ACTA MÉDICA PORTUGUESA
A Revista Científica da Ordem dos Médicos

Validation of the European Portuguese Version of a Pediatric Palliative Needs Assessment Tool: The Pediatric Palliative Screening Scale

Validação da Versão Portuguesa de um Instrumento de Avaliação de Necessidades Paliativas Pediátricas: A Pediatric Palliative Screening Scale

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Acta Med Port 2023 May;36(5):326-335 ▪ https://doi.org/10.20344/amp.18071

ABSTRACT

Introduction: The Pediatric Palliative Screening Scale (PaPaS Scale) was designed to help professionals to identify life-limiting or life-threatening children/young people with complex chronic conditions who would benefit from pediatric palliative care and facilitate their timely and appropriate referral. The aim of this study was to translate, culturally adapt and validate the PaPaS Scale for the Portuguese pediatric population.

Material and Methods: A quantitative methodological study involving translation, cultural adaptation and validation of a scale was performed. In the first phase, the translation and cultural adaptation of the original version of the PaPaS Scale from English to European Portuguese was undertaken. The second phase consisted of evaluating the psychometric properties of the Portuguese version of the PaPaS Scale.

Results: Fifty-one enquires pertaining to children/young adults with complex chronic conditions were completed and returned, the sum of the responses to the items on the scale revealed that 84.4% of the patients had an indication for referral to pediatric palliative care. The internal consistency analysis obtained a value of Cronbach's alpha above 0.80, so the scale was considered adequate for the analyzed data. In our sample, the item-total correlation values indicated that the 11 variables measured the PaPaS Scale with good reliability and unidimensionally. The confirmatory factor analysis suggested that the items were significant, consistent, and presented convergent validity globally. Only item "2.2. Treatment side effects" obtained a value below the defined threshold.

Conclusion: The PaPaS Scale was translated and adapted to the European Portuguese version, allowing its immediate use in the Portuguese population. It will be essential to design multicentric studies to expand the knowledge about the psychometric characteristics of this scale.

Keywords: Child; Chronic Disease; Needs Assessment; Palliative Care; Pediatrics; Portugal

RESUMO

Introdução: A *Pediatric Palliative Screening Scale* (PaPaS *Scale*) foi desenhada para ajudar os profissionais a identificar as crianças/jovens com doença crónica complexa, limitante ou ameaçadora da vida que beneficiariam de cuidados paliativos pediátricos e facilitar referenciação atempada e apropriada. O objetivo deste estudo foi traduzir, adaptar culturalmente e validar a *PaPaS Scale* para a população pediátrica portuguesa.

Material e Métodos: Realizou-se um estudo metodológico quantitativo de tradução, adaptação cultural e validação de uma escala. Numa primeira fase, procedeu-se à tradução e adaptação cultural da versão original da PaPaS *Scale* de inglês para português europeu. A segunda fase consistiu na avaliação das propriedades psicométricas da versão portuguesa da Escala PaPaS.

Resultados: Numa amostra de 51 questionários referentes a crianças/jovens com doença crónica complexa, a soma das respostas aos itens da escala revelou que 84,4% dos doentes tinham indicação para ser referenciados aos cuidados paliativos pediátricos. Na análise de consistência interna obteve-se um valor do alfa de Cronbach superior a 0,80, pelo pelo que se considera a escala adequada aos dados analisados. De facto, os valores de correlação item-total indicaram que as 11 variáveis mediram com boa fiabilidade e de forma unidimensional a escala PaPaS. Na análise fatorial confirmatória, os resultados obtidos indicaram que globalmente os itens eram significativos, consistentes e apresentaram validade convergente. Apenas o item "2.2. Efeitos secundários do tratamento" obteve um valor abaixo do limiar definido.

Conclusão: A *PaPaS Scale* foi traduzida e adaptada para a versão em português europeu, o que permite a sua utilização imediata na população portuguesa. Torna-se importante o desenho de estudos, preferencialmente multicêntricos, que aprofundem as características psicométricas desta escala.

Palavras-chave: Avaliação de Necessidades; Criança; Cuidados Paliativos; Doença Crónica; Pediatria; Portugal

INTRODUCTION

Palliative care for children [paediatric palliative care PPC)] is a basic human right[1-5], particularly for those affected by life-limiting or life-threatening complex chronic diseases (CCDs).

According to the International Children's Palliative Care Network (ICPCN)[1], Portugal was officially a country with no PPC provision in early 2013 (level 1); in March 2013, the country has risen to level 2 (evidence of growing capacity in PPC provision) and in October 2018 to level 4[1,6] (evidence of available professional training in PPC provision, with plans focused on the development of departments and integration into healthcare services).

The Portuguese paediatric population requiring palliative care was estimated at 7,828 patients in 2018.[7] Nationwide, a reduction of 500 patients with CCDs was found between 2013 and 2018, even though showing regional asymmetries. The highest increase (64 patients) was found in Lisbon and the highest decrease (123 patients) in Porto.[7]

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Recebido/*Received*: 07/02/2022 - **Aceite/*Accepted*:** 20/09/2022 - **Publicado *Online*/*Published Online*:** 09/01/2023 - **Publicado/*Published*:** 02/05/2023

Approximately 200 patients (50% within the first year of life) die from CCDs and require PPC each year. Most have died in hospitals.[8]

The PPC approach is aimed at reducing excessive interventions and therapies in advanced CCDs, improving quality of life through effective symptom control and reducing the emotional burden on both the patients and their parents and family.[9] PPC should be integrated into healthcare provision (in a link between hospital, primary and community care) at three levels: universal, generalist and specialised.[5] PPC is currently characterised by high medical intervention, centralisation in specialised hospitals, lack of organisation and coordination of care provision and suboptimal home and psychosocial support.[4]

Worldwide access to PPC is still limited.[4] Despite the World Health Organization's recommendations, the introduction of PPC and timely referral to specialised teams still comes late in the trajectory of CCDs.[9,10] The current definitions of PPC are unclear as to when these should be integrated and, furthermore, there is variable knowledge among healthcare professionals regarding the specific skills for PPC provision.[9] There are different factors that contribute to late referral: the benefit of PPC being overlooked at the beginning of the illness, especially if the likelihood of cure or disease control is overestimated; the possible negative interpretation of 'palliative care' by the family; the pressure exerted by families towards worthless therapies that could keep giving hope.[9]

There are different scales for referral to palliative care, mostly designed for adult patients.[9] These are tools focused on assessing prognosis and estimating life expectancy, especially regarding end-of-life decisions.[9] A paediatric assessment tool should be focused on the palliative requirements of patients in the early stages of diseases, in line with what happens with adult patients.[9]

A screening tool [the Paediatric Palliative Screening (PaPas) Scale] was developed in 2013 and was aimed at patients in need for PPC by Bergsträsser *et al.*, designed for the identification of patients who would benefit from PPC and allowing for timely and appropriate referral.[9] Different revisions and modifications were made during the conceptualisation of this scale. Currently, the assessed domains[9,10] are as follows:

1) Trajectory of the disease and impact on the patient's activities of daily living;

2) Estimated outcomes and side effects of treatment;

3) Symptom control;

4) Preferences/requirements of patients, family, and healthcare professionals;

5) Estimated life expectancy.[9]

Each domain was divided into two to five items, with 11 items in total. Each item included several options scored from 0 to 4. High individual or total scores would suggest a greater need for PPC. In clinical terms, referral to PPC would be gradual, aimed at integrating a three-stage palliative care model (Fig. 1):

- Stage 1: Score ≥ 10 points - Introduction to PPC – The concept of PPC;
- Stage 2: PPC - Score ≥ 15 points – Preparation for PPC - Basic symptom control associated with treatment of the underlying disease;
- Stage 3: PPC - Score ≥ 25 points – Staring PPC - PPC is the focus of the care plan.

A heterogeneous instrument has been developed, aimed at the assessment of palliative needs of patients presenting with CCDs, aged 1-19. Newborns and infants were

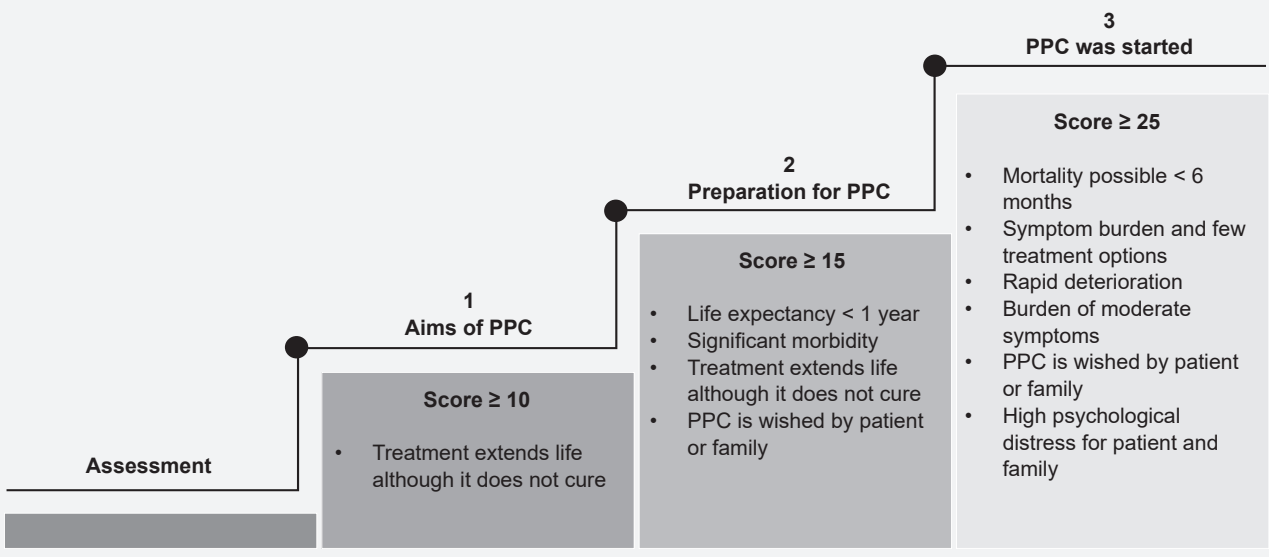

Figure 1 – Approach to PPC, based on the score of PaPaS scale

excluded from the study as the disease trajectories can be very short, and two thirds of the patients usually die within the first few weeks of life in an intensive care setting.[9,11,12]

The PaPaS scale has been currently validated as the paediatric scale for the identification of patients presenting with CCDs requiring palliative care and allowing for an early referral and guidance to specialist PPC teams. The classification and stratification of patient groups leads to an integrated and comprehensive approach to PPC. The PaPaS scale is based on the taxonomy created by Together for Short Lives Association,[13] so it is not restricted to end-of-life care. It is an educational tool that can support non-specialist teams to provide better care to patients with CCDs.[9,10]

A modification of this scale has been recently proposed and the importance of its use in assessing and maintaining continuity of care in patients already referred to PPC teams has been emphasised.[14]

This study was aimed at translating, adapting, and validating the scale for the Portuguese paediatric population.

MATERIAL AND METHODS

Study design

This was a quantitative methodological study aimed at the translation, cultural adaptation, and validity of the scale. The original version of the PaPaS scale was translated and culturally adapted from English into European Portuguese within a first stage, while the assessment of the psychometric properties of the Portuguese version of the PaPaS scale was carried out at a second stage.

Stage 1: translation and cultural adaptation

This was carried out upon contact by email with the author of the scale, Eva Bergsträsser, and upon obtaining her consent. The approval of the Head of the Paediatrics Department and the Ethics Committee of the *Centro Hospitalar Universitário Lisboa Norte* and *Centro Académico Médico de Lisboa* was also obtained.

The methodology presented in the Guidelines for the Process of Cross-Cultural Adaptation of Self-Report Measures was followed by the research[15] and the adaptation of the original (English language) version of the PaPaS scale into the European Portuguese language and culture was carried out in accordance with the defined stages.[15]

The translation was carried out by two independent native Portuguese translators who were proficient in the original language of the document. The first translator was aware of the assessment while the second was unaware of the translation objectives.

Translated versions were obtained and compared with the original instrument. Their format was analysed and assessed in relation to semantic, idiomatic, conceptual, linguistic, contextual and cultural equivalences and discrepancies, aimed at obtaining a single final version.[16,17] The translations were submitted to a consensus meeting attended by doctors and nurses, where a synthesis of the translations was carried out, leading to a document with the unified version of the PaPaS scale for the Portuguese paediatric population, consistent with the original version.

Reverse translation was carried out independently by two different translators with native English proficiency and a high level of oral and written fluency in Portuguese, unaware of the original English version. Both independent reverse translations were compared with the original (English version) and a final version adapted to the Portuguese reality was defined in a consensus meeting with both translators.

The committee of experts (responsible for content validity) included healthcare professionals (a doctor and a nurse), a Portuguese teacher, the translators, and the researcher. All previous documents and the original instrument were analysed until a consensus was reached. A preliminary version of the scale was developed, which was culturally adapted and suitable for pre-testing. This stage was crucial for the identification of any inadequate expressions and concepts in the translation.

A pilot study was carried out with a small group of patients (10%), replicating the characteristics of the target sample/population, aimed at the identification and correction of any issues in the European Portuguese version of this instrument. The participants were informed about the purpose of the pre-test and received a questionnaire whose structure could not be modified. The content, clarity, and comprehension of the different items of the scale were assessed. Cultural, semantic, and conceptual aspects were reviewed[17,18] and there were no constraints regarding its readability. No issues were found in understanding and applying the questionnaire, so it became the final version in European Portuguese, with no need for any reformulation.

There were different contacts with the author, leading to the approval of the final document (Appendix 1: https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/18071/15018) for the Portuguese version of the PaPaS scale.

All the steps of the procedures, according to the adaptation by Beaton *et al.* are shown in Fig. 2.[15]

Stage 2: psychometric properties of the scale (scale validity)

The final version of the questionnaire was applied with a descriptive introduction of the study's objective. Ethical principles were complied with, confidentiality was ensured, everyone participated intentionally and there were no costs or losses.

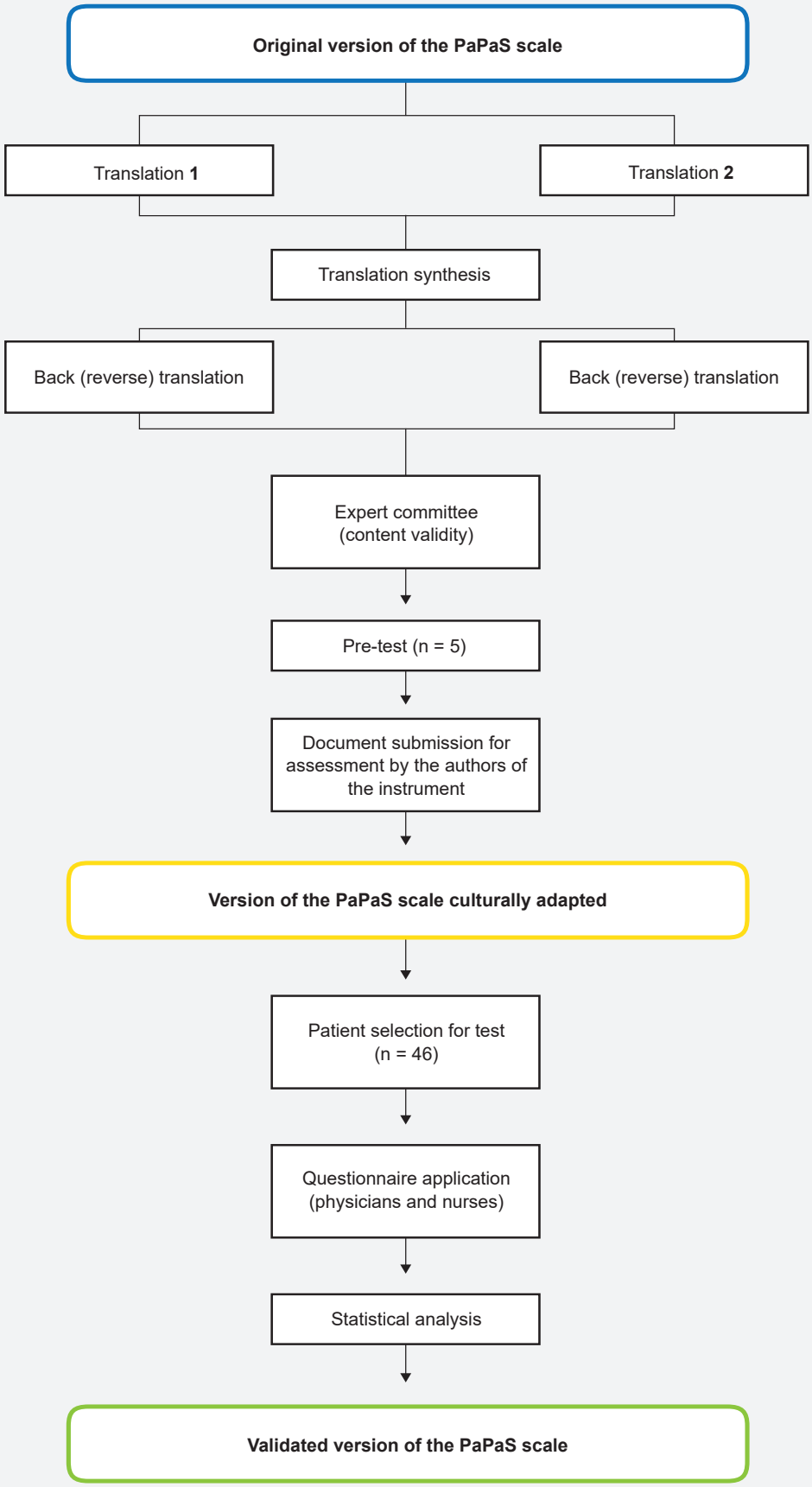

Figure 2 – Procedures: translation, cultural adaptation and validity of the PaPaS scale

Participants and readability criteria

Data collection was carried out from October to November 2019. The study took place in a public hospital with administrative, financial, and patrimonial autonomy.

A non-probabilistic convenience sample including 17 paediatricians and three nurses was used, involving the completion of 51 questionnaires related to patients presenting with CCDs. All the professionals were involved in direct care and had specific expertise in paediatric CCD, and European Portuguese was their native language. The professionals completed between one and nine questionnaires, depending on the patients they looked after.

Statistical methods

Data were processed and statistically analysed using the Statistical Package for the Social Sciences (SPSS IBM®, version 24). The demographic and clinical characterisation of the group of patients were based on different descriptive statistics as appropriate[19-21]: frequency (n), ratio (%), mean, median, standard deviation (SD), minimum (min) and maximum (max) values.

The internal consistency analysis[22-27] was checked using the Cronbach's alpha coefficient[28] and the corrected item-total correlation. In this study, Cronbach's alpha values > 0.80 were considered as adequate, while those between 0.60-0.80 were considered as acceptable.[25,26,29]

The validity of the measurement scale was checked by confirmatory factor analysis.[30-37] Validity analysis included checking the statistical significance of the items ($p < 0.05$),[38-47] measuring high factor saturations (> 0.5), high internal consistency and composite reliability (> 0.8),[39] and a high extraction ratio of variance (> 0.5).[40] The assessment of the measurement scale using fit indices was also carried out,[38,42,43] including absolute index (χ^2) (< 5), discrepancy index (RMSEA, root mean square error of approximation) (< 0.08), relative index (NFI, normed fit index) (> 0.8) and comparative index (CFI, comparative fit index) (> 0.8).

RESULTS

Descriptive statistics and scale results

The PaPaS scale was applied to 51 patients presenting with CCDs (Table 1) [mean age 11.2 (median of 10), 53% female]. More than half of the underlying diagnoses corresponded to neurological and metabolic conditions, that were defined within the first year of life. As regards the different categories of palliative care needs, 31.4 per cent of the patients presented with pathologies included in group IV (irreversible, non-progressive condition with high morbidity and likelihood of premature death), 29.4 per cent in group II (conditions underlying premature death, but with long survival when treated) and 19.6 per cent in group I (potentially fatal but curable conditions) and group III (progressive conditions, but with no possible cure) respectively (Table 1).

The results of the descriptive analysis of responses within the PaPaS scale domains are shown in Table 2.

A mean total score of 17.5 was obtained with the PaPaS scale, with a standard deviation of 7.4, ranging from a minimum value of 6 to a maximum value of 37. The score of each questionnaire was recoded into levels of palliative care provision (Table 3).

Internal consistency analysis

A Cronbach's alpha value of 0.809 was obtained. All items had a positive item-total correlation value (Table 4), suggesting that the questionnaire is a unidimensional tool. Additional tests showed that items 2.2. and 3.2. prevented the alpha value from being higher, and only item 2.2. showed a low, albeit positive, correlation (Table 4).

Confirmatory factor analysis

A first analysis showed that all the saturations of the variables (items) measured in each dimension were statistically significant ($p < 0.05$) with a value above or close to 0.5, except regarding item 2.2. However, a 0.565 average factor saturation has been found (above the established threshold). The composite reliability was 0.995 (well above the threshold), and only the value for the ratio of extracted variance was slightly below the target, with a value of 0.369.

As regards the fit indices, the χ^2 showed a good overall fit with a value of 2.482. The other indices, even though out of the desired range, were close to the desirable threshold, with RMSEA at 0.175, NFI at 0.588 and CFI at 0.673.

DISCUSSION

This study was aimed at describing the translation, cultural adaptation, and validity of the European Portuguese version of the Paediatric Palliative Screening Scale. This is an instrument aimed at healthcare professionals looking after patients presenting with CCDs and at the assessment of their palliative needs. Few studies have been aimed at the application of the PaPaS scale.[10,14,48-50] It is more widely used in English-speaking countries with a high level of provision of PPC.

The study was carried out in a hospital providing specialised care to patients presenting with CCDs. The number of professionals involved was lower than the number of tests applied because the care activity is referred, concentrated, and limited to specific professionals.

Our small group of patients showed age diversity, in line with the usual characteristics of the population of patients with palliative needs and with long clinical trajectories and uncertain prognosis.[4,5]

More than 70% of the patients presented with neurological, metabolic and genetic conditions, reflecting the

Table 1 – Descriptive analysis of our group of patients (n = 51)

Age, mean (SD); median [min, max]	11.2 (5.1); 10 [1.0. 18.0]
Gender, n (%)	
Male	24 (47.1)
Female	27 (52.9)
Age at diagnosis (years)[a], n (%)	
0 – 1	26 (52.0)
1 – 5	17 (34.0)
6 – 10	6 (12.0)
11 – 15	1 (2.0)
Diagnosis, n (%)	
Neurology	19 (37.3)
Metabolic medicine	10 (19.6)
Clinical genetics	7 (13.7)
Respiratory medicine	6 (11.8)
Haematology	4 (7.8)
Renal medicine	3 (5.9)
Gastroenterology	1 (2.0)
Medical oncology	1 (2.0)
Palliative needs	
Group I – Life-threatening diseases for which curative treatment may be feasible	10 (19.6)
Group II – Diseases associated with premature mortality, with potential long survival when treated	15 (29.4)
Group III – Progressive conditions, with no curative treatment options	10 (19.6)
Group IV – Irreversible but non-progressive diseases, associated with increased morbidity and premature mortality	16 (31.4)

[a]: one missing value

significant weight and impact of these chronic diseases in this group of patients and in PPC in general, in line with the most frequent groups of diagnoses described in literature.[13,48] This heterogeneity is also relevant for the defined objectives, although patients presenting with cancer, representing around 20% to 30% of paediatric patients with palliative needs, were not included.[14] The follow-up of paediatric cancer in Portugal is made by specific hospitals with paediatric oncology departments. However, this does not detract this study, as the scale was developed for global CCDs. The author of the scale did not consider this factor to be an impediment to the progress of the research.

The first year of life was the most frequent age at diagnosis (around half of the patients), showing that mostly congenital disorders have been found, with clinical manifestations within this period of life, associated with complex symptoms that are usually difficult to manage and requiring a precise diagnostic approach.

As regards the categories of pathologies with palliative needs, the distribution was also heterogeneous, with categories II (29.4%) and IV (31.4%) as the most frequently found. These categories of pathologies with palliative needs are those with the longest survival times and the highest prevalence: in group II, death can occur between the second and third decade of life and in group IV, death usually occurs in the second decade of life. In groups I and III, earlier mortality is usually found,[4,13,48] the reason why the prevalence was lower, as described in literature.

The descriptive statistical analysis of the responses to the PaPaS scale showed that there had been no significant need for hospitalisation within the past three months. Patients' conditions were not cured or controlled with treatment in around two thirds of the patients. The influence of the treatment's side effects on the patients and their families was mostly mild to moderate, representing a potential bias in the healthcare professional's judgement and devaluation of the impact of treatment. Suboptimal symptomatic control was found in 43.1% of the patients. The psychological impact on the patients was low, since most of the patients presented with neurometabolic disorders leading to cognitive impairment and constraints in assessing the psychological effects. These were very significant for the parents and

Table 2 – PaPaS scale domains (n = 51)

Domain 1. Trajectory of disease and impact on daily activities of patients	
1.1. Trajectory of disease and impact on daily activities of patients (comparison with the patients' age group within the previous four weeks), n (%)	
Stable	15 (29.4)
Slow deterioration with no impact on daily activities	8 (15.7)
Unstable and with impact on daily activities and restriction	14 (27.5)
Significant deterioration with severe restriction in activities	14 (27.5)
1.2. Increased number of hospital admissions (> 50% within 3 months, compared to previous periods), n (%)	
No	40 (78.4)
Yes	11 (21.6)
Domain 2. Expected outcome of treatment and associated side effects	
2.1. Treatment directed at the disease (not related to the treatment of complications, including pain, dyspnoea, or fatigue, for instance), n (%)	
Curative	3 (5.9)
Controlled disease and extends life with good QOL	13 (25.5)
No cure or disease control, even though with a positive effect on QOL	24 (47.1)
Uncontrolled condition and no effect on QOL	11 (21.6)
2.2. Side effects of treatment (impact on patients and families, including hospital admission, on the perspective of the patients or families), n (%)	
None of mild	12 (23.5)
Mild	15 (29.4)
Moderate	19 (37.3)
Severe	5 (9.8)
Domain 3. Sign/symptom and problem burden	
3.1. Intensity of signs/symptoms and/or issues in controlling these (within the previous 4 weeks), n (%)	
Asymptomatic	3 (5.9)
Mild and easily controlled sign(s)/symptom(s)	9 (17.6)
Any sign/symptom is moderate and manageable	17 (33.3)
Any sign/symptom is severe and difficult to manage	22 (43.1)
3.2. Intensity of signs/symptoms and/or difficult control of these (within the past 4 weeks), n (%)	
Absent	20 (39.2)
Mild	17 (33.3)
Moderate	8 (15.7)
Significant (severe)	6 (11.8)
3.3. Psychological disorders (stress) of parents or families, related to the signs/symptoms and patient's distress	
Absent	2 (3.9)
Mild	11 (21.6)
Moderate	16 (31.4)
Significant (severe)	22 (43.1)
Domain 4. Preference/needs of patients or parents Preference of healthcare professionals	
4.1. The patient/parents wish to get palliative care or describe needs that are like palliative care, n (%)	
No	14 (27.5)
Yes	37 (72.5)
4.2. The professional or the team feel that this patient would benefit from palliative care, n (%)[a]	
No	4 (28.6)
YEs	10 (71.4)
Domain 5. Estimated life expectancy	
5.1. Estimated life expectancy, n (%)	
Several years	35 (68.6)
Months to 1 - 2 years	12 (23.5)
Weeks to months	2 (3.9)
Days to weeks	2 (3.9)
5.2. "Would you be surprised if this patient would suddenly die within the next six months?", n (%)	
Yes	24 (47.1)
No	27 (52.9)

[a]: n = 14. QOL: quality of life

Table 3 – Results and distribution by level of care (n = 51)

PaPaS scale, mean (SD) - median [min, max]	17.5 (7.4) - 16 [6.0. 37.0]
Level of care, n (%)	
Assessment (≤ 10)	8 (15.7)
Aims of palliative care (> 10 and ≤ 15)	13 (25.5)
Preparation for palliative care (> 15 and ≤ 25)	20 (39.2)
Starting palliative care (> 25)	10 (19.2)

caused great suffering. Ninety-two per cent of the responses showed the benefit of integrating these patients into the PPC typology. As regards life expectancy, around two thirds of the responses estimated a survival of several years. An unexpected death based on the 'surprise question' ("Would you be surprised if this patient suddenly died within the next 6 months?") was described by half of the respondents. This has shown and reinforced that a long survival is expected for these patients presenting with CCD and that an early and timely referral and integration into PPC is crucial.

The total score obtained with the PaPaS scale allowed for the definition of the level of care to be implemented for each patient. In this population, 84.4% of the patients had an indication for referral to a PPC team, and around 60% needed structured, integrated follow-up by a differentiated PPC team. These results reinforced the urgent need to create paediatric palliative care teams in all Portuguese paediatric departments.

The PaPaS scale is an 11-item ordinal scale including five domains. A Cronbach's alpha value of 0.809 was obtained in the internal consistency analysis (above the threshold), and all the items showed positive item-total correlation values; therefore, the questionnaire can be considered as adequate and unidimensional (the 11 variables acceptably measured a single dimension: the PaPaS scale). Additional tests suggested that greater internal consistency could be reached by removing item 2.2., due to its low item-total correlation. This item attempted to assess the 'side effects of treatment'. Its removal could make the questionnaire more consistent in the Portuguese context. However, other criteria had to be considered, including the relevance of the item and the consistency of the scale with the original version. In addition, the removal of item 2.2. would lead to the loss of information, which is not compensated for any other item.

Table 4 – Item-total correlation and effect of removal of each item: PaPaS scale

Item	Corrected item-total correlation	Cronbach's alpha without the item
1.1.	0.723	0.763
1.2.	0.458	0.795
2.1.	0.389	0.801
2.2.	0.063	0.828
3.1.	0.797	0.758
3.2.	0.292	0.811
3.3.	0.500	0.791
4.1.	0.414	0.806
4.2.	0.351	0.804
5.1.	0.648	0.782
5.2.	0.677	0.779

Factor saturation, composite reliability and the extraction ratio of variance were also obtained, consistent with a scale measuring convergent validity. As regards the fit indices, the χ^2 clearly showed a good overall fit and, even though the remaining indices were not within the desired range, the results allowed for the quality of the fit.

All the results obtained allowed the conclusion that, overall, the items are significant, consistent, with convergent validity and showed that the model had good overall fit.

Limitations

The lack of validity of item 2.2 – "Side effects of treatment (including impact on family and patients, e.g., hospitalisations from the perspective of the patients or family)" was the main limitation of the assessment of this scale. We have reached the conclusion that it could not have been sufficiently clear and explicit, raising doubts regarding the response, upon contacting the professionals responsible for filling in the questionnaire. Shong[14] has proposed changing this item to: "Direct burden of the disease itself and of the treatment (frequency and empowerment, including side effects, hospitalisations and consequences for the patients)". Other possible factors for the non-validation of this item included the small unicentric size of the sample, the lack of training and perception of professionals in PPC, and the discrepancy between palliative needs from the professional's point of view and the assessment of needs with patients and families.

The authors have already reformulated the item after evaluating it and reaching a consensus with different experts and are proposing to carry out a national multicentric study. This study would be aimed at the definition of the palliative needs of the Portuguese paediatric population and using the scale to assess continuity of care in patients

already referred to PPC teams.[14,49] The application of this scale could also be relevant in other clinical contexts, particularly in primary health care.[50]

CONCLUSION

The PaPaS scale was translated and adapted into European Portuguese. The internal consistency analysis of the results supported the conclusion that it is suitable for the data analysed. The item-total correlation values showed that the 11 variables measured the PaPaS scale with good reliability and in a unidimensional way. All the results obtained from this Portuguese version showed that the items were globally significant, consistent, with convergent validity and with good overall fit. In short, the use of the PaPas scale in the Portuguese context has been supported by this study.

This was a pioneer study in the assessment of PPC needs in Portugal and its disclosure will help ensuring that Portuguese patients presenting with CCD and palliative needs will be referred earlier to PPC.

ACKNOWLEDGMENTS

To the members of the research team: Inês Viegas, João Sollari Lopes and Paulo Pereira.

PREVIOUS AWARDS AND PRESENTATIONS

This study was presented in public trial leading to the master's degree in palliative care held at the Lisbon Faculty of Medicine on 27 Jan 2021.

AUTHOR CONTRIBUTION

MJP: Relevant contribution to the study's conception and design. Data acquisition, analysis, and interpretation in addition to the writing of the manuscript. Approval of the final version. Responsible for all the questions regarding accuracy and integrity.

FT, MCM: Relevant contribution to the study's conception and design. Critical revision of the content and approval of the final version. Responsible for all the questions regarding accuracy and integrity.

HUMAN AND ANIMAL PROTECTION

The authors declare that this project complied with the regulations that were established by the Ethics and Clinical Research Committee, according to the 2013 update of the Helsinki Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest in writing this manuscript.

FINANCIAL SUPPORT

The authors declare that there was no financial support in writing this manuscript.

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