening and early referral to PPC teams for pediatric patients aged 12 months to 18 years with life-threatening or life-limiting illnesses.

Methods. Translation and cultural adaptation of the PaPaS Scale into Spanish, consisting of five phases: obtaining authorization from the scale's authors, direct translation, back-translation, evaluation by a committee of experts, and pretesting.

Results. Authorization was obtained from the scale's author, Eva Bergstraesser; this was followed by a direct translation (with subsequent reconciliation), a back-translation of the resulting scale into English, validation by a committee of experts in research, health sciences, and humanities; and a pretest consisting of an evaluation of the scale by five physicians specializing in PPC. At each stage, the necessary changes were made to adapt the scale.

Conclusion. A culturally adapted Spanish-language scale was developed that could serve as a useful tool for the early identification of PPC in pediatric care, following appropriate validation.

Keywords: *palliative care; pediatrics; needs assessment; chronic illness; Argentina.*

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INTRODUCTION

Despite technological, diagnostic, and therapeutic advances in pediatrics, various barriers still prevent early referral to and involvement of pediatric palliative care (PPC) teams in the treatment of patients with life-threatening or life-limiting conditions.[1] According to the World Health Organization, the definition of PPC includes comprehensive care for the child's body, mind, and spirit, as well as support for the family. From their inception, PPC teams were designed to be integrated into children's care at the moment a life-threatening condition is diagnosed, regardless of the specific treatment for that condition (whether such treatment exists, is curative, or not).[2,3]

The palliative care approach to medicine does not negate the curative focus on patients; rather, it seeks to integrate these approaches and work as a team to ensure the greatest comfort and well-being for children, while striving to achieve a cure or, as closely as possible, to come as close as possible to that state.[4] With this philosophy in mind, numerous studies were conducted that demonstrated the benefits of using palliative care units (PCUs) in the treatment of patients with various conditions.[5,6] Despite this, cultural and educational barriers still stand in the way of the appropriate early referral of patients to PCUs, such as an overestimation of the possibility of cure or disease control, the healthcare team's failure to recognize the terminal status of patients, misinterpretations of the term "palliative care," and futile medical treatment to avoid the family's and professionals' sense of "giving up," among others.[4] Unfortunately, this situation is exacerbated by the fact that there are few validated scales to assess the need for referral to a palliative care team. Furthermore, there are no validated scales for our country, which would be an extremely valuable tool for more appropriate interdisciplinary treatment of these patients.

The Paediatric Palliative Screening Scale (PaPaS Scale) is a multidimensional tool developed by Eva Bergstreasser and colleagues and first published in *BMC Palliative Care* in 2013. It is a scale with 11 domains and closed-ended questions. It was designed to help identify children who would benefit from receiving PPC, to facilitate appropriate and early referral, and applies to children aged 1 to 18 years.[4,7] Taking into account these biases and misconceptions, and the daily reality that referral to a palliative care team rarely occurs at the appropriate time, the researchers assessed the urgent need for a scale capable of identifying patients with complex chronic conditions who would benefit from palliative care, to guide early referral to palliative care teams. To this end, it was decided to conduct a cross-cultural adaptation of the PaPaS Scale (the original version of which can be found (*Figure 1*).

Primary objective

To translate and culturally adapt the PaPaS Scale into Spanish as a screening tool for early referral to palliative care teams for pediatric patients aged 12 months to 18 years with life-threatening or life-limiting illnesses.

Secondary objectives

- To produce a translation that is conceptually and semantically equivalent and culturally adapted to the target population of the PaPaS Scale.
- Have the scale evaluated by a committee of PPC specialists to assess the equivalence of concepts between the translated scale and the original.

METHODS

Study design

Translation and cultural adaptation of the PaPaS Scale into Spanish, consisting of five phases: obtaining authorization from the scale's authors, direct translation and reconciliation, back-translation, consolidation of the scale by a committee of experts, and pretesting.

Sample population

For the meetings outlined in the pretest, five physicians specialized in PPC, each with at least two years of experience in the field, were selected to evaluate the measurement instrument.

Inclusion criteria

Pediatricians who were specialists in PPC (holding a specialist degree issued by a university), with at least two years of experience, and who were actively practicing in that specialty.

Exclusion criteria

There are no exclusion criteria.

Ethical considerations

This research study was approved by the Research Protocol Ethics Committee of the Hospital Italiano de Buenos Aires on November 23, 2023 (protocol number #6902).

Qualitative analysis sampling

A non-probabilistic convenience sample was selected, including physicians specializing in palliative care who were members of the Palliative Care Committee of the Sociedad Argentina de Pediatría and/or who were part of palliative care teams at institutions and/or the Asociación Argentina de Medicina y Cuidados Paliativos during the study period and who met the selection criteria. Given the nature of the instrument, the plan was to include between 5 and 10 physicians specializing in PPC; however, after 5 meetings, discourse saturation was reached, so no additional individuals were included.

Meetings

Individual meetings with medical experts in PPC were held between July and August 2025. The principal investigators led these meetings. They were designed to allow the experts to voice their concerns about the developed instrument and to generate suggestions for improving the scale and addressing those concerns. The meetings, held via Google Meet, were scheduled at a day and time convenient for each specialist, and at least one principal investigator participated in each.

At each meeting, a member of the research team read the translated scale aloud without providing any conceptual explanations. After reading each item, sufficient time was allowed for each specialist to voice any questions or comments regarding the scale, which were recorded verbatim by the research team member. There was no predefined script, as the aim was to assess the medical specialists' understanding (both semantic and conceptual) of the scale. At the end of the meeting, the expert was provided with the researchers' contact information in case any concerns or questions arose.

All meetings were recorded, and a record was subsequently compiled of each physician's contributions, which was cross-checked against the notes taken by the team member present at the meeting. The research team then held a joint session to conduct coding, build consensus, and synthesize changes for the development of the final scale.[3]

RESULTS

The translation and cultural adaptation were carried out in accordance with the recommendations of expert consensus panels,[8,9] in five consecutive phases.

The original and final scales are shown in *Figures 1* and *2.* Detailed reports on the adjustments made to the scale during the various phases can be found in *Supplementary Materials 1 and 2*.

Phase 1. Obtaining authorization from the authors of the scale

Through direct contact via email, authorization and consent were obtained from the author of the original scale, Dr. Eva Bergstraesser, to conduct the study and publish it in this paper *(Supplementary Material 3*).

Phase 2. Direct translation and reconciliation

Direct translation of the scale from English into Spanish was performed by two unrelated, bilingual translators whose native language is Spanish. Both hold advanced-level English-language certifications issued by a recognized authority. One of them has medical expertise, while the other is a layperson in the field.

After both translations were completed, the research team and the non-medical translator reviewed and discussed any discrepancies (since the medical translator was unable to attend the meeting due to circumstances beyond her control). Where significant differences arose, the necessary adjustments were made to arrive at a single, unified version. Subsequently, the medical translator approved of the changes. In cases of significant discrepancies where no agreement could be reached, Dr. Bergstraesser was contacted to determine the best course of action.

Phase 3. Back-translation

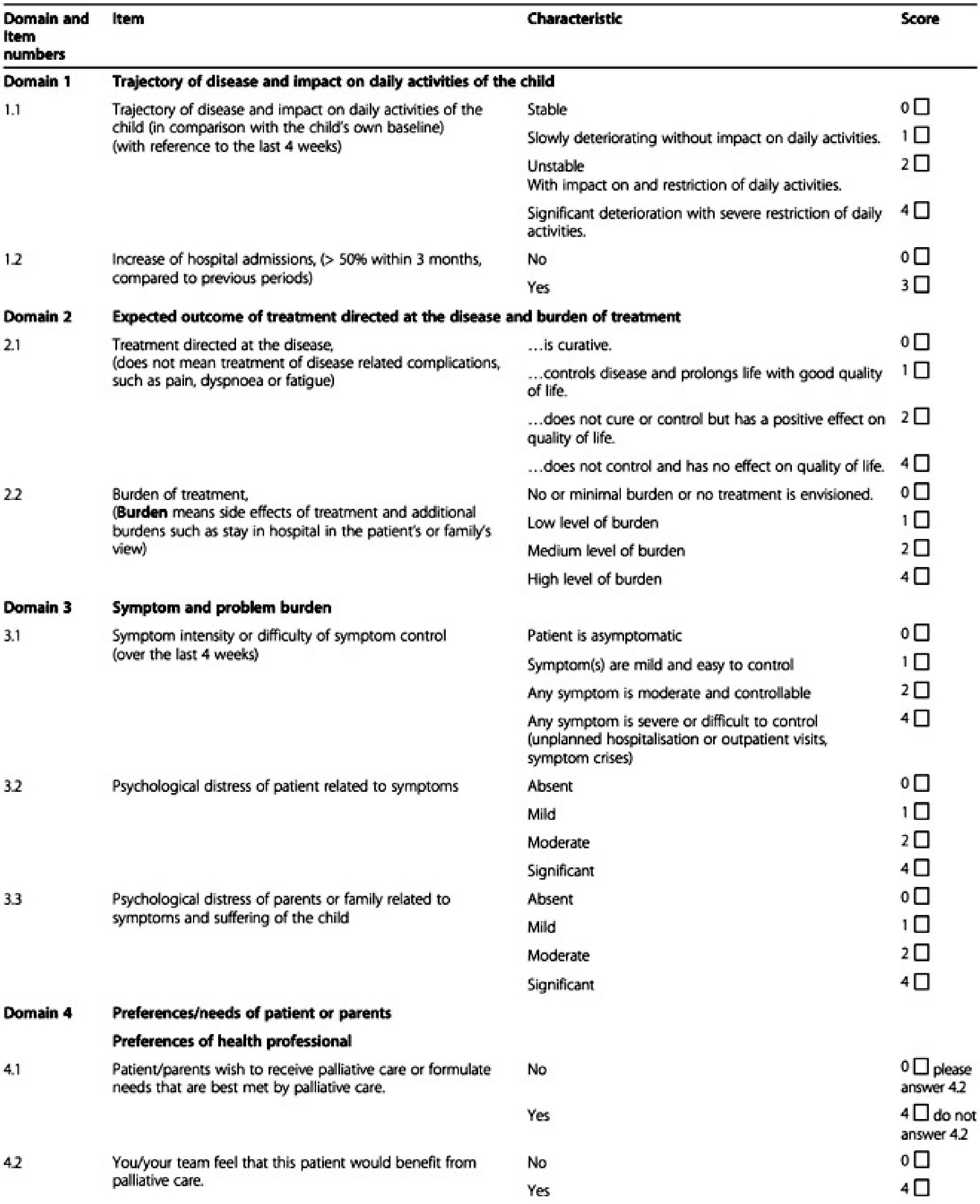
Two unrelated bilingual translators, both native English speakers, performed the back-translation (from the new Spanish-language scale into English). Both hold advanced-level certification in Spanish issued by a recognized authority. Neither has any prior medical training.

Some discrepancies were identified in the literal translation of the new scale. Following these findings, the research team held a meeting and concluded that the discrepancies were secondary to differences in the cultural usage of certain expressions between English and Spanish; therefore, the translated scale was not modified in phase 2.

Phase 4. Finalization by a committee of experts

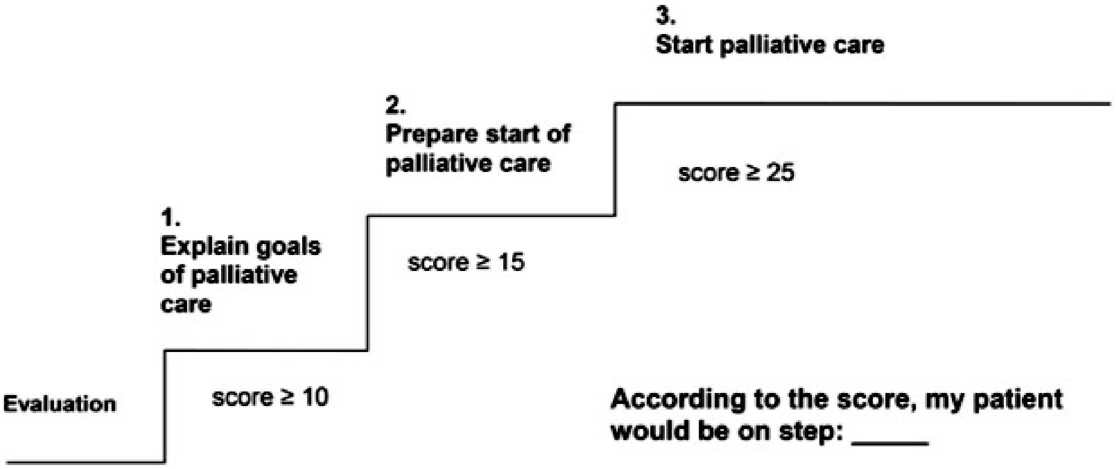
A multidisciplinary committee of experts was formed, comprising an expert in research

FIGURE 1. Pediatric Palliative Screening Scale in its original language*



Domain and Item numbers	Item	Characteristic	Score
Domain 1	**Trajectory of disease and impact on daily activities of the child**		
1.1	Trajectory of disease and impact on daily activities of the child (in comparison with the child's own baseline) (with reference to the last 4 weeks)	Stable	0 ☐
		Slowly deteriorating without impact on daily activities.	1 ☐
		Unstable With impact on and restriction of daily activities.	2 ☐
		Significant deterioration with severe restriction of daily activities.	4 ☐
1.2	Increase of hospital admissions, (> 50% within 3 months, compared to previous periods)	No	0 ☐
		Yes	3 ☐
Domain 2	**Expected outcome of treatment directed at the disease and burden of treatment**		
2.1	Treatment directed at the disease, (does not mean treatment of disease related complications, such as pain, dyspnoea or fatigue)	…is curative.	0 ☐
		…controls disease and prolongs life with good quality of life.	1 ☐
		…does not cure or control but has a positive effect on quality of life.	2 ☐
		…does not control and has no effect on quality of life.	4 ☐
2.2	Burden of treatment, (**Burden** means side effects of treatment and additional burdens such as stay in hospital in the patient's or family's view)	No or minimal burden or no treatment is envisioned.	0 ☐
		Low level of burden	1 ☐
		Medium level of burden	2 ☐
		High level of burden	4 ☐
Domain 3	**Symptom and problem burden**		
3.1	Symptom intensity or difficulty of symptom control (over the last 4 weeks)	Patient is asymptomatic	0 ☐
		Symptom(s) are mild and easy to control	1 ☐
		Any symptom is moderate and controllable	2 ☐
		Any symptom is severe or difficult to control (unplanned hospitalisation or outpatient visits, symptom crises)	4 ☐
3.2	Psychological distress of patient related to symptoms	Absent	0 ☐
		Mild	1 ☐
		Moderate	2 ☐
		Significant	4 ☐
3.3	Psychological distress of parents or family related to symptoms and suffering of the child	Absent	0 ☐
		Mild	1 ☐
		Moderate	2 ☐
		Significant	4 ☐
Domain 4	**Preferences/needs of patient or parents**		
	Preferences of health professional		
4.1	Patient/parents wish to receive palliative care or formulate needs that are best met by palliative care.	No	0 ☐ please answer 4.2
		Yes	4 ☐ do not answer 4.2
4.2	You/your team feel that this patient would benefit from palliative care.	No	0 ☐
		Yes	4 ☐

Domain 5	**Estimated life expectancy**		
5.1	Estimated life expectancy	Several years	0 ☐ please answer 5.2
		Months to 1–2 years	1 ☐ please answer 5.2
		Weeks to months	3 ☐ do not answer 5.2
		Days to weeks	4 ☐ do not answer 5.2
5.2	"Would you be surprised if this child were to suddenly die in 6 months time?"	Yes	0 ☐
		No	2 ☐
		Total score:	



**Published by Eva Bergstraesser et al. in the journal BMC Palliative Care in 2013.*

methodology, a professor of the humanities, and a pediatric intensivist. The research team was present during the meeting in case any major questions arose, but did not actively participate. To this end, the scale was provided to the committee, read aloud, and, after each item, each participant offered a comment on the scale's semantic, methodological, and medical content, based on their respective fields of expertise. Adjustments were made to the instrument developed in phase 2, and a pre-final version was drafted that was understandable and equivalent to the original questionnaire.

Phase 5. Pretest

The pre-final version of the scale was evaluated by five physicians specializing in PPC. They were presented with the instrument and given sufficient time to evaluate it. The research team held a 30-60-minute meeting to assess the scale's theoretical coherence from a palliative care perspective. Using data from all the meetings, the research team met and finalized the Spanish translation of the scale.

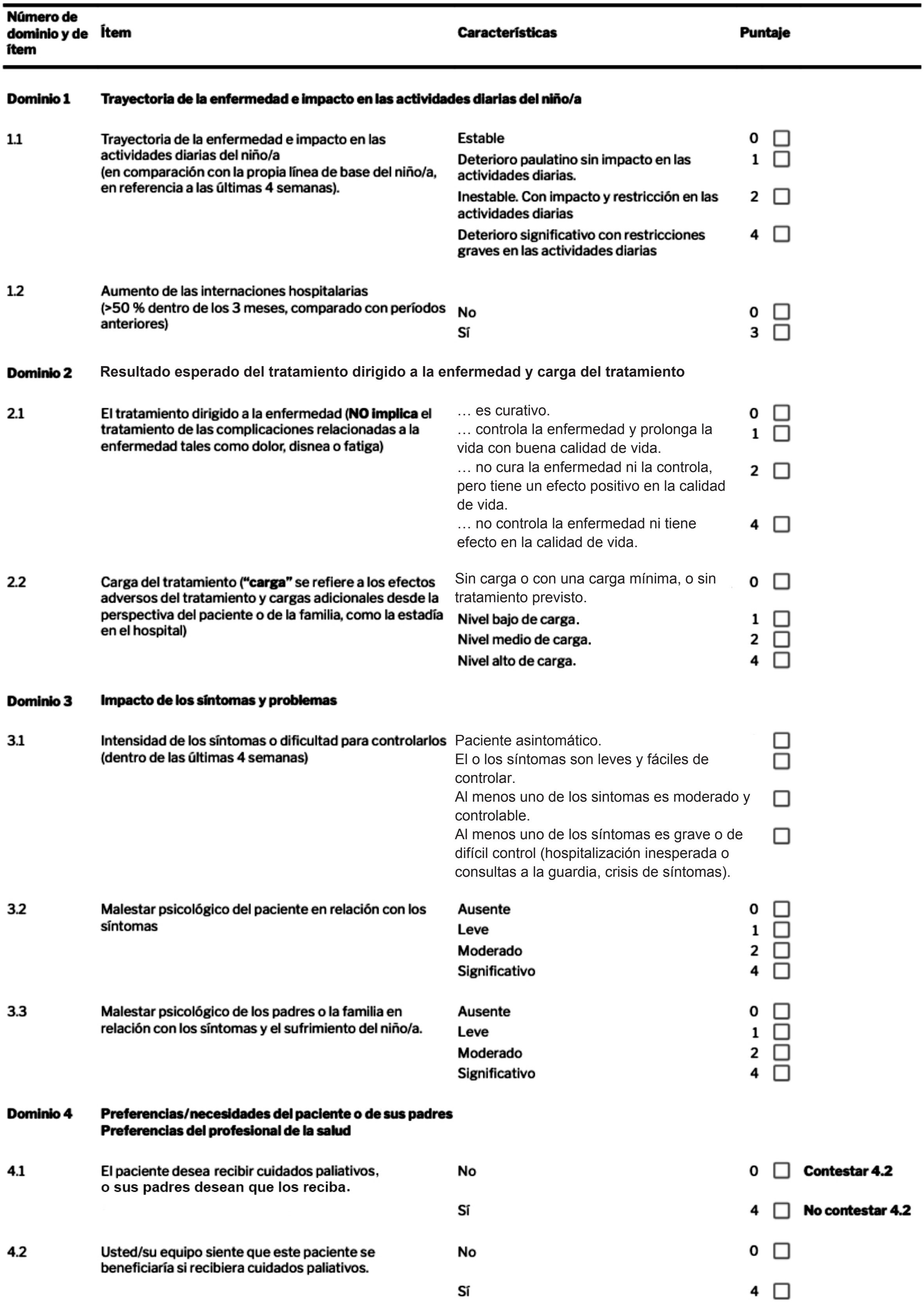
Despite cultural differences, every effort was made to ensure that the translated scale remained as semantically and conceptually equivalent to the original as possible. Changes were made to the phased approach in accordance with current guidelines for the palliative care of patients with life-threatening or life-limiting illnesses.[10-14]

DISCUSSION

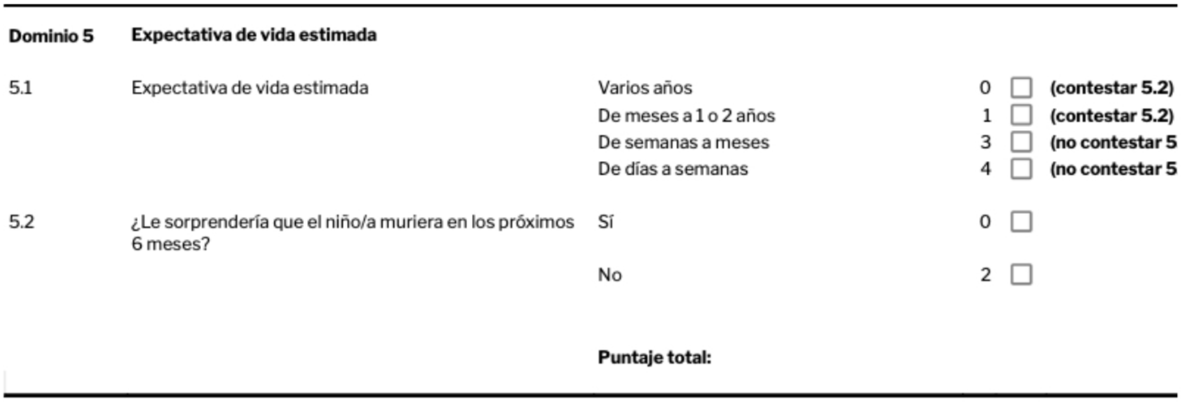
In Argentina, there is a clear theoretical gap regarding the scope and objectives of PPC services. This leads doctors (both those in training and those currently practicing) to underestimate or even overlook the importance of incorporating this level of care into the treatment of patients with life-threatening or life-limiting illnesses.[1] For this reason, we consider it an urgent necessity to obtain tools that assist the healthcare team when deciding to refer these patients to palliative care services, a need that is further heightened by the enactment of Law 27678 on Palliative Care, which aims to ensure patients' access to palliative care services.[15]

In pediatrics, there is currently no validated

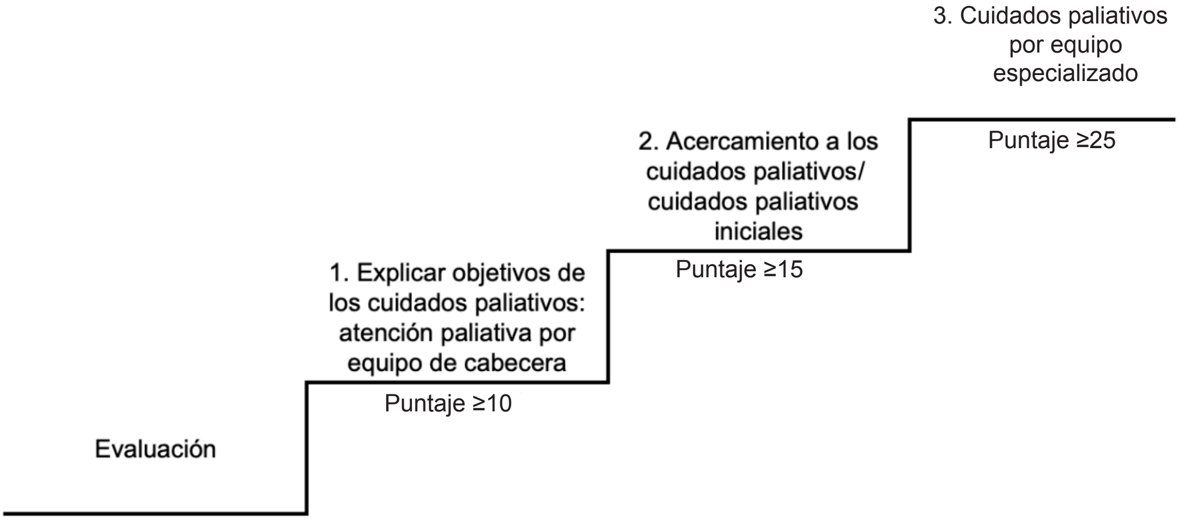
Figure 2. Final version of the Paedriatic Palliative Screening Scale in Spanish



Número de dominio y de ítem	**Ítem**	**Características**	**Puntaje**
Dominio 1	**Trayectoria de la enfermedad e impacto en las actividades diarias del niño/a**		
1.1	Trayectoria de la enfermedad e impacto en las actividades diarias del niño/a (en comparación con la propia línea de base del niño/a, en referencia a las últimas 4 semanas).	Estable	0 ☐
		Deterioro paulatino sin impacto en las actividades diarias.	1 ☐
		Inestable. Con impacto y restricción en las actividades diarias	2 ☐
		Deterioro significativo con restricciones graves en las actividades diarias	4 ☐
1.2	Aumento de las internaciones hospitalarias (>50 % dentro de los 3 meses, comparado con períodos anteriores)	No	0 ☐
		Sí	3 ☐
Dominio 2	**Resultado esperado del tratamiento dirigido a la enfermedad y carga del tratamiento**		
2.1	El tratamiento dirigido a la enfermedad (**NO implica** el tratamiento de las complicaciones relacionadas a la enfermedad tales como dolor, disnea o fatiga)	… es curativo.	0 ☐
		… controla la enfermedad y prolonga la vida con buena calidad de vida.	1 ☐
		… no cura la enfermedad ni la controla, pero tiene un efecto positivo en la calidad de vida.	2 ☐
		… no controla la enfermedad ni tiene efecto en la calidad de vida.	4 ☐
2.2	Carga del tratamiento (**"carga"** se refiere a los efectos adversos del tratamiento y cargas adicionales desde la perspectiva del paciente o de la familia, como la estadía en el hospital)	Sin carga o con una carga mínima, o sin tratamiento previsto.	0 ☐
		Nivel bajo de carga.	1 ☐
		Nivel medio de carga.	2 ☐
		Nivel alto de carga.	4 ☐
Dominio 3	**Impacto de los síntomas y problemas**		
3.1	Intensidad de los síntomas o dificultad para controlarlos (dentro de las últimas 4 semanas)	Paciente asintomático.	☐
		El o los síntomas son leves y fáciles de controlar.	☐
		Al menos uno de los sintomas es moderado y controlable.	☐
		Al menos uno de los síntomas es grave o de difícil control (hospitalización inesperada o consultas a la guardia, crisis de síntomas).	☐
3.2	Malestar psicológico del paciente en relación con los síntomas	Ausente	0 ☐
		Leve	1 ☐
		Moderado	2 ☐
		Significativo	4 ☐
3.3	Malestar psicológico de los padres o la familia en relación con los síntomas y el sufrimiento del niño/a.	Ausente	0 ☐
		Leve	1 ☐
		Moderado	2 ☐
		Significativo	4 ☐
Dominio 4	**Preferencias/necesidades del paciente o de sus padres** **Preferencias del profesional de la salud**		
4.1	El paciente desea recibir cuidados paliativos, o sus padres desean que los reciba.	No	0 ☐ **Contestar 4.2**
		Sí	4 ☐ **No contestar 4.2**
4.2	Usted/su equipo siente que este paciente se beneficiaría si recibiera cuidados paliativos.	No	0 ☐
		Sí	4 ☐



Dominio 5	**Expectativa de vida estimada**				
5.1	Expectativa de vida estimada	Varios años	0	☐	**(contestar 5.2)**
		De meses a 1 o 2 años	1	☐	**(contestar 5.2)**
		De semanas a meses	3	☐	**(no contestar 5**
		De días a semanas	4	☐	**(no contestar 5**
5.2	¿Le sorprendería que el niño/a muriera en los próximos 6 meses?	Sí	0	☐	
		No	2	☐	
		Puntaje total:			



De acuerdo al puntaje, mi paciente estaría en el estadio:

Spanish-language scale to assess the need for early referral of patients to palliative care specialists. The Paediatric Palliative Screening Scale (PaPaS Scale) is a qualitative tool developed by an international group to facilitate timely referrals to palliative care throughout the course of illness in critically ill children. This scale is one of the most widely used in English-speaking countries and has the necessary resources to provide high-quality palliative care.[4,16]

The objective of this study was to adapt the instrument into Spanish culturally. To this end, the authors sought to introduce a tool currently unavailable in pediatric healthcare. However, since the instrument was not validated using quantitative methods nor administered to the target population (practicing and trainee pediatricians), its use is not recommended until these steps have been completed. Furthermore, pediatricians (both practicing and in training) were not included in this study because the focus was on cultural adaptation (while maintaining the semantic and conceptual structure of the original scale as much as possible); however, the authors plan to conduct a second-phase study in which the scale will be administered to the target users, with the final validation of the adapted scale.

To keep the scale as conceptually and semantically faithful as possible to its original version, only the minimum changes necessary were made to maximize comprehensibility without altering its nature. It was determined that the stages in the final phased approach were oriented toward a PPC reality that no longer aligns with current practice; therefore, changes were made to adapt the scale's applicability to new trends and developments in this medical specialty.[10-14] Despite this, no major changes were made between the direct translation of the scale and the final version evaluated by the expert committee and medical specialists, as there were no cultural, semantic, or conceptual barriers during the development of the final scale.

As limitations of the study, the authors acknowledge that during phase 2, it was not possible to schedule a meeting with both translators; they attempted to address this by meeting with the available translator and subsequently obtaining the absent translator's approval of the changes. They also note the lack of quantitative assessment of the scale's internal consistency and psychometric validation of the developed scale; therefore, the authors plan to conduct this analysis in a subsequent study.

Among the study's strengths, the authors highlight the importance of translating a questionnaire that did not previously exist in Spanish and of adhering to ISPRO standards in conducting the procedure.

CONCLUSION

A culturally adapted Spanish-language scale was developed that could serve as a useful tool for the early integration of PPC into pediatric care, pending appropriate validation. ■

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The supplementary material provided with this article is presented as submitted by the authors. It is available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2026/10927_AO_Vera_Garcia_Anexo.pdf

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