The Neonatal Palliative Care Attitude Scale: Psychometric properties for Portuguese neonatal nurses

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Abstract

Background. This study is aimed to perform the translation and cultural adaptation of the Neonatal Palliative Care Attitude Scale (NiPCAS) and evaluation of its psychometric properties with Portuguese neonatal nurses.

Methods. The research started with a scoping review that allowed the identification of the NiPCAS. It was a methodological study with a quantitative approach. The semantic equivalence of the items was adjusted with the participation of 20 neonatal nurse experts. They performed facial and quantitative content validation. Psychometric validation of the NiPCAS was performed on a nonprobability nurses sample ($n = 283$) in 13 level 3 neonatal units between July 2021 and February 2022. Confirmatory factor analysis using the polychoric correlation matrix was performed to estimate factor validity using the "lavaan" package for R statistical software. Internal consistency was estimated using Cronbach's alpha coefficient, and item sensitivity was assessed using the asymmetry and kurtosis coefficients. Empirical indices were considered: chi-square over degrees of freedom; comparative fit index; normed fit index; Tucker–Lewis index, and root mean square error of approximation; average extracted variance and composite reliability were used to assess convergent validity.

Results. Asymmetry and kurtosis were $<|3|$ and $<|7|$, respectively, suggesting psychometric sensitivity. The convergent validity of the factors was: F1, FCF1 = 0.90 and for F2, FCF2 = 0.80, and a lower value for F3, FCF3 = 0.40. According to the squared correlation criterion average variance extracted (AVE) between the factors, there was no discriminant validity for F1 and F2, but there was discriminant validity for F1, F3, F2, and F3.

Significance of results. This instrument has implications for providing end-of-life care to newborns and their families. The use of this instrument reveals several barriers and facilitating elements inherent in the organization and culture of the facility and nursing education.

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Introduction

Scientific and technological progress in the field of neonatology has enabled the survival of premature newborns at the limit of viability and other newborns with very severe pathologies. However, the possibility of a healthy life with well-being is decreasing due to morbidity, disability, and complex chronic diseases (CCD) that are life-limiting or life-threatening (Wolke et al., 2019). Therefore, neonatal intensive care units (NICU) need to adopt a palliative care model that supports newborns and their families (Quinn and Gephart, 2016; Kilcullen and Ireland, 2017) to improve the quality of life, dignity, and comfort and positively influence disease progression.

Neonatal palliative care (NPC) requires a holistic, active approach that includes physical, developmental, emotional, social, and spiritual elements. The goal of NPC is to prevent, control, and alleviate pain and symptoms of the suffering newborn and provide psychosocial support to the family (Carter, 2004; Sataloff et al., 2018). NPC is not only about death, but also about helping children and families live their lives to the fullest while facing complex medical conditions (Himelstein, 2006). Palliative care helps to improve children's quality of life and support their families, even as they grieve (Catlin and Carter, 2002).

Palliative care should be considered when there is prenatal or postnatal diagnosis through genetic and other tests, and the agreement of the multidisciplinary team as to prognosis, as well as the agreement of the parents. Palliative care for newborns is important in cases of severe prematurity or severe congenital anomalies, such as anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18, and bilateral renal agenesis. Also when there is a high risk of

morbidity or death (e.g., hypoplastic left heart syndrome and severe bilateral hydronephrosis), postnatal situations with a high risk of sequelae and impaired quality of life (e.g., severe hypoxic-ischemic encephalopathy, severe intraventricular hemorrhage, brain ischemia, and permanent neurodevelopmental disorders) (Sataloff et al., 2018). These newborns have a short existence and those who survive have high morbidity and, therefore, benefit from the implementation of palliative care.

The decision to initiate NPC should take into account the relevant facts related to the newborn's medical condition, the opinion of caregivers, including parents, and, if necessary, the opinion of an expert palliative care team and the ethics committee (Alshehri et al., 2020), defining an integrated, individualized, and dynamic care plan that allows for consistent decision-making and care delivery.

The transition to palliative care in the NICU is still inconsistent and depends on the opinion and attitude of individual health professionals, the demands of parents, and the organization's policy (Kain and Willkinson, 2013; Oliveira et al., 2018; Beckstrand et al., 2019). The lack of knowledge of diagnosis and uncertainty of prognosis, lack of education and training, non-acceptance of the newborn's death (Martin, 2013; Quinn and Gephart, 2016), unsuitable physical environment, and shortage of resources (Cerratti et al., 2020; Sadeghi et al., 2021) are some of the challenges or barriers that healthcare professionals encounter when making decisions about discontinuing curative treatment. These barriers lead to emotional distress, avoidance, frustration, and sadness. They affect health workers' attitudes toward palliative care and the end of life and hinder family-centered and non-traumatic care.

To recognize the barriers and facilitator elements for the implementation of NPC in the NICU and to understand the nurses' attitudes toward palliative care, Victoria Kain developed the Neonatal Palliative Care Attitude Scale (NiPCAS; Kain et al., 2009). This instrument has important implications for perceptions, attitudes, and the way neonatal nurses provide care to newborns and their families in end-of-life circumstances or when prognoses are very reserved and involve CCD that will accompany families after discharge (Kain et al., 2009). The use of NiPCAS highlighted the difficulties that exist in providing PC to newborns and their families and the need to implement policies that help health professionals to make consistent and holistic decisions (Cavinder, 2014; Forouzi et al., 2017; Cerratti et al., 2020; Di and Chin, 2020; Ismail et al., 2020; Kyc et al., 2020).

Portuguese nurses also face challenges in caring for newborns in end-of-life situations. For example, they experience difficulties in making end-of-life decisions and reported having already had conflict situations with other health professionals due to differences of opinion. They experience ambivalent, negative, and powerless emotions which influence the quality of care (Carvalhais et al., 2019; Silva et al., 2019). In Portugal and the Portuguese language, no known instrument assesses nurses' attitudes toward NPC. Therefore, this study aimed to perform the translation and cultural adaptation of the NiPCAS and the assessment of its psychometric properties with Portuguese neonatal nurses.

Methods

Methodological type and design

This methodological study with a quantitative approach was conducted in three phases: (1) conducting secondary research, namely a scoping review to identify an instrument that assesses nurses' attitudes toward palliative care in the NICU; (2)

translation and cultural adaptation of the NiPCAS (12 items) and data collection; and (3) assessment of the psychometric properties of the Portuguese version of the NiPCAS (12 items).

The research process complied with ethical–legal principles and the boards of directors and ethics committees of the hospitals involved, and a Data Protector Officer approved it. All nurses signed informed consent forms.

Phase I: Identification of the instrument to assess nurses' attitudes toward palliative care in the NICU

A scoping review preceded the current study. One of its purposes was to identify in the scientific literature the instruments that assess nurses' attitudes toward palliative care in the NICU. The search considered studies written in Portuguese, English, French, and Spanish, which were published between 2016 and 2021. Through the thematic analysis of the 16 articles included in the review, it was identified an instrument developed for the specific context of neonatology to examine the nurses' attitudes toward palliative care, namely the NiPCAS (Kain, 2006; Kain et al., 2009).

Phase II: Translation and cultural adaptation of the NiPCAS

The original author of NiPCAS authorized its translation and adaptation to the Portuguese cultural context and language. Following the recommendations of Cross-Cultural Adaptation of Health-Related Quality-of-Life Measures (Guillemin et al., 1993), two independent translators, bilingual in English and Portuguese, translated NiPCAS into Portuguese. The Portuguese versions were back-translated into English, again by two independent translators. The Portuguese and English versions were compared, looking for discrepancies that were discussed with the translators and the authors of the study resulting in one preliminary Portuguese version of the NiPCAS scale. A content evaluation panel was set up with 20 experts, nurses in the field of neonatology, to quantify the content validity of the NiPCAS preliminary Portuguese version according to the method proposed by Lawshe (1975). The experts were asked to assess each item of the instrument as "Not necessary", "Useful, but not essential," and "Essential" to assess nurses' attitudes toward palliative care in the NICU. The minimum critical content validity ratio (CVR) proposed by Lawshe for a content assessment panel of 20 experts is a CVR of 0.42. The answers of the content assessment panel show that of the 26 questions assessed, 10 scored a CVR of < 0.42 (less than half), and 16 of the 20 experts (80%) considered the items of the draft Portuguese version of the NiPCAS as "essential". According to Lawshe's method, a level of 50% agreement between the experts gives some assurance of content validity, and the more experts consider the item "essential", the higher the level of its content validity.

A pretest was conducted after content validation, with 30 neonatal nurses at a level 3 NICU, who were invited to provide suggestions to improve the wording of the items. Those with less consensus were reformulated, and at the end of NiPCAS content validation, all items were kept.

Once considering the cross-cultural adaptation performed, the final instrument was named NiPCAS-PT.

Data collection

Sample

Data collection took place between July 2021 and February 2022 in 13 level 3 NICUs in mainland Portugal and Madeira Island.

The NiPCAS-PT scale was converted into a Google form whose URL was sent by email to participants after their written consent. A socio-demographic questionnaire was included to characterize the participants.

A nonrandom convenience sampling (Marôco, 2018) was carried out, with the participation of Portuguese neonatal nurses. It was used the sample-to-item ratio criterion to calculate the sample size. This criterion is based on the number of items of the instrument under the study. The ratio should not be less than 5-to-1 (Memon et al., 2020). In the present study, the ratio used was 20-to-1, which guaranteed the principle of variability to estimate the parameters (Curado et al., 2017). Since NiPCAS-PT is composed of 12 items, at least 240 respondents were required. A total of 384 electronic questionnaires were sent out and 283 neonatal nurses replied, corresponding to 73.7% of the questionnaires sent out.

Instrument

Neonatal Palliative Care Attitude Scale

The original instrument developed by Kain et al. (2009) to measure the Barriers and Facilitators of Palliative Care in Neonatal Nursing is a 5-point scale (strongly disagree to strongly agree), which is composed of 26 items and 6 factors. After its factorial and confirmatory analysis, the items were reduced to 12 and the factors to 3. Factor 1 — Organization (items 5, 8, 15, 16, and 19) measures the extent to which the institutional setting in which the neonatal nurses operate presents barriers to and facilitators of palliative care practice. Factor 2 — Resources (items 6, 7, 13, 14, and 24) measure the available resources to support a palliative model of care. Factor 3 — Clinician (items 20 and 21) measure a construct relating to the attitudes, in terms of moral and ethical concerns of clinicians. The remaining 14 items were used to assess nurse's experiences and beliefs about palliative care.

The NiPCAS-PT presents the same factor structure (3 factors) and integrates the same 12 items which is in line with Kain's scale and other studies (Kain et al., 2009; Forouzi et al., 2017; Cerratti et al., 2020; Akay and Aytekin, 2021; Kachlová and Bužgová, 2021). Table 1 shows the descriptors of NiPCAS-PT and the items numbered according to the original scale, which acquire new numbering in the Portuguese version.

Ethical considerations

The Board of Directors, Ethics Committee, Data Protector, and the Nursing Boards of the 13 NICUs that agreed to participate approved this study. All participants signed the informed consent and willingly provided the email to which the electronic form was sent.

Third phase: Psychometric validation

Data analysis

Descriptive data analysis was carried out using the Statistical Package for the Social Sciences for Windows v. 26 (IBM®, SPSS® Inc., New York, NY, USA). The confirmatory factor analysis (CFA) was used by applying the polychoric correlation matrix, which was performed on the *lavaan* package for R Statistical Software. Descriptive statistics in terms of percentages and frequencies were used to analyze the socio-demographic characteristics. Internal consistency was estimated using Cronbach's alpha coefficient, adequate if $\alpha \geq 0.70$ (Hill and Hill, 2008).

Item sensitivity was assessed using asymmetry (g_1) and kurtosis (g_2) coefficients. We established that the items with values ranging between the maximum and minimum of the measurement scale and with low absolute asymmetry (g_1) and kurtosis (g_2) values of $g_1 < |3|$ and $g_2 < |7|$, respectively (Kline, 2016), showed psychometric sensitivity (Marôco, 2021). For the items, we considered factor loadings above the reference value of $\beta = 0.40$. CFA was used to estimate factor validity, applying the polychoric

Table 1. Descriptors of the NiPCAS, Portuguese version (NiPCAS-PT) associated with English numerals (NiPCAS)

Items (NiPCAS-PT)	Answer options 5-point Likert scale — Strongly Disagree to Strongly Agree Descriptors of items numbered in the original scale NiPCAS™®
Item 1	(Item 5) Na minha unidade, a equipa médica apoia os cuidados paliativos aos bebés em fim de vida.
Item 2	(Item 8) Na minha unidade os Pais são envolvidos nas decisões relativas ao seu bebé em fim de vida.
Item 3	(Item 15) Na minha unidade, quando há um diagnóstico com mau prognóstico, os Pais são informados acerca das opções em cuidados paliativos.
Item 4	(Item 16) Na minha unidade, a equipa expressa as suas opiniões, valores e crenças no que respeita aos cuidados a bebés em fim de vida.
Item 5	(Item 19) Na minha unidade, todos os membros da equipa multidisciplinar concordam e apoiam os cuidados paliativos quando estes são implementados para um bebé em fim de vida.
Item 6	(Item 6) O ambiente físico da minha unidade é ideal para providenciar cuidados paliativos aos bebés em fim de vida.
Item 7	(Item 7) A minha unidade tem uma equipa adequada para satisfazer as necessidades de bebés em fim de vida que requerem cuidados paliativos e às suas famílias.
Item 8	(Item 13) Na minha unidade, quando um bebé morre, tenho tempo suficiente para estar com a família.
Item 9	(Item 14) Na minha unidade, existem normas/recomendações para fundamentar os cuidados paliativos.
Item 10	(Item 24) Na minha unidade, quando um bebé morre, o aconselhamento está disponível se eu necessitar.
Item 11	(item 20) Na minha unidade, a equipa vai além daquilo que se sente confortável no que respeita ao uso de tecnologia de suporte de vida.
Item 12	(Item 21) Na minha unidade, os Pais solicitam à equipa de saúde, para continuar com cuidados que prolongam a vida para além do que a equipa sente que é correto.

correlation matrix (ordinal data) *lavaan* package for R Statistical Software. The following empirical indices were set to assess goodness of fit of the factor model: chi-square over degrees of freedom (χ^2/df $\leq$ 4.0); Comparative Fit Index (CFI $\geq$ 0.90); Normed Fit Index (NFI $\geq$ 0.90); Tucker–Lewis index (TLI $\geq$ 0.90), and root mean square error for approximation (RMSEA) ($\leq$0.10). Average variance extracted (AVE) and composite reliability (CR) were used to evaluate convergent validity (adequate if AVE $\geq$ 0.50 and CR $\geq$ 0.70) (Fornell and Larcker, 1981).

Results

Characteristics of the participants

A total of 283 neonatal nurses from 13 level 3 NICUs were participated in the study. Of the participants, 95% were female and 5% were male. The age ranged between 21 and 64 years old (minimum = 21, maximum = 64), and the average age was 39 years old (mean = 38.67; SD = 10.33). Regarding religion, 73% practiced religion and 27% did not. Of the practitioners, 71% were Catholics, 1% were Spiritists, and 1% Jehovah's Witnesses. The length of service in the NICU was between 1 and 43 years with an average of 13 years (mean = 12.72; SD = 9.47). With regard to academic background, 57.9% had a degree in nursing, 24.1% had a specialty, and of these, 33% had a specialty in child health and pediatric nursing; 17.2% had a Master's degree, and 0.8% a PhD in Nursing. In relation to specific training in palliative care, 67.4% of the nurses had no training in palliative care.

Psychometric properties of NiPCAS-PT

The psychometric properties were assessed by the estimation of the sensitivity, validity, and reliability of the 12 items in the three factors using a sample of 283 neonatal nurses.

The sensitivity of the items was assessed with the asymmetry and kurtosis coefficients, considering that the items present psychometric sensitivity if $g_1 < |3|$ and $g_2 < |7|$.

The reliability of the NiPCAS-PT factors was estimated from the internal consistency of the items using Cronbach's alpha coefficient (adequate if $\alpha \geq$ 0.70).

Table 2 presents the descriptive statistics for the NiPCAS-PT items.

All the absolute values of 12 items for g_1 and g_2 were below |3| and |7|, respectively, which show a good sensitivity.

Table 3 shows the factor loadings and the Cronbach's alpha value (α) of the 12 items of the NiPCAS-PT: total α = 0.76; for Factor 1 — **Organization** (5 items): α = 0.75; Factor 2 — **Resources** (5 items): α = 0.60; and Factor 3 — **Clinician** (2 items): α = 0.30.

The items' standardized estimates show factor weights, which were mostly higher than the reference value (β = 0.40), with items 10 and 11 having a factor loading slightly below that value.

Validity

CFA was used to estimate factor validity, applying the polychoric correlation matrix. The polychoric correlation matrix is a measure of association for ordinal variables (Ekström, 2011).

Figure 1 shows the NiPCAS-PT factor model, with the factor loadings and goodness-of-fit indices that support the three factors. The empirical indices of the goodness of fit of the factor model showed a good overall fit, even though two of the items

Table 2. Median (Me), Maximum (Max.), and Minimum (Min.) values and measures of shape – asymmetry (g_1) and kurtosis (g_2) for the 12 items of the NiPCAS-PT (n = 283)

Descriptive statistics items of the NiPCAS-PT	Me	g_1	g_2	Max.	Min.
Item 1	3	−0.02	−1.06	5	1
Item 2	4	−0.64	−0.44	5	1
Item 3	3	−0.21	−1.03	5	1
Item 4	4	−0.54	−0.52	5	1
Item 5	3	−0.29	−0.911	5	1
Item 6	2	0.74	−0.499	5	1
Item 7	3	−0.14	−1.232	5	1
Item 8	3	−0.12	−1.070	5	1
Item 9	3	0.14	−1.099	5	1
Item 10	2	0.42	−1.094	5	1
Item 11	3	−0.35	−0.510	5	1
Item 12	3	−0.27	−0.751	5	1

Table 3. Factor loadings obtained from the CFA applying a polychoric correlation matrix and internal consistency analysis (Cronbach's α) of the three factors of the NiPCAS-PT (12 items) (n = 283)

	NiPCAS-PT factors		
	F 1 – Organization (5 items)	F 2 – Resources (5 items)	F 3 – Clinician (2 items)
	α = 0.75	α = 0.60	α = 0.30
NiPCAS-PT	Factor loadings (β)		
Item 1 (5)	0.66		
Item 2 (8)	0.64		
Item 3 (15)	0.75		
Item 4 (16)	0.65		
Item 5 (19)	0.52		
Item 6 (6)		0.46	
Item 7 (7)		0.65	
Item 8 (13)		0.46	
Item 9 (14)		0.69	
Item 10 (24)		0.39	
Item 11 (20)			0.39
Item 12 (21)			0.46

had low weights (0.39). The empirical indices of the NiPCAS-PT model's goodness of fit to the variance and covariance data of the items were considered: chi-square over degrees of freedom χ^2/df = 2.02; CFI = 0.95; NFI = 0.91; TLI = 0.94; and RMSEA = 0.06.

CR estimates the internal consistency of the reflective items of the factor or construct. The results of the NiPCAS-PT factors showed appropriate values for Factor 1 (FC_{F1} = 0.90) and Factor 2 (FC_{F2} = 0.80), and a lower value for Factor 3 (FC_{F3} = 0.40).
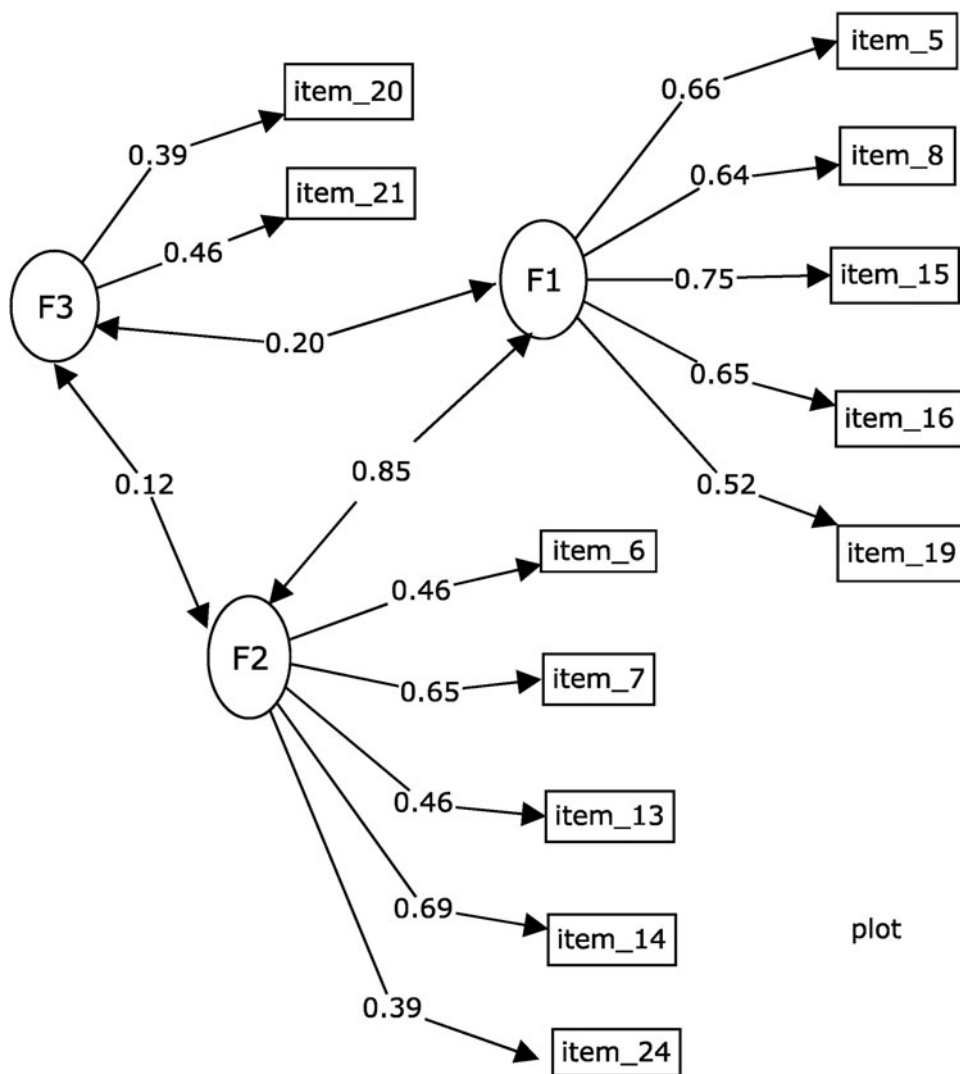
Fig. 1. CFA of the NiPCAS-PT 3 factorial model.

According to the AVE-squared correlation between factors criterion, there was no discriminant validity for F1 and F2 (AVE_{F1} = 0.42, AVE_{F2} = 0.30 < R^2 = 0.73), but there was discriminant validity for F1 and F3 (R^2 = 0.04) and F2 and F3 (R^2 = 0.02).

Discussion

The NiPCAS, Portuguese version (NiPCAS-PT) showed good item sensitivity; the absolute values for skewness and kurtosis were below |3| and |7|, respectively. The internal consistency was adequate for the 12 items, and for the five items of F1 — **Organization**, and F2 — **Resources**, respectively. However, was not adequate for F3 — **Clinician**, probably because that factor only included two items. There were two items with low weights (less than 0.4), but even so, the global adjustment of the model was good. According to the AVE squared correlation between factors criterion, there was no discriminant validity for F1 and F2, but there was discriminant validity for F1 and F3 and F2 and F3.

According to those results, the Portuguese version of the NiPCAS was found to be a valid and reliable instrument for the assessment of nurses' attitudes toward NPC in the Portuguese population and to identify the barriers and facilitators of providing palliative care in the NICU.

Study limitations

A limitation of the current study was the use of a nonrandom convenience sample. The sample size was not large, but it met the assumption of 20 responses per item. This guaranteed the principle of variability to estimate the parameters.

Conclusions

The translation and adaptation to the Portuguese cultural context and language and the statistical validation of the NiPCAS-PT for Portuguese neonatal nurses provide a valid instrument for determining attitudes toward NPC.

In addition to identifying barriers and facilitators of palliative care, this tool allows the identification of the training needs of neonatal nurses and the gaps in institutions with regard to the existence of policies related to the implementation of palliative care in the NICU.

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