

# Communication in Neonatal Intensive Care: Translation and Validation of the "Parents' Experiences of Communication in Neonatal Care" Questionnaire for the Portuguese Population

Comunicação em Cuidados Intensivos Neonatais: Tradução e Validação do Questionário "Parents' Experiences of Communication in Neonatal Care" para a População Portuguesa

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#### ABSTRACT

Introduction: Communication is a fundamental aspect in healthcare, more so in fragile environments such as Neonatology. To optimize communication strategies with parents, it is essential to assess its quality. The aim of this study was to validate, for the Portuguese population, an instrument for assessing the quality of communication between healthcare professionals and parents in neonatal care units.

Methods: The Parents' Experiences of Communication in Neonatal Care questionnaire was developed in the United Kingdom to evaluate communication with parents specifically. The 28-question instrument was adapted and translated to European Portuguese following a three-step protocol: translation, review, and back-translation. Subsequently, the validation process was conducted in three stages: (1) face validity through cognitive interviews; (2) content validity through external panel evaluation; and (3) performance assessment through a four-month pilot study in a tertiary neonatal intensive care unit. Results: Cultural adaptation resulted in the removal of two questions. The remaining questions were translated to Portuguese. Cognitive interviews were conducted with a convenience sample of ten parents, leading to important revisions in two questions. Five external professionals evaluated the item's relevance in a 4-point Likert scale. Four questions presented an item content validity index value below the threshold of 0.78. Two questions were adjusted and two were eliminated at this stage. The questionnaire was delivered to 31 parents, with a total of 60 questionnaires completed. Five questions were reviewed due to a non-response rate greater than 5%, and one for exceeding 95% uniform responses. No question had a dropout rate greater than 5%, nor did any have a rate of non-informative answers exceeding 5%. A significant correlation (Kendall's Tau > 0.7) was found between three sets of questions. Conclusion: The European Portuguese version of Parents' Experiences of Communication in Neonatal Care survey contains 24 questions. This is the first comprehensive and valid instrument at national level to objectively measure satisfaction with communication of parents of children admitted to the neonatal intensive care units. Its use will enable monitoring of interventions aimed at improving communication, which is crucial for enhancing family-portored care.

Keywords: Communication; Intensive Care Units, Neonatal; Parents/psychology; Portugal; Surveys and Questionnaires; Translations

# RESUMO

Introdução: A comunicação é um aspeto fundamental na prestação de cuidados de saúde, especialmente em ambientes de maior fragilidade como a Neonatologia. Para a otimização de estratégias de comunicação com os pais é essencial avaliar a sua qualidade. Este estudo teve como objetivo a validação de um instrumento de avaliação da qualidade da comunicação dos profissionais de saúde com os pais em unidades de cuidados neonatais para a população portuguesa.

Métodos: O questionário Parents' Experiences of Communication in Neonatal Care foi desenvolvido no Reino Unido para avaliação específica da comunicação com os pais. O instrumento com 28 questões foi adaptado e traduzido para português Europeu em três etapas protocoladas: tradução, revisão e tradução reversa. Posteriormente, o processo de validação realizou-se em três fases: 1) validade de face através de entrevistas cognitivas; 2) validade de conteúdo através da avaliação por um painel externo; 3) avaliação de desempenho através de um estudo piloto de quatro meses numa unidade de apoio perinatal diferenciado.

Resultados: O processo de adaptação cultural resultou na remoção de duas questões. As restantes questões foram traduzidas para a língua portuguesa. Realizaram-se entrevistas cognitivas a uma amostra de conveniência de 10 pais, conduzindo à revisão de duas questões. Um painel de cinco profissionais externos avaliou a relevância de cada item numa escala de Likert de quatro pontos. Quatro questões apresentaram um índice de validade de conteúdo inferior a 0,78. Nesta fase, duas questões foram ajustadas e duas foram removidas. O questionário foi entregue a 31 pais, num total de 60 questionários preenchidos. Nesta avaliação cinco questões foram revistas por ausência de resposta em > 5% dos questionários e uma por > 95% de respostas uniformes. Foi encontrada uma correlação significativa, com Tau de Kendall superior a 0,7, entre três conjuntos de questões.

Conclusão: A versão portuguesa do questionário *Parents' Experiences of Communication in Neonatal Care* contém 24 questões. Este é o primeiro instrumento nacional validado para avaliar objetivamente a satisfação dos pais com a comunicação durante o internamento em cuidados intensivos neonatais. A sua utilização permitirá monitorizar intervenções que visam melhorar a comunicação, fundamentais para a melhoria dos cuidados centrados na família.

Palavras-chave: Comunicação; Inquéritos e Questionários; Pais/psicologia; Portugal; Traduções; Unidades de Cuidados Intensivos Neonatais

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# **KEY MESSAGES**

# Strengths:

- Communication plays a central role in family-centered care, and its evaluation is essential for improving the quality
  of care.
- The European Portuguese version of the "Parents' Experiences of Communication in Neonatal Care" (PEC) questionnaire enables real-time assessment of communication with parents, driving improvement strategies that can be continuously monitored.
- The translation and cultural adaptation of the PEC questionnaire involved parent participation and an external evaluation of content validity.

#### Limitations:

- · The translated version was evaluated in a single center, which may not be fully representative.
- This study did not include parents who do not fluently speak European Portuguese, a group that may be particularly vulnerable to communication issues.

#### INTRODUCTION

Communication is a fundamental aspect of quality in health care, playing a critical role in several aspects such as promoting healthy habits and primary prevention, establishing a therapeutic relationship between healthcare professionals and patients, effectively guiding diagnostic investigations, and defining and ensuring adherence to a treatment plan.<sup>1,2</sup>

The communication process is strategically important as it can significantly influence the families' perceptions of the quality of care, psychological adaptation to the clinical situation, and behaviors of therapeutic compliance. 1,2

The main challenges in communication between health-care professionals and families relate to four key aspects: the transmission of information; interpersonal styles and attitudes of both professionals and families toward communication; non-verbal communication; and the cultural, linguistic, and social factors specific to each family. To ensure effective communication it is essential to consider the dynamic needs of the family including the clinical, affective, social, and cultural aspects.<sup>2</sup>

In Neonatology, effective communication serves several purposes: to inform and clarify the parents of the newborn's clinical condition, to encourage their participation in every-day care as well as their involvement in the decision processes. It is also an important tool for emotional support to the families.<sup>3</sup> The quality of communication with parents during Neonatal Intensive Care Unit (NICU) admission can have a significant impact. Ineffective communication has been shown to negatively affect parental stress and anxiety, which can hinder the parent-newborn bonding process. Conversely, effective communication can positively influence family satisfaction and their autonomy in care, while also benefiting the well-being and satisfaction of the staff.<sup>4-7</sup>

The NICU's specific features influence communication between parents and healthcare professionals. The quality of communication is affected by the complex NICU environ-

ment, which is highly technological and often lacks privacy. Additionally, working dynamics characterized by periods of agitation, the need to prioritize urgent tasks, and staff turnover can impair interactions with parents. Beyond these constraints, it is crucial to consider the vulnerability of the newborn and the inherent risks of complications that impact both short- and long-term prognosis. The emotional needs and expectations of families must also be taken into account.<sup>5,8</sup>

To improve the quality of care, it is essential to evaluate parents' experiences and perceptions regarding the quality of communication. This assessment is challenging and often relies on unvalidated instruments that retrospectively evaluate communication alongside other aspects of parental satisfaction.<sup>9</sup>

In this regard, a new instrument was recently developed in the United Kingdom (UK) to evaluate parental satisfaction in neonatal care, specifically focusing on communication of clinical information and parental involvement in care. This new survey, entitled "Parents' Experiences of Communication in Neonatal Care" (PEC) was assessed for the United Kingdom population and enables real-time evaluation of parental experiences, as well as monitoring of interventions aimed at improving communication.<sup>10</sup>

In Portugal there are few publications about communication in neonatology. The existing literature primarily addresses the importance of this topic and suggests strategies for evaluating and improving healthcare professionals' communication skills.<sup>8,11</sup> However, in the literature review conducted by the authors, no tools specifically designed to evaluate aspects of communication with families in neonatal care were identified that are validated for the Portuguese population.

The evaluation of communication using an objective tool that measures parents' perceptions is a crucial step toward implementing targeted strategies to improve

communication between parents and healthcare professionals in Portuguese NICUs, facilitating shared decision-making and enhancing parental involvement in care. Interventions can be tailored to each NICU and may include staff training, the development of protocols and communication strategies, care planning meetings, and improved access to written and audiovisual information.<sup>3,6</sup> A tool that can assess the effectiveness of these measures, such as the PEC questionnaire, is particularly valuable.

Our main objective was to validate an instrument for assessing the communication of healthcare professionals with parents during NICU admissions for the Portuguese population.

#### **METHODS**

# Stage 1: Translation and adaptation to the Portuguese language

The translation of the original PEC survey into Portuguese followed a structured method and adhered to the survey adaptation recommendations of the Picker Institute. The authors initially reviewed the questionnaire to ensure that the questions were relevant to the Portuguese context. The survey was then translated using a three-step process: 1) forward translation by an independent translator, 2) revision by an expert panel composed by the independent translator, one neonatologist, and one statistician, 3) backward translation conducted by a second independent translator, which was subsequently assessed by the Picker Institute to ensure consistency with the original version.

# Stage 2: Face validity and cognitive testing

The translated version of the survey was used in cognitive interviews. A sample of ten parents was selected from those whose newborns were admitted to the NICU in a differentiated perinatal support unit. The cognitive interviews were conducted individually by a member of the research team, following the model described by Tourangeau. <sup>12</sup> Participants were asked to respond to each question orally, and their answers were compared to the responses they had provided on a previously completed printed version of the questionnaire. To establish face validity, the response process, level of comprehension, and cultural appropriateness of each question were evaluated. The structure, flow and length of the questionnaire were also assessed. Upon revision of the issues raised during the interviews, the final version of the translated questionnaire was established. <sup>13</sup>

# Stage 3: Content validity

To establish content validity, the final translated version was evaluated by a panel of five external neonatology professionals. This panel comprised three neonatologists and two specialized neonatal nurses, with between ten and

twenty years of clinical experience. The experts were selected from a range of neonatal care settings in Portugal, including intensive care (differentiated perinatal support) and intermediate care (perinatal support) units, and a unit in a private hospital. The panel broadly assessed the scope and comprehensiveness of the questionnaire. Each question was individually graded in terms of relevance on a 4-point Likert scale (1 = non-relevant, 2 = mildly relevant, 3 = relevant, 4 = very relevant). The item content validity index (I-CVI) was calculated for each question, and the average content validity index (A-CVI) was calculated for the questionnaire. An I-CVI below 0.78 indicates that the question should be reviewed or considered for removal. An A-CVI above 0.8 - 0.9 is considered sufficient to establish content validity, depending on the reference.<sup>14</sup>

# Stage 4: Survey evaluation

To formally evaluate the survey, we conducted an observational prospective study in a Portuguese NICU over a period of four months. Study participants included parents or legal representatives of newborns admitted to the NICU for longer than 48 hours. Parents who could not speak Portuguese fluently were excluded. The translated version of the PEC survey was distributed weekly to all parents present who met the inclusion criteria. Demographic variables of the participants were registered.

The evaluation of the questionnaire included the following components:

- Non-response rate: an absence of answers exceeding 5% for each question was considered significant.
- Dropout rate: determined by the last question answered by each participant.
- Rate of non-informative answers: a rate of uninformative responses (e.g., "don't know") greater than 5% for any question was deemed significant.
- Rate of uniform answers: a rate of uniform responses greater than 95% for any question was considered significant.
- Correlation between questions: Kendall's tau correlation coefficient was calculated for questions with numerical answers, correlations greater than 0.7 were considered relevant. For parents who completed more than one questionnaire, responses were aggregated by calculating the mean value for each question, which was then used to compute the Kendall's tau coefficient.

Statistical analysis was performed with the software  $R^{\tiny{\scriptsize{0}},15}$ 

# Ethical and legal considerations

The use of the Parents' Experiences of Communication in Neonatal Care survey was licensed by the Picker Institute

version, along with formatting issues. Inconsistencies between written and verbal responses revealed comprehension issues, leading to wording adjustments in questions A4 and A8. No questions were removed or added at this stage.

for translation and adaptation into Portuguese. The study received approval from the ethics committee of Hospital Garcia de Orta. All participants provided written informed consent, and their responses were kept anonymous.

# **RESULTS**

# Stage 1: Translation and adaptation to the Portuguese language

The adaptation and translation process were conducted as outlined. An initial review by the research team led to the removal of two questions (B3 and B8 from the original version). These questions addressed parental presence during medical rounds and access to medical records, two aspects that do not apply to the reality of the clinical practice of NI-CU's in Portugal. Information regarding ethnicity was also excluded due to ethical concerns.

The survey was subsequently translated using the previously described three-step process. The back-translation review by the Picker Institute resulted in minor grammatical changes to the translated version.

# Stage 2: Face validity and cognitive testing

Cognitive interviews were conducted in March 2024. Ten parents of newborns admitted to the NICU were selected through convenience sampling. Participant demographics are presented in Table 1. Most participants were female (n = 8), with a predominant age range of 30 - 34 years (n = 4), though all age groups were represented. Gestational ages ranged from 24 to 39 weeks, with the majority being less than 32 weeks. The length of stay varied from under one week to over six months, with most stays being under two weeks. The parents who participated in the cognitive interviews represented a range of educational levels (basic, secondary, and tertiary education) and diverse socioeconomic backgrounds (including lower- and middle-income households, as well as Portuguese-speaking immigrant families), reflecting the profile of the population typically admitted to this NICU.

Doubts regarding wording throughout the questionnaire, identified during the interviews, were corrected in the final

The interviews confirmed that this sample of parents understood the questionnaire's purpose, the meaning of each question, and were able to provide accurate responses. thereby establishing the face validity of the translated version.

# Stage 3: Content validity

Overall, the questionnaire received positive evaluations, with all external professionals considering it an important, easy-to-understand, and sufficiently comprehensive tool. However, three of the five professionals found the questionnaire to be too long. Each panel member rated the questions based on their relevance, and the I-CVI was calculated. Table 2 displays questions with an I-CVI of less than 1 in the translated PEC questionnaire. All other questions were unanimously rated as relevant or very relevant.

Questions with an I-CVI below 0.78 were reviewed. The questions with the lowest I-CVI (0.4), B6 and B9 from the original version, were removed, as both addressed the frequency of communication with doctors and nurses, a topic covered by other questions. The other two questions, B5 and B7, were retained to avoid narrowing the scope of the survey.

Based on a suggestion during the content validity evaluation, an open-response field was added to question C4, allowing parents to explain why they feel insufficiently involved in their baby's care.

With the removal of these questions, the a-CVI was calculated at 0.91, confirming the content validity of the translated version of the PEC questionnaire.

#### Stage 4: Survey evaluation

A prospective study was conducted between June and September 2024 in a differentiated perinatal support unit at Hospital Garcia de Orta in Portugal. During the study period, 60 questionnaires were completed by 31 parents, with

Table 1 – Demographics for cognitive interview participants

Sex	n	<b>Age</b> (years)	n	Gestational age	n	Time since admission	n
Male	2	18 - 24	1	24 - 27 weeks	3	< 1 week	4
Female	8	25 - 29	2	28 - 31 weeks	4	1 - 2 weeks	2
		30 - 34	4	32 - 36 weeks	2	1 - 2 months	3
		> 35	3	36 - 40 weeks	1	> 6 months	1

Table 2 – Item content validity index values < 1 (original version numbering)

Question	A2	A8	B2	B4	B5	В6	В7	В9	B10	B11	D1
I-CVI	8.0	0.8	0.8	8.0	0.6	0.4	0.6	0.4	8.0	0.8	0.8

Table 3 – Demographic details for questionnaire responses in the prospective study

Sex	n (%)	Age (years)	n (%)	Gestational age	n (%)	Time since admission	n (%)
Male	16 (27)	< 18	2 (3)	24 - 27 weeks	16 (27)	< 1 week	11 (18)
Female	44 (73)	18 - 24	1 (2)	28 - 31 weeks	28 (47)	1 - 2 weeks	15 (25)
		25 - 29	20 (33)	32 - 36 weeks	9 (15)	2 - 4 weeks	8 (13)
		30 - 34	9 (15)	36 - 39 weeks	4 (7)	1 - 2 months	18 (30)
		≥ 35	28 (47)	≥ 40 weeks	2 (3)	2 - 4 months	3 (5)
						≥ 6 months	5 (8)

the number of questionnaires per parent ranging from 1 (18 parents) to 8 (1 parent), averaging 1.94 per parent. Each response corresponded to a specific time point during the newborn's admission.

Demographic details for each response are presented in Table 3. Most respondents were female (73%) and over 25 years of age (95%). Gestational ages ranged from 24 to 41 weeks, with most under 32 weeks. The length of stay corresponding to each response is also included.

The following aspects were analyzed:

- Non-response rate: five questions had a missing response rate greater than 5%. One question was removed during the content validity evaluation, while the remaining four questions were retained and reformulated to preserve the survey's scope.
- Dropout rate: apart from the final open question, which was previously reviewed in the later parameter, no other question exhibited a dropout rate exceeding 5%.

- Uniform response rate: one question had 100% uniform responses. This question was retained.
- Uninformative responses rate: no question had an uninformative response rate greater than 5%. The reviewed questions and subsequent alterations are presented in Table 4.
- Correlation between questions: Three sets of questions from the Portuguese (PT) version revealed a significant correlation (Fig. 1). B5 and B8a (PT) (Kendall's tau = 0.74, p < 0.0001), indicating that parents who were more satisfied with the frequency of information provided by nurses were also more satisfied with how verbal information was delivered. B8a is also correlated with B8b (Kendall's tau = 0.81, p < 0.0001) and B8d (Kendall's tau = 0.76, p < 0.0001) indicating that parents who were more satisfied with how verbal information was delivered were also more satisfied with information conveyed by telephone and overall form of information delivery. Although the</li>

Table 4 – Questions reviewed and subsequent changes to the questionnaire (original version numbering)

Question	Missing responses > 5%	%	Decision and changes to the questionnaire
A7	"Qual a principal razão pela qual não tem conseguido falar com o médico as vezes que gostaria?"	15	Retained. Clarification on how to respond this question was added in question A6: (ir para questão A7/A8)
A8	"Têm-lhe sido transmitidas informações contraditórias, pelos profissionais, sobre o estado de saúde ou cuidados ao seu bebé?"	6.7	Retained. The word contradictory was clarified: different professionals transmitting opposite information ( <i>profissionais diferentes transmitem informações opostas</i> ).
В6	"Nas últimas 24h, quantas vezes pediu presencialmente, ao/à enfermeiro/a, uma atualização sobre o seu bebé?"	11	Removed. The question performed poorly on both the content validity evaluation and the prospective study.
B12c B12b	"Numa escala de 1 a 10, quão satisfeito está com a forma como recebe informação sobre o seu bebé na Unidade?"	8.3 15	Both retained. The questions highlight important sources of information. This result is significantly improved compared to the original survey, following the addition of the 'not applicable' option. The formatting was altered.
E1	"Se existe mais alguma coisa que gostasse de nos dizer sobre a sua experiência dos cuidados na Unidade de Neonatologia, por favor faça-o aqui."	71.7	Retained. It is the only open-ended question in the survey, allowing parents to express concerns that may not be addressed elsewhere.
	> 95% uniform responses	%	Decision and changes to the questionnaire
А3	"Foram-lhe explicadas as práticas de controlo de infeção, nomeadamente a lavagem das mãos e os procedimentos para visitas?"	100	Retained. The question addresses an important topic for evaluating quality in NICUs.

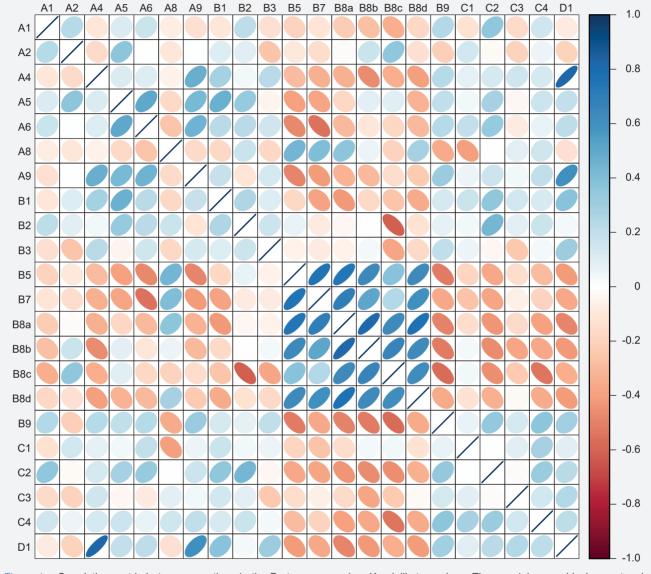


Figure 1 – Correlation matrix between questions in the Portuguese version, Kendall's tau values. The remaining graphical aspects, although redundant in relation to the correlation value, are useful as they allow for the rapid identification of groups of questions with similar correlations between them (flattening/compression of the ellipses: the higher the compression, the higher the absolute value of the correlation; orientation of the longest axis of the ellipse: positive for positive correlation, negative for negative correlation).

set A4 and D1 also presented an adequate Kendall's tau value, we did not consider this correlation significant due to the low variability in answers in both questions after the aggregated answer per parent. All questions were retained, as they measure different aspects of communication, and the correlations

highlight important factors for improving parents' satisfaction with communication.

The final version of the Portuguese PEC questionnaire has 24 questions. It can be directly compared with the English version (Table 5).

Table 5 – Numbering equivalence between the English (EN) and Portuguese (PT) versions of the PEC questionnaire.

EN	A1	<b>A2</b>	А3	<b>A4</b>	<b>A5</b>	A6	<b>A</b> 7	<b>A8</b>	A9	В1	B2	ВЗ	B4	В5	В6	В7	В8	В9	B10	B11	B12	B13	C1	C2	СЗ	C4	D1	E1
PT	A1	<b>A2</b>	А3	<b>A</b> 4	Α5	A6	Α7	A8	A9	В1	B2	Χ	В3	В4	Χ	В5	Х	Χ	В6	B7	B8	В9	C1	C2	СЗ	C4	D1	E1

#### DISCUSSION

We adapted, translated and validated the Parents' Experiences of Communication in Neonatal Care questionnaire to the Portuguese population, a tool to assess the level of satisfaction of parents with communication during NICU admission

The assessment of communication practices in neonatal care is challenging yet essential for advancing the field. Using surveys to measure parental satisfaction is a valuable resource in neonatal care. The development of surveys focused on communication can help to evaluate quality and enable parents to voice concerns about specific aspects, allowing targeted strategies to enhance both communication and care. <sup>16,17</sup>

We have identified previously developed and validated tools specifically designed to evaluate communication in NICU settings. The Perceptions of Parent-Staff Communication questionnaire was developed to assess communication quality at two different points during the first two weeks of admission. While it is a reliable instrument, its applicability to other periods remains unknown. The EMpowerment of PArents in the Intensive Care-Neonatology (EMPATHICN) is another valid and reliable instrument for measuring parental satisfaction and has been translated into several languages, including European and Brazilian Portuguese. This tool evaluates both communication and parental involvement in care, although it also includes additional aspects of parental satisfaction and is administered to parents only after discharge. 18-20

The Parents' Experiences of Communication in Neonatal Care (PEC) questionnaire is adapted from a broader, previously developed survey. This former tool, the Parents' Experiences of Neonatal Care questionnaire, was created by the Picker Institute Europe in 2010 and assesses parents' perceptions of care quality across seven distinct domains. Developed in collaboration with parents, this questionnaire was later used in two large-scale surveys in England, in 2010 and 2014, providing valuable data to guide targeted improvement measures in neonatal units.<sup>21,22</sup> To develop the PEC survey, researchers from the Picker Institute and Imperial College London adapted questions from the Parents' Experiences of Neonatal Care survey that focused on communication and parental involvement in care. The new survey was designed to capture real-time feedback, allowing for continuous performance assessment and monitoring improvement interventions. Cognitive interviews and a performance evaluation confirmed its effectiveness in assessing communication in the neonatal parent population.<sup>10</sup>

The translation of the PEC questionnaire to European Portuguese adhered to a rigorous methodology focused on concept and cultural adequacy to achieve a conceptual equivalence rather than a literal translation. A structured,

stepwise approach in collaboration with the original developers ensured the Portuguese version retained the fundamental aspects of the original instrument.

Cognitive interviews confirmed that this instrument is clear, comprehensible and easy to complete. Parental collaboration was essential to maintaining the tool's focus on capturing the parent perspective accurately. Content validity assessment plays a critical role in the development of new instruments, as well as in the translation and adaptation of existing tools. In our study this step ensured representativeness and appropriateness of the content of the questionnaire. The calculation of the I-CVI confirmed the relevance of each included item, and the removal of two items raised the a-CVI to 0.91, a universally accepted value indicating strong content validity.<sup>14</sup>

Performance evaluation demonstrated that this tool is feasible for routine application in everyday practice. Parents adhered to the survey and were willing to repeat it several times if needed to monitor ongoing interventions while still admitted, maintaining a good response rate.

Our study has some limitations. The translated survey was evaluated at a single center which may not fully represent Portuguese hospitals. However, the tool used has been previously tested in a European country, and the sample analyzed is representative of the target population, including mothers and fathers of all ages, at various stages of admission, and requiring different levels of neonatal care. Additionally, the content validity evaluation conducted by professionals from other Portuguese neonatal units helped to address this limitation. In both the cognitive interviews and performance evaluation, an increased number of mothers participated, as they were more frequently present in the unit for several and complex reasons, making it more challenging to enroll additional fathers. Given the limited sample size in our study factor analysis and reliability assessment were not possible. The application of this instrument in larger samples and other units will allow these studies, thus helping to strengthen our validation data.

Lastly, this study and the resulting questionnaire did not include parents who are not fluent in Portuguese, a group that currently represents a significant percentage of admissions. Communication with parents who do not speak the primary language is particularly challenging, and many of these parents feel that the language barrier limits their understanding of their child's condition and hinders their ability to express doubts and concerns.<sup>23</sup> This, in turn, negatively impacts outcomes, as previously noted. Addressing this issue is beyond the scope of this study since the main objective is the validation of the European Portuguese language. However, it is essential to consider this population when designing procedures to measure and improve communication in the NICU, which should address their difficulties.

This can include the translation of this tool into other lanquages.

The PEC survey and European Portuguese translation are available under license through Picker Institute. It is the authors' intention to apply the survey in the differentiated perinatal support unit where it was tested, aiming to specifically identify weaknesses and develop strategies to improve communication with parents. This validated tool will enable the measurement of communication quality and reassessment after implementing the proposed strategies. Additionally, the results may be correlated with parental stress and anxiety scores to provide further information on these outcomes.

Administering the survey in neonatal units across Portugal will support further research involving larger and more diverse populations. Direct comparisons with data gathered using the original version are straightforward (Table 5), facilitating international studies.

#### CONCLUSION

The validation of the PEC questionnaire in Portuguese established the first tool at a national level for objectively assessing the quality of communication with parents in neonatal units. The survey will allow the monitoring of interventions to improve communication, a central feature of familycentered care. Its wider application may also contribute to the development of communication studies nationwide in larger samples and comparison with objective international data.

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# **AUTHOR CONTRIBUTIONS**

RMP: Study design, data collection and interpretation, writing of the manuscript.

RG: Study design, data collection and interpretation, critical review of the manuscript.

LG, RG: Data collection, critical review of the manu-

BS: Study design, critical review of the manuscript.

MCR, AC: Critical review of the manuscript.

All authors approved the final version to be published.

# PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in October 2024.

# **DATA CONFIDENTIALITY**

The authors declare having followed the protocols in use at their working center regarding patients' data publica-

#### **COMPETING INTERESTS**

AC participated on a data safety monitoring board or advisory board for Chiesi.

All other authors have declared that no competing interests exist.

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