



Cultural adaptation and validation for the Portuguese language of the *Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)**

Adaptação cultural e validação para a língua portuguesa da Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)

Adaptación cultural y validación al idioma portugués del Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)

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ABSTRACT

Objective: To translate, perform cultural adaptation and validation of the scale *Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU)* for the Portuguese language. **Methods:** We used the descriptive validation method of measurement instruments, based on the steps proposed by Guillemin et al. The reliability analysis was performed by means of the test - retest method and internal consistency. In the clinical validation, 163 parents of newborns hospitalized in the Neonatal Intensive Care Unit (NICU) were included. **Results:** The intraclass correlation coefficients were around 0.70, showing good stability between the two assessments. Factor analysis by principal components method used the same criteria as the original scale, with Varimax rotation, with an appropriate degree of variance of 57.9%. The highest stress levels of parents were obtained in the subscale, “*changing role of parents.*” **Conclusion:** The PSS: NICU in the Portuguese version is a valid and reliable tool for evaluating the stress of parents with children hospitalized in the NICU.

Keywords: Stress, psychological; Parents; Neonatal nursing; Intensive care units, neonatal; Validation studies; Questionnaires; Language

RESUMO

Objetivo: Traduzir, realizar a adaptação cultural e validar a escala *Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)* para a língua portuguesa. **Métodos:** Utilizou-se o método descritivo de validação de instrumentos de medida, baseado nas etapas propostas por Guillemin et al. A análise da confiabilidade foi realizada por meio dos testes e retestes e da consistência interna. Na validação clínica, participaram 163 pais de recém-nascidos internados em Unidade de Terapia Intensiva Neonatal (UTIN). **Resultados:** Os coeficientes de correlação intraclassa ficaram em torno de 0,70 mostrando boa estabilidade entre as duas avaliações. A análise fatorial pelo método de componentes principais utilizou os mesmos critérios da escala original, com rotação Varimax, com grau de variância adequado de 57,9%. Os maiores níveis de estresse dos pais foram obtidos na subescala “*alteração do papel de pais.*” **Conclusão:** A PSS:NICU na versão em português é uma ferramenta válida e confiável para avaliação do estresse de pais com filho internado na UTIN.

Descritores: Estresse psicológico; Pais; Enfermagem neonatal; Unidades de terapia intensiva neonatal; Estudos de validação; Questionários; Linguagem

RESUMEN

Objetivo: Traducir, realizar la adaptación cultural y validar la escala *Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)* al idioma portugués. **Métodos:** Se utilizó el método descriptivo de validación de instrumentos de medida, basado en las etapas propuestas por Guillemin et al. El análisis de la confiabilidad fue realizado por medio de los tests y retests y de la consistencia interna. En la validación clínica, participaron 163 padres de recién nacidos internados en una Unidad de Cuidados Intensivos Neonatal (UCIN). **Resultados:** Los coeficientes de correlación intraclassa quedaron alrededor de 0,70 mostrando buena estabilidad entre las dos evaluaciones. El análisis factorial por el método de componentes principales utilizó los mismos criterios de la escala original, con rotación Varimax, con grado de varianza adecuado de 57,9%. Los mayores niveles de estrés de los padres fueron obtenidos en la subescala “*alteración del papel de padres.*” **Conclusión:** La PSS:NICU en la versión en portugués es una herramienta válida y confiable para la evaluación del estrés de padres con un hijo internado en la UCIN.

Descriptor: Estrés psicológico; Padres; Enfermería neonatal; Unidades de cuidado intensivo neonatal; Estudios de validación; Cuestionarios; Lenguaje

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INTRODUCTION

Technical advances have been important in the survival of infants who used to be considered unfeasible because of extreme prematurity or illnesses that demanded intensive care. These advances do not prepare these little survivors' parents to cope with the hospitalization and separation from the expected baby, as this possibility is often unexpected. Reactions to the child's hospitalization range from cries of lament due to having an ill child to organic alterations and psychological problems^(1,2). This new situation, associated with difficulties to understand what is actually happening with their child, the stay in an unfamiliar environment, with sounds, frightening equipment and people moving around the whole time are considered stressors for patients and relatives, which can lead to stress, anxiety and depression^(3,4). As parents experience stress at the Neonatal Intensive Care Unit (NICU) when accompanying their newborn child, nurses need instruments to know how they cope with their child's hospitalization. In the bibliographic search about the theme, no instrument was found to measure stress in this context. In international literature, however, the *Parental Stress Scale: Neonatal Intensive Care Unit* (PSS:NICU)⁽⁴⁾ is cited, which measures parents' stress at the NICU⁽⁵⁾. This scale is used in the United States of America⁽⁶⁾, Argentina⁽⁷⁾, England⁽⁸⁾, Japan⁽⁹⁾ and Australia⁽¹⁰⁾.

Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU)

The PSS:NICU was constructed to assess the stress experienced by parents of infants hospitalized at that unit. Miles et al⁽⁵⁾ validated it in 1993. It consists of 26 items, distributed in three subscales, which are "sights and sounds", "baby looks and behaves" and "changes in parental role". The parents indicate on a five-point Likert scale whether they experienced stress concerning the scale items. Score "1" refers to non-stressing, "2" a bit stressing, "3" moderately stressing, "4" very stressing and "5" extremely stressing⁽⁴⁾. Answers to the scale can be assessed in three ways: **Measure 1:** Stress Occurrence Level – the stress level the situation occurs in. In this case, only parents who mentioned the stress experience score the item; those who reported no stress experience are coded as absent. The scale scores are then calculated through the mean number of answers with stress on the items listed in each and on the total scale. It is important to observe that the denominator to obtain the means for each scale is the number of items the parent experienced in each. **Measure 2:** General Stress Level – the general stress level in the environment. In this case, parents who did

not report an experience concerning one of the items receive score 1, indicating that no stress occurred in the situation. The scale scores are calculated through the mean of these stress related answers for the items in each and for the total scale. The denominator to obtain the means for each scale is the number of items in the scale. **Measure 3:** Total number of experiences – the number of items the parent experienced in each of the three scales can be calculated by simple counting the number of affirmative answers (s)he gave on the items in each of the three scales. These numbers can be added up to indicate the total number of experiences in the PSS:NICU the parent went through.

In Portuguese, the validation of the PSS:NICU allows nurses to use an objective tool to assess parents' perception about the stressors present in the physical and psychosocial environment of the NICU and to direct nursing interventions at that unit, permitting parents' forwarding to support groups or interventions with expert professionals, when necessary. The aim of the study was to determine the validity and reliability of the *Parental Stress Scale: Neonatal Intensive Care Unit* (PSS:NICU) for use with Brazilian parents.

METHODS

The descriptive measurement instrument validation method was used, based on the phases Guillemín et al⁽¹¹⁾ proposed: translation, back-translation, expert committee analysis, pretest, data analysis. The places of study were two hospitals affiliated with a public university in São Paulo State, which offer NICU and semi-intensive units. The subjects were part of an expert committee with seven professionals: three nurses, one neonatologist, one resident physician in neonatology, a social workers and a psychologist in the cultural adaptation phase; in the pretest and clinical application phases, fathers and/or mothers of children hospitalized at the hospitals' NICU and semi-intensive unit served as the subjects. Before forwarding the project to the ethics committees, authorization was requested from the author to validate and use the PSS: NICU, first by e-mail and then personally. The research complied with all requirements of Resolution 196/96, as it was submitted to the Ethics Committees, registered under No. 408/2008 and No.01303/08. The study participants signed the Informed Consent Term. Secrecy and the right to cease participation in the research at any time were guaranteed. For the clinical validation phase, a data collection instrument was constructed. The first part included the study population's characteristics and clinical and demographic data on the child and parents. The second part comprised the final version of the PSS:NICU in Portuguese. The collected data were

stored in an Excel database the author created, and analyzed descriptively through absolute frequencies (n) and percentages (%), means and standard deviations.

The test-retest (replicability) and internal consistency analysis were used to ascertain the reliability of the PSS:NICU. For the test-retest, a sample of 33 parents was used to check the replicability of the translated and adapted scale, showing its stability over time. The intra-class correlation coefficient (ICC) was applied between the first and second assessment of the same father/mother, at a 24-hour interval from the application of the instrument. The reliability investigation included the internal consistency analysis of the items and their respective subscales and total scale.

Cronbach's Alpha coefficient was used to analyze the instrument's internal consistency and main component factorial analysis with VARIMAX rotation for construct validation purposes. The translation, adaptation and validation process of the Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU) to Portuguese is schematically presented in Figure 1.

RESULTS

Two independent translators with precise knowledge on both languages elaborated the translation of the PSS:NICU from English to Portuguese. These two translators did not participate in the remainder of the research. Two translators fluent in both languages back-translated the final version in Portuguese, obtained in the previous phase, to English. These translators did not participate in the first phase. The Expert Committee analyzed the Portuguese version of the PSS:NICU, observing semantic, idiomatic, cultural and conceptual equivalence, until reaching an agreement level higher than 80%.

Next, 20 parents assessed the scale for understanding in Portuguese. Results were satisfactory, as all subjects in this cultural adaptation phase answered the questionnaire and indicated no doubts concerning the items of the three PSS:NICU subscales.

The subscale sights and sounds showed a Cronbach's alpha of 0.84 on Measure 1 and 0.8 on Measure 2, evidencing good internal consistency. On the baby looks and behaves and changes in parental role subscales, both Measure 1 and Measure 2 exceeded 0.89, which means a perfect correlation, demonstrating internal consistency, i.e. adequate reliability of the instrument items. Internal consistency was calculated for the scores of each instrument subscale, ranging between 0 and 1. A Cronbach coefficient of approximately 0.70 was considered acceptable^(12,13).

No statistically significant difference was found ($p > 0.05$) between the first and second application of

the PSS:NICU. The obtained intra-class correlation coefficients (ICC) for Measures 1 and 2 varied around 0.70, showing good stability between both assessments.

Once the final version of the PSS:NICU had been obtained in Portuguese, the scale was subject to clinical validation. Participants in the validation process were 121 mothers (74.2%) and 42 fathers (25.8%). The participants' predominant age range was between 20 and 29 years. Concerning education, among the parents, 56 (35.9%) had not finished primary education; 10 (6.4%) had finished primary education; 24 (15.4%) had not finished secondary education; 66 (42.3%) had finished secondary education and none of the participants had finished higher education.

Stress analysis based on Measure 1 showed the highest stress level on the subscale "changes in parental role". The mean stress level was 3.7, i.e. highly stressful (Table 1).

Table 1. Descriptive statistics for PSS:NICU. São Paulo, 2009.

	Sights and Sounds	Looks and Behaves	Parenting Role	Total Score
Measure 1				
N	163	163	163	163
Mean	2.3	2.9	3.7	3
Standard deviation	1	1.2	1.2	1
Median	2.2	3	4	3.1
1 st quartile	1.5	1.8	2.8	2.2
3 rd quartile	3	3.8	4.7	3.7
Minimum	1	1	1	1
Maximum	5	5	5	5
Measure 2				
N	163	163	163	163
Mean	2.2	2.6	3.4	2.7
Standard deviation	0.9	1.1	1.2	0.9
Median	2	2.7	3.6	2.8
1 st quartile	1.3	1.5	2.5	1.9
3 rd quartile	2.7	3.5	4.4	3.4
Minimum	1	1	1	1
Maximum	4.8	4.9	5	4.9

The results of this Brazilian study also demonstrated that the subscale *sights and sounds* caused a lesser stress level of the parents of ICU-hospitalized infants. The mean scores of the parents' answers ranged between 2.2 and 2.3, which means little stress in these parents.

Concerning the construct analysis of the scale in Brazilian parents, the initial analysis revealed three factors with variances of 57.2%, which is considered good⁽¹⁴⁾ (Table 2). The scale items demonstrated good grouping among the

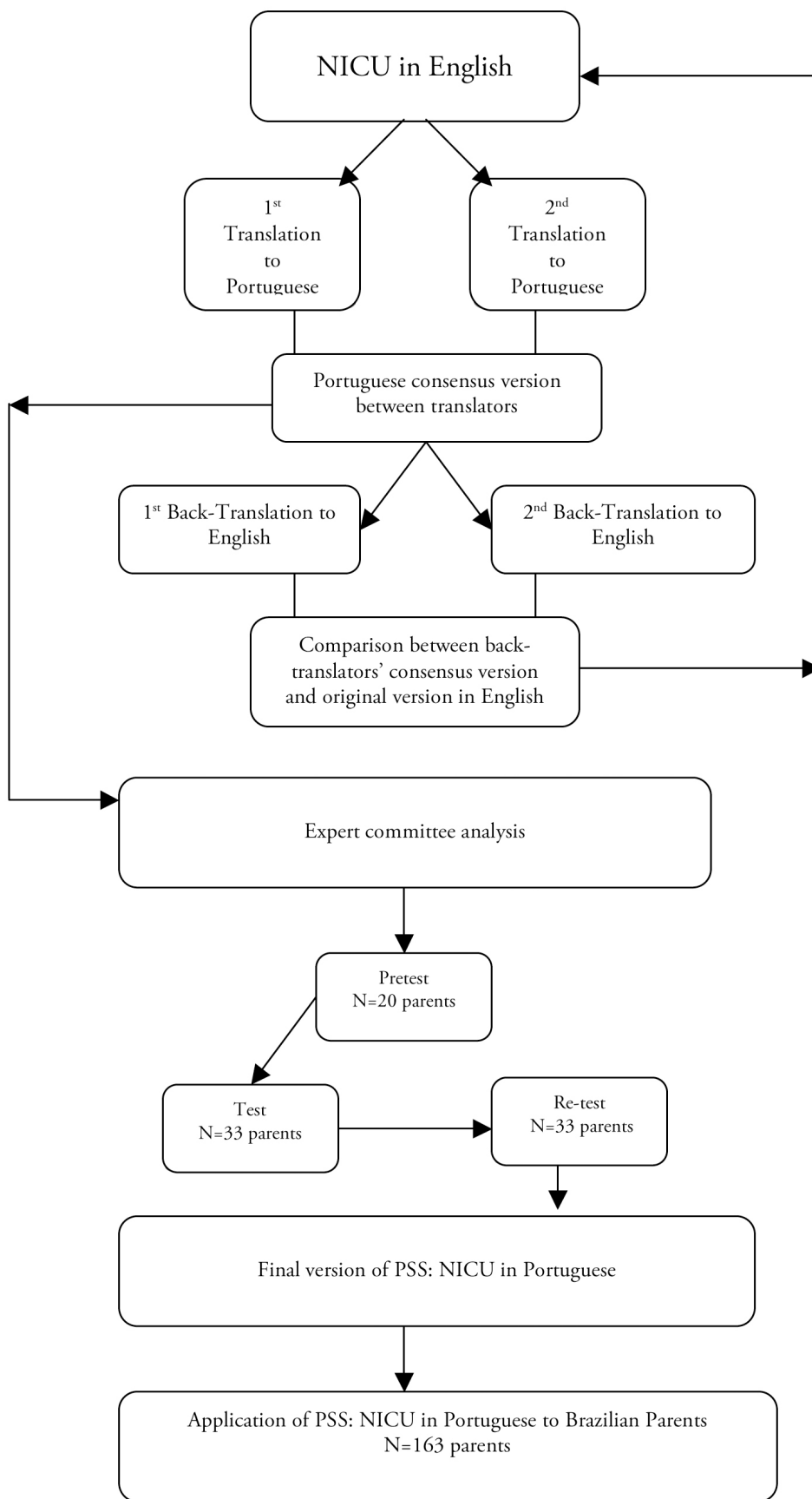


Figure 1. Diagram of the translation, cultural adaptation and validation process of the PSS: NICU to Portuguese

Table 2. Factorial analysis based on the main components method. São Paulo, 2009.

PSS:NICU items	Factor loadings		
	Factor 1	Factor 2	Factor 3
Baby looks and behaves			
Tubes and equipment on or near my baby.	0.487	0.378	0.514
Bruises, cuts or incisions on my baby.	0.689	0.286	0.208
The unusual color of my baby (for example looking pale or yellow jaundiced)	0.753	0.109	0.069
My baby's unusual or abnormal breathing patterns	0.611	0.438	0.218
The small size of my baby	0.459	0.195	0.276
The wrinkled appearance of my baby	0.646	-0.022	0.194
Seeing needles and tubes in my baby.	0.485	0.476	0.303
Seeing my baby being fed by an intravenous catheter or a tube.	0.658	0.359	0.293
My baby being fed by an intravenous line or tube	0.756	0.320	0.105
When my baby seemed to be in pain	0.727	0.245	0.259
When my baby looked sad	0.587	0.338	0.280
The limp and weak appearance of my baby	0.611	0.272	0.267
Jerky or restless movements of my baby	0.479	0.396	0.202
Parental role			
Seeing separated from my baby	0.184	0.734	0.198
Not feeding my baby myself	0.206	0.811	0.128
Not being able to care for my baby myself (for example, diapering, bathing)	0.130	0.796	0.180
Not being able to hold my baby when I want to	0.232	0.754	0.112
Feeling helpless and unable to protect my baby from pain and painful procedures	0.326	0.707	0.187
Feeling helpless about how to help my baby during this time	0.295	0.745	0.211
Not having time to be alone with my baby	0.237	0.656	0.217
Sights and sounds			
the presence of monitors and equipment	0.215	0.212	0.746
The constant noise of monitors and equipment	0.165	0.224	0.777
The sudden noise of the monitor alarm	0.156	0.374	0.735
The other sick babies in the room	0.257	0.044	0.590
The large number of people working in the unit.	0.148	0.033	0.472
Having a machine (respirator) breathe for my baby	0.251	0.416	0.607

The three factors explain 57.9% of variance.

three a priori defined subscales of the PSS:NICU. Some items of the baby looks and behaves subscale showed high factor loadings, for the parenting role subscale in two items and for the sights and sounds subscale in one.

DISCUSSION

The cultural adaptation phases of the PSS:NICU followed recommendations by Guillemin et al.⁽¹¹⁾, which different international and national researchers have used. The study by Bracher⁽¹⁴⁾ demonstrated that, out of 21 studies published in 2007 about the cultural adaptation of instruments, 13 used the method Guillemin et al.⁽¹¹⁾ proposed.

The internal consistency of the PSS:NICU scale for use in Brazilian parents is similar to the findings in original validation studies of the scale in English, in which the sights and sounds subscale obtained a Cronbach's alpha

coefficient of 0.80 on Measure 1 and 0.73 on Measure 2, disclosing good internal consistency. On the baby looks and behaves and changes in parenting role subscales, coefficients exceeded 0.83 for Measure 1 and 2, which indicates excellent internal consistency, i.e. adequate reliability⁽⁵⁾.

The clinical validation results of the PSS:NICU in Brazil are in accordance with the results found in the United States of America^(5,6), England⁽⁸⁾ and Argentina⁽⁷⁾. In another initial study in 1987⁽⁴⁾, aimed at developing the PSS:NICU, Miles observed that parents were more concerned by the baby's fragile appearance than with the changes in parenting role. In a larger study to validate the scale, however, the researcher identified that the change in parenting roles is the main stress cause at the NICU⁽⁵⁾. The author also showed that the baby's looks and behaves were the second most stressing factor for the parents, also confirmed in the current study among Brazilian parents.

Brazilian data go against the results of a stress study involving 83 mothers in the South of the USA, which demonstrated higher stress levels for sights and sounds. The items of this subscale refer to the relation between stress and the NICU environment. At first sight, equipment used to save the infants' lives, like respirators for example, cause stress in parents, because they are unknown and frightening⁽¹⁵⁾.

In this subscale, the low stress level of Brazilian parents can be explained by the fact that, during the first days, the parents do not always perceive the environment because of their concern with their child⁽¹⁶⁾. When the parents have the opportunity to see their children for the first time, they identify many stressing agents in their looks and behaviors. Thus, they perceive their child's weakness and feel apprehension about a possible death. Many parents are not prepared to see such small and fragile infants, as they had developed the image of the "ideal", healthy, large and beautiful baby during the pregnancy⁽¹⁵⁾.

In a research developed in Australia, using the PSS:NICU, the subscale "*baby looks and behaves*" obtained the highest stress level, followed by "*parenting role*"⁽¹⁰⁾. The main stressors found among Brazilian parents were related to the subscale "change in parenting role". This finding is present in other studies' results⁽⁵⁻⁸⁾ about parents' experiences at the NICU, affirming that the main stressors for parents of NICU-hospitalized infants are

related to the parenting role. The feeling of a changed role is more enhanced in the mothers, as they cannot develop their "mothering actions", such as breastfeeding, holding the baby and participating in the child's care. Other parents remained passive at their children's side due to the team's lack of encouragement to participate, which hampers a tighter parent-child relation^(7,10,15,17-18).

CONCLUSION

The cultural adaptation of the PSS:NICU in Portuguese obtained a high level of understanding by Brazilian parents, indicating that the semantic and conceptual changes resulted in a clearly written scale without psychometric alterations. Based on the analysis results of the PSS:NICU in Portuguese, it was concluded that this scale is reliable and valid for application among Brazilian parents.

Study limitations

Although this study provided data on parents' stress, further research in different Brazilian populations is needed to obtain broader scale reliability and validity data. Studies with different ranges are needed at high and medium-risk (semi-intensive) units, with a view to more specific data to guide interventions.

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