

# Validation of an instrument for family participation in the care of hospitalized newborns

Validação de instrumento de participação da família no cuidado do recém-nascido hospitalizado  
Validación de instrumento de participación de la familia en el cuidado del recién nacido hospitalizado

Carolina Queiroz de Souza Mendes<sup>1,2</sup>  <https://orcid.org/0000-0002-8408-6408>

Thaís Morengue Di Lello Boyamian<sup>2</sup>  <https://orcid.org/0000-0001-5056-0522>

Nathália Norma Oliveira de Castro<sup>2</sup>  <https://orcid.org/0000-0003-2876-5593>

Cecília de Souza Lima Michelone<sup>2</sup>  <https://orcid.org/0000-0002-2756-2025>

Myriam Aparecida Mandetta<sup>2</sup>  <https://orcid.org/0000-0003-4399-2479>

Maria Magda Ferreira Gomes Balieiro<sup>2</sup>  <https://orcid.org/0000-0002-4367-5855>

## How to cite:

Mendes CQ, Boyamian TM, Castro NN, Michelone CS, Mandetta MA, Balieiro MM. Validation of an instrument for family participation in the care of hospitalized newborns. Acta Paul Enferm. 2020;33:eAPE20180282.

## DOI

<http://dx.doi.org/10.37689/acta-ape/2020A0022855>



## Keywords

Infant, newborn; Family; Neonatal nursing; Psychometrics; Validation studies

## Descritores

Recém-nascido; Família; Enfermagem neonatal; Psicometria; Estudos de validação

## Descriptores

Recién nacido; Familia; Enfermería neonatal; Psicometría; Estudios de validación

## Submitted

September 11, 2018

## Accepted

January 28, 2020

## Corresponding author

Carolina Queiroz de Souza Mendes  
Email: carolqsmendes@yahoo.com.br

## Abstract

**Objective:** To build and validate an instrument for family participation in newborn care at the neonatal unit.

**Methods:** A methodological research. The construction procedures of assessment instruments proposed by Pasquali were adopted to conduct the theoretical, empirical and analytical steps. Forty representatives of hospitalized newborn families participated in the pilot study; 20 for the semantic validation phase; and 20 for the test and rest. In data analysis, the instrument was validated through psychometric analysis and statistical procedures to verify reliability, validity, estimation of items parameters, and family participation measure.

**Results:** In the theoretical phase, the reception, information, shared autonomy, self-confidence and collaborative relationships constructs, which make up the phenomenal family participation in the care of hospitalized newborns, were identified from integrative literature review. Therefore, the measurement instrument's first version was built, containing 32 items, with Likert-type responses, which was submitted to assessment by the judges. After two rounds, the second version was generated with an 81% agreement percentage and 0.81 content validation index (CVI). In the semantic validation, representatives of twenty families demonstrated an understanding of the items. They considered them relevant, clear, and had no difficulty in answering them. In the empirical phase, the instrument was applied with twenty representatives of families in which a 0.92 Cronbach's Alpha was obtained. In the analytical phase, the 32 items assessed generated seven factors, whose factor loads allowed their maintenance in the final instrument.

**Conclusion:** The instrument proved to have excellent internal consistency, stability over time and items that demonstrated to belong to the analyzed phenomenon. It is necessary to broaden the target population's sample for this indicator to be used to target interventions with the family at the neonatal unit.

## Resumo

**Objetivo:** Construir e validar um instrumento de participação da família nos cuidados do recém-nascido no contexto neonatal.

**Métodos:** Pesquisa metodológica. Os procedimentos de construção de instrumentos de avaliação propostos por Pasquali foram adotados para a condução das etapas teórica, empírica e analítica. Participaram do estudo piloto 40 representantes de famílias de recém-nascido hospitalizados, sendo 20 para a fase de validação semântica e 20 para o teste e resteste. Na análise dos dados o instrumento foi validado por meio da análise psicométrica e dos procedimentos estatísticos para verificar a confiabilidade, validade, estimação dos parâmetros dos itens e da medida da participação da família.

**Resultados:** Na fase teórica identificou-se a partir de revisão integrativa da literatura os constructos acolhimento, informação, autonomia compartilhada, autoconfiança e relacionamento colaborativo, que

<sup>1</sup>Hospital e Maternidade Santa Joana, São Paulo, SP, Brazil.

<sup>2</sup>Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

Conflicts of interest: nothing to declare.

compõem o fenômeno participação da família no cuidado do recém-nascido hospitalizado. Dessa maneira construiu-se a versão I do instrumento de medida, contendo 32 itens, com respostas do tipo *Likert*, que foi submetida a avaliação entre os juízes e após duas rodadas gerou a versão II com percentual de concordância 81% e índice de validação de conteúdo (IVC) de 0,81. Na validação semântica, representantes de vinte famílias demonstraram compreensão dos itens, considerando-os relevantes, com clareza e sem dificuldade para responde-los. Na fase empírica, o instrumento foi aplicado com vinte representantes de famílias em que se obteve *Alpha de Cronbach* de 0,92. Na fase analítica, os 32 itens avaliados geraram sete fatores, cujas cargas fatoriais permitiram sua manutenção no instrumento final.

**Conclusão:** O instrumento demonstrou uma excelente consistência interna, estabilidade ao longo do tempo e itens que demonstraram pertencerem ao fenômeno analisado. Para que este indicador seja utilizado para direcionar as intervenções com família no contexto da unidade neonatal torna-se necessário ampliar a amostra da população-alvo.

## Resumen

**Objetivo:** Elaborar y validar un instrumento de participación de la familia en los cuidados del recién nacido en el contexto neonatal.

**Métodos:** Investigación metodológica. Se adoptaron los procedimientos de elaboración de instrumentos de evaluación propuestos por Pasquali para conducir la etapa teórica, empírica y analítica. Cuarenta representantes de familias del recién nacido hospitalizado participaron en el estudio piloto, de los cuales 20 formaron parte de la fase de validación semántica y 20 del test-retest. En el análisis de los datos, el instrumento se validó por medio del análisis psicométrico y de los procedimientos estadísticos para verificar la confiabilidad, validez, estimación de los parámetros de los ítems y de la medida de participación de la familia.

**Resultados:** En la fase teórica, a partir de la revisión integradora de la literatura, se identificaron los constructos acogida, información, autonomía compartida, autoconfianza y relación colaborativa, que componen el fenómeno participación de la familia en el cuidado del recién nacido hospitalizado. De esta manera, se elaboró la versión I del instrumento de medida, que contenía 32 ítems con respuestas tipo *Likert*, y que fue evaluada por los jueces y, luego de dos rondas, se creó la versión II con un porcentaje de concordancia de 81 % y un índice de validación de contenido (IVC) de 0,81. En la validación semántica, representantes de 20 familias demostraron comprensión de los ítems, fueron considerados relevantes, con claridad y sin dificultad para responderlos. En la fase empírica, se aplicó el instrumento a 20 representantes de familias y se obtuvo un alfa de Cronbach de 0,92. En la fase analítica, los 32 ítems evaluados generaron 7 factores, cuyas cargas factoriales permitieron que se mantengan en el instrumento final.

**Conclusión:** El instrumento demostró una excelente consistencia interna, estabilidad a lo largo del tiempo e ítems que pertenecen al fenómeno analizado. Para que este indicador sea utilizado para orientar las intervenciones con la familia en el contexto de la unidad neonatal, es necesario ampliar la muestra de la población destinataria.

## Introduction

With the increase in survival rates, the focus of neonatal care over the past two decades has shifted to a paradigm centered on improving the quality of care, reducing morbidity through interventions that include developmental care and family-centered care. This change aims at reducing stress, providing support, creating self-regulation, promoting positive experiences for newborns (NB), as well as making their family members essential in routine care.<sup>(1,2)</sup>

In Brazil, the Ministry of Health, through the Brazilian National Humanization Policy (*Política Nacional de Humanização*), establishes reception as an operational guideline for the health work process that requires a new behavior, based on the protagonism of the subjects involved in the health production process; i.e., appreciation and openness to the meeting between health professionals and users. This guideline needs to occur at all levels of health care.<sup>(3,4)</sup>

The Patient- and Family-Centered Care model<sup>(5,6)</sup> recognizes family as a constant in the lives of its members and as the primary responsible entity

for health care. Therefore, in hospitalization there must be a partnership between health professionals and families, with their inclusion in care and decision-making. Family members participate in planning, providing and assessing care together with the team, with mutual benefits among patients, families, and care providers.

Newborn hospitalization in the neonatal unit brings intense suffering and demands to the family members,<sup>(7,8)</sup> highlighting their need to be informed about the clinical conditions and to be able to participate in child care and decision-making.<sup>(6)</sup> The inclusion and promotion of family participation in NB care in the neonatal unit encourages affective bonding, favors NBs' physical and emotional development,<sup>(9,10)</sup> reduces parental stress<sup>(11)</sup> and promotes support for the construction of parenting.<sup>(12)</sup>

With the insertion of patient families in hospitals, the object of nursing care is extended to the child-family binomial, triggering the need to train the health team to meet the demands arising from this care practice. Professionals need to understand that child care should not be disconnected from families and their needs.<sup>(13,14)</sup>

In the science of nursing, the number of studies on measures of subjective phenomena in clinical practice has increased. Among the proposed instruments, there is a gap in empirical indicators on the participation construct from the Patient- and Family-Centered Care model (PFCC) perspective in Brazil and in other countries.<sup>(15-18)</sup> It is believed that a reliable Brazilian instrument for measuring family participation may allow the assessment of interventions by health teams in family care at neonatal units.

This study aimed to build and validate the *Participação da Família do Recém-Nascido em Unidade Neonatal* (PFRN-UN – freely translated as Newborns' Family Participation in a Neonatal Unit) instrument.

## Methods

This is a methodological research for the construction of instruments that adopted the steps proposed by Pasquali regarding the conduct of theoretical, empirical and analytical steps.<sup>(19)</sup>

In the theoretical stage, an integrative review was conducted seeking to identify the indicators of family participation, using the PFCC model as its theoretical framework. Furthermore, the analytical framework was guided by Qualitative Content Analysis. Thus, the themes that emerged from the integrative review comprised the domains and items of the instrument, respecting the 12 criteria recommended by Pasquali,<sup>(20)</sup> which are: amplitude, balance, behavior, simplicity, clarity, relevance, accuracy, modality, typicality, objectivity, variety, and credibility.

From the integrative review, PFRN-UN's first version was built. The instrument assesses family participation in newborn care in neonatal units. The instrument consists of 32 items referring to the five constructs or domains: reception, shared information, autonomy, self-confidence, and collaborative relationship. The Likert-type responses vary between: Never (0), Very rarely (1), Rarely (2), Almost always (3) and Always (4). The score for each domain is the sum of responses to the items divided by

the number of items. Overall score is the sum of the responses of all items divided by the total number of items in the instrument (32). The overall score interpretation is given by the Likert scale gradation value, from zero to four, which varies from never participating in my child's care (zero) to always participating in my child's care (four).

Reception contains seven items on approach and reception of the family at the unit, considering care environment, support, rules and routines that favor family presence and sense of belonging (seven sub-items).

Shared information includes six items related to family members' need to be guided on the evolution of newborns' clinical conditions, in a clear, complete, gradual manner and at the right time.

Autonomy is assessed in six items that address the guarantee of family participation in decision-making, and the availability of spaces for negotiation with the team about the limits of family performance.

Self-confidence includes aspects of family safety and competence in child care and includes six items.

Collaborative relationship describes family members' need to establish a relationship with the multidisciplinary team, in which they feel welcomed, respected and partner in their child care (seven items).

PFRN-UN's first version was submitted to a Committee of Judges specialized in the theme, composed of health professionals who worked in teaching or in a neonatology unit for more than three years and who met the criteria for specialist classification according to Fehring's Validation Model<sup>(21)</sup> adapted for this study, with a score equal to or greater than five. The Committee was composed of two nurses, a doctor, a physiotherapist and a psychologist, in addition to a family representative with a child admitted to the neonatal unit. Some authors<sup>(22)</sup> consider that the inclusion of lay people in the study population ensures the correction of phrases and terms that are not very clear.

This Committee of Judges assessed the instrument in terms of semantics, understanding of items, writing and conceptual relevance. The Delphi tech-

nique was adopted to seek agreement. A questionnaire was filled out by the members, with spaces for each item to be commented in relation to its relevance and for suggestions to be issued. The percentage of agreement, established among the judges, was above 80%. CVI was above 0.80. Thus, from the agreement, PFRN-UN's second version was generated, which was subjected to semantic validation by 20 representatives of families of hospitalized NBs in a neonatal unit for analysis and verification of understanding, clarity of the items, and difficulty in its use. At this stage, the inclusion criterion was to be a family representative of a hospitalized NB in the neonatal unit for more than 72 hours. The exclusion criterion was to be a family representative with self-reported emotional and cognitive disorders, which would result in communication barriers. A questionnaire containing instrument items and space for issuing suggestions was used.

The empirical stage included PFRN-UN's third version application, with another 20 representatives of families of hospitalized NBs in the neonatal unit, for the test-retest, adopting the same inclusion and exclusion criteria.

The field of study of the empirical stage of the measurement instrument validation was a neonatal unit of a teaching hospital in the south of the city of São Paulo. This unit has eight beds for intensive care and 14 beds for semi-intensive care. The multidisciplinary health team is composed of neonatologists, nursing and medical professors, nurses, nursing technicians, physiotherapists, a psychologist, a nutritionist and graduate students in medicine, nursing, physiotherapy and speech therapy.

At the neonatal unit, parents are encouraged to carry out daily activities related to newborns' body hygiene, such as bathing, changing diapers, dressing on umbilical stumps, oral hygiene, and eye cleaning. We adopted the Kangaroo Mother Care strategy, Parents Group and listening with psychological assistance. Since 2014, the family-centered care model has been established with professional awareness and adoption of good practices with families to be followed in this space.

For the empirical phase, the same inclusion and exclusion criteria were used as in the previous

phases. The variables defined for the sociodemographic characterization of the family representatives were: sex, color, education level, profession, number of children and family composition, family income (in minimum wage) and adopted religion. The perinatal and neonatal variables were: number of prenatal consultations, length of hospital stay at the time of the interview with the family representative, gestational age at birth, birth weight, sex, Apgar score, type of delivery and medical diagnoses.

The analysis stage aimed to validate the instrument through psychometric analysis and statistical procedures to verify reliability, validity, estimation of item parameters and family participation measurement.

In this stage, family participants' sociodemographic variables and scale application results were analyzed using descriptive statistics. Categorical variables presented absolute frequency (n) and relative frequency (%); numerical variables, by appropriate measure, such as means, medians, standard deviation and confidence interval.

Internal item consistency was analyzed by Cronbach's Alpha ( $\alpha$ ). The intraclass correlation coefficient was used to measure reliability, and thus instrument stability and reproducibility in the test-retest, which was applied with an interval of 72 hours. Its value ranges from -1 to 1 and, for better understanding, it was transformed into a percentage.<sup>(19,23)</sup>

The Kaiser-Meyer-Olkin (KMO) measure was used to verify sample adequacy for the factor analysis.

For construct validity, exploratory factor analysis and main component analysis with orthogonal rotation were adopted, by the Varimax method, applied with the objective of maximizing the sum of the variances of the factor matrix loads.<sup>(19)</sup> An acceptable factor load was considered to be values above 0.4 for maintaining the item in the final instrument.<sup>(19)</sup>

In the comparison, in the test-retest, of the answers per question and in the overall score of the instrument, Wilcoxon's non-parametric test was applied.

The significance level adopted for the tests was 5% ( $p = 0.005$ ), and the statistical package used was

SPSS for Windows, version 17.0 (SPSS Inc. Chicago, Illinois), Minitab 16 and Excel Office 2010.

The project complied with national and international principles (CNS Resolution (*Conselho Nacional de Saúde* – Brazilian National Health Board) n° 466/12) adopted to research with human beings. It has been approved by the Research Ethics Committee of the institution the researchers are part of, under Opinion n° 449,048.

## Results

In the theoretical phase, the PFRN-UN instrument presented 28 items, a percentage of agreement among the judges of 100% and an 1.0 CVI. In four items, there has been 83.3% agreement and 0.83 CVI, after two rounds of assessment. The instrument as a whole obtained a 0.81 CVI. The items with the least agreement were found in the Reception (one item); Shared Information (two items); and Autonomy (one item) domains. Suggestions were related to text wording format, with no changes in the conceptual content of each of the instrument items. This way, the PFRN-UN second version was generated.

Regarding semantic validation, representatives of twenty families demonstrated an understanding of the items. They considered the items relevant, clear, and they had no difficulty in answering them. Only in item 31 there was a suggestion to modify the word “opening” by “space”, which was accepted by the researchers. Thus, PFRN-UN’s third version was generated, without changing its conceptual content.

In the empirical phase of instrument construction, with the participation of 20 representatives, all were female (100%), with complete secondary education (60%), white (60%) and with a partner (75%), 50% were in a stable union and 25% declared to be married. The mean age was 26.9 ( $\pm 6.6$ ) years. Most respondents had no employment (75%), adopted the Catholic religion (60%) and came from the city of São Paulo (75%).

Family composition averaged 4.8 ( $\pm 1.2$ ) people per family, 2.5 ( $\pm 1.2$ ) children and a mean income of 4.9 ( $\pm 1.7$ ) minimum wages.

As for perinatal and neonatal variables, mothers performed a mean of 9.0 ( $\pm 4.0$ ) prenatal consultations. Most NBs were born by cesarean delivery (80%), their mean birth weight was 2264 ( $\pm 865$ ) grams; Apgar score in the first minute of 5.4 ( $\pm 1.3$  points) and 7.4 ( $\pm 1.3$  points) in the fifth minute; and 36<sup>4/7</sup> ( $\pm 1$ <sup>4/7</sup> confidence interval) weeks of gestational age.

The most frequent diagnosis presented by NBs were prematurity (75%), followed by congenital anomaly (55%), perinatal asphyxia (15%) and congenital infection (10%).

As for PFRN-UN’s third version, there were three statistically significant differences in the test-retest, in the following items: 7. “*The presence of other family members at my side in the unit is guaranteed*” ( $p = 0.034$ ); 25. “*I can understand the situations experienced by my son and the interventions that support his child development*” ( $p = 0.034$ ); and 30. “*The health team respects my strength and understands how I experience and face my child’s hospitalization*” ( $p = 0.034$ ). This shows that in most items the results were the same, that is, reliable.

In the analytical stage, PFRN-UN’s third version application data reliability showed statistically significant correlations in most items (Table 1). Therefore, the responses to the PFRN-UN items are stable over time. However, item 12. “*The health team has been supportive for me to understand the information about my son*” ( $p = 0.207$ ) did not demonstrate reliability in the test-retest.

To analyze instrument item grouping into domains or factors, the KMO was initially calculated, with a result of 0.835 that allowed the factorial analysis to be carried out. The result of the Bartlett test was significant ( $p < 0.001$ ), demonstrating that the data are correlated with each other.

The factor analysis by the main component method demonstrated the variability explained by each factor, with eigenvalues greater than one. The 32 items generated seven factors, in which the total variability was 89.95%, which is considered excellent. The first factor holds 36.22% of the data variability. Factorial loads found for questions or items allow them to be kept in the instrument (Table 2).

**Table 1.** Intraclass correlation index (ICI) of the test-retest per item of the Newborns' Family Participation in a Neonatal Unit instrument

	PFRN-UM items	ICI	p-value*
Reception	q1. I have support from the health team to be with my son in the neonatal unit.	92.6%	<0.001
	q2. I know the characteristics and functioning of the neonatal unit environment.	83.1%	<0.001
	q3. There is a private environment for me to stay in the unit.	82.3%	<0.001
	q4. I have accommodations to be with my son.	92.3%	<0.001
	q5. My access to the unit is free to be with my son.	81.4%	<0.001
	q6. I feel as part of the unit's health team.	89.3%	<0.001
Autonomy	q7. The presence of other family members at my side in the unit is guaranteed	94.4%	<0.001
	q8. Information about my child is provided in a clear and easy to understand manner.	71.4%	0.004
	q9. I receive information in a complete way that meets my needs.	72.8%	0.003
	q10. I receive information about my child in writing.	79.1%	0.001
	q11. I am informed about the care received by my child at different times of hospitalization (admission, period of hospitalization and discharge).	77.0%	0.001
	q12. The health team has been supportive for me to understand information about my son.	31.7%	0.207
Shared information	q13. I have the information at the right time to make a decision about my son.	61.3%	0.023
	q14. Decision-making about my child is done with my participation.	86.8%	<0.001
	q15. I can negotiate about my child's care with the team.	83.6%	<0.001
	q16. I am open to discuss with the health team about the limits of my participation in the care of my child.	90.6%	<0.001
	q17. I am considered by the health team as the main responsible person for my son.	82.1%	<0.001
	q18. I have my independence guaranteed in the care of my son.	73.3%	0.003
Self-confidence	q19. My ideas, beliefs, values and knowledge are considered by the team.	86.1%	<0.001
	q20. I feel more confident for hospital discharge when I take care of my son.	84.2%	<0.001
	q21. I am encouraged and supported by the health team to take care of my child.	82.0%	<0.001
	q22. I perceive the health team stimulating my bond with the baby.	66.0%	0.012
	q23. I feel like a partner in the care of my son.	59.5%	0.028
	q24. I am taught by the health team to recognize my child's individualities.	79.1%	0.001
Collaborative relationship	q25. I can understand the situations experienced by my son and the interventions that support his child development.	73.0%	0.003
	q26. I am welcomed by the health team without judgment.	82.6%	<0.001
	q27. I am invited to attend meetings and clinical visits.	78.4%	0.001
	q28. I consider that I have a bond and partnership relationship with the health team.	83.7%	<0.001
	q29. I am understood by the health team in my social history.	82.2%	<0.001
	q30. The health team respects my strength and understands how I experience and face my child's hospitalization.	87.3%	<0.001
	q31. I have space to have my questions answered.	74.5%	0.002
	q32. My emotional needs are met.	82.8%	<0.001
	Overall score	93.1%	<0.001

\* Wilcoxon's Test

**Table 2.** Factor load of the Newborns' Family Participation in a Neonatal Unit instrument items in each factor

Questions	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
q.22	0.937						
q.12	0.855						
q.21	0.758						
q.3	0.755						
q.30	0.740						
q.24	0.739						
q.25	0.703						
q.28	0.654						
q.11	0.642						
q.8	0.551						
q.7		0.909					
q.6		0.893					
q.5		0.767					
q.16		0.698					
q.4		0.696					
q.1		0.659					
q.15		0.583					
q.31			0.836				
q.32			0.831				
q.17			0.816				
q.29			0.712				
q.25			0.589				
q.18			0.536				
q.9				0.822			
q.14				0.775			
q.19				0.486			
q.20.					-0.878		
q.13					0.665		
q.24					0.635		
q.10					0.551		
q.2						0.845	
q.27							0.857

Extraction Method: Main Component Analysis; Rotation Method: Varimax with Normalization of Kaiser Normalization; Rotation converted into 14 interactions.

PFRN-UN third version internal consistency calculated by Cronbach's Alpha was high (0.922).

PFRN-UN overall score, measured by PFRN-UN pilot application, with twenty representatives of families, presented a median of 1.94, and a mean of 2.01 (± 0.48), evidencing the perception that very rarely the family participates in NB care at the neonatal unit.

The highest item scores were related to knowledge of the characteristics and functioning of the neonatal unit; recognition of their responsibility for the NB; the support of the team for the family to remain in the unit; and the feeling of being prepared for hospital discharge of NBs, with a response of almost always (mean of 3.0).

PFRN-UN third version internal consistency calculated by Cronbach's Alpha was high (0.922).

PFRN-UN overall score, measured by PFRN-UN pilot application, with twenty representatives of families, presented a median of 1.94, and a mean of 2.01 ( $\pm$  0.48), evidencing the perception that very rarely the family participates in NB care at the neonatal unit. The highest item scores were related to knowledge of the characteristics and functioning of the neonatal unit; recognition of their responsibility for the NB; the support of the team for the family to remain in the unit; and the feeling of being prepared for hospital discharge of NBs, with a response of “almost always” (mean of 3.0). The answer “never” of the family representatives was present in the items related to receiving written information and inclusion of the family in meetings or clinical visits. However, the answer “very rarely” was scored in item 19, regarding having their ideas, beliefs, values and knowledge considered by the health team; item 28, having a bond and partnership with the team and item 29, being understood in their life history.

## Discussion

The results obtained through PFRN-UN validation in the pilot study indicated satisfactory psychometric properties for its use in clinical practice.

PFRN-UN third version obtained a high value of Cronbach's Alpha. This is an indicative of excellent internal consistency;<sup>(18,19)</sup> ease of understanding by participants; content adequacy and reliability. Therefore, the instrument items refer to the construct that is being measured, meeting the recommendations in validation studies.<sup>(23)</sup>

Among the 32 items, two were each constituted in an isolated factor, with a high factor load, which requires its permanence on the scale, but indicates the need for further refinement. Thus, there is a need to broaden the sample size to confirm this result, considering that validation studies recommend the use of a larger sample to report more reliable results.<sup>(23)</sup> Another possibility is sample calculation adoption, based on the pilot test of the study, considering a 5% statistical error. Sample size broadening may modify

the configuration of PFRN-UN version III instrument in the groupings by domains.

The results of the instrument application showed data that contribute to practice assessment related to PFCC. In this study, respondents very rarely perceive the family participating in NB care in the neonatal unit. The literature shows that family participation in the NICU benefits children's neuropsychomotor development. Skin-to-skin contact accelerates brain maturation and breastfeeding favors cognitive development, especially in premature infants. Moreover, it reduces anxiety, depression and parental stress.<sup>(24,25)</sup>

Health professionals also demonstrate beliefs and behaviors restrictive to the presence of families in the neonatal unit. Also, they often do not realize that, by limiting their participation, they harm the emotional bond between parents and newborns. In the daily of the life of the neonatal unit, it is still possible to identify the request for the family companion to leave for invasive procedures, during medical visit times, due to reduced physical space and shortage of human resources.<sup>(26,27)</sup>

The use of an instrument to measure family participation at the neonatal unit may be an indicator of family insertion in the neonatal unit and contribute to improving the quality of care in this context.

Thus, it is necessary to expand the target population sample, refining the domains to ensure their reliability and use in other hospital contexts.

## Conclusion

The instrument obtained a high level of agreement between the judges and the target population, as well as good internal consistency. The 32 items that make up the instrument generated seven factors or domains. Factor loads allowed their maintenance in the final version of the instrument. The data from PFRN-UN application may be an indicator in user satisfaction assessment with health system organization and in relation to professional performance while approaching the family.

## Collaborations

Mendes CQS, Boyamian TMDL, Castro NNO, Michelone CSL, Mandetta MA, Balieiro MMFG collaborated in the stages of study design, analysis, data interpretation, article writing, relevant critical review of the intellectual content and final approval of the version to be published.

## References

- Morisaki N, Zhang X, Ganchimeg T, Vogel JP, Souza JP, Cecatti JG, et al. Provider-initiated delivery, late preterm birth and perinatal mortality: a secondary analysis of the WHO multicountry survey on maternal and newborn health. *BMJ Glob Health*. 2017;2(2):e000204.
- Samra HA, McGrath JM, Wehbe M, Clapper J. Epigenetics and family-centered developmental care for the preterm infant. *Adv Neonatal Care*. 2012;12 Suppl 5:S2–9.
- Martins CP, Luzio, CA. Experimentações no apoio a partir das apostas da Política Nacional de Humanização - HumanizaSUS. *Interface - Comunicação, Saúde, Educação*. 2014; 18(1):1099-106.
- Freitas FD, Silva RN, Araújo FP, Ferreira MA. Environment and humanization: resumption of nightingale's discourse in the national humanization. *Esc Anna Nery*. 2013;17(4):654–60.
- DiGioia AM, Greenhouse PK. Creating value with the patient- and family-centered care methodology and practice: what trainees need to know, why, and strategies for medical education. *AMA J Ethics*. 2016;18(1):33–9.
- Ramezani T, Hadian Shirazi Z, Sabet Sarvestani R, Moattari M. Family-centered care in neonatal intensive care unit: a concept analysis. *Int J Community Based Nurs Midwifery*. 2014;2(4):268–78.
- Wang L, He JL, Fei SL. Perceived Needs of Parents of Premature Infants in NICU. *West J Nurs Res*. 2018;40(5):688–700.
- Conz CA, Merighi MA, de Jesus MC. Promoção de vínculo afetivo na unidade de terapia intensiva neonatal: um desafio para as enfermeiras. *Rev Esc Enferm USP*. 2009;43(4):849–55.
- O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy Childbirth*. 2013;13 Suppl 1:S12.
- White-Traut RC, Rankin KM, Yoder JC, Liu L, Vasa R, Geraldo V, et al. Influence of H-HOPE intervention for premature infants on growth, feeding progression and length of stay during initial hospitalization. *J Perinatol*. 2015;35(8):636–41.
- Milgrom J, Newnam C, Martin PR, Anderson PJ, Doyle LW, Hunt RW, et al. Early communication in preterm infants following intervention in the NICU. *Early Hum Dev*. 2013;89(9):755–62.
- Hall SL, Hynan MT, Phillips R, Lassen S, Craig JW, Goyer E, et al. The neonatal intensive parenting unit: an introduction. *J Perinatol*. 2017;37(12):1259–64.
- Melo EM, Ferreira PL, Lima RA, Mello DF. The involvement of parents in the healthcare provided to hospitalized children. *Rev Lat Am Enfermagem*. 2014;22(3):432–9.
- Galarza-Winton ME, Dicky T, O'Leary L, Lee SK, O'Brien K. Implementing family-integrated care in the NICU: educating nurses. *Adv Neonatal Care*. 2013;13(5):335–40.
- Cruz AC, Angelo M, Santos BP. Self-efficacy scale for the establishment of good relationships with families in neonatal and pediatric hospital settings. *Rev Esc Enferm USP*. 2017;51:e03222.
- Quemelo PR, Milani D, Bento VF, Vieira ER, Zaia JE. Literacia em saúde: tradução e validação de instrumento para pesquisa em promoção da saúde no Brasil. *Cad Saude Publica*. 2017;33(2):e00179715.
- Arigliani M, Castriotta L, Pusiol A, Titolo A, Petoello E, Brun Peressut A, et al. Measuring empathy in pediatrics: validation of the Visual CARE measure. *BMC Pediatr*. 2018;18(1):57.
- Andrade RC, Leite AC, Alvarenga WA, Martimiano RR, Santos CB, Nascimento LC. Tradução e adaptação cultural do Needs of Parents Questionnaire (NPQ) para uso no Brasil. *Esc Anna Nery*. 2018;22(1):e20170104.
- Pasquali L. Princípios de elaboração de escalas psicológicas. *Rev Psiquiatr Clin (Santiago)*. 1998;25(5):206–13.
- Pasquali L. Psicometria. *Rev Esc Enferm USP*. 2009; 43(Esp):992-9.
- Fehring RJ. The Fehring model. In: Carrol-Johnson RM, Paquete M, editores. *Classification of nursing diagnoses: proceedings of the Tenth Conference*; 1994. Philadelphia: J.B. Lippincott; 1994. p. 55-62.
- Coluci MZ, Alexandre NM, Milani D. Construção de instrumentos de medição na área da saúde. *Cien Saude Colet*. 2015;20(3):925–36.
- Streiner DL, Kottner J. Recommendations for reporting the results of studies of instrument and scale development and testing. *J Adv Nurs*. 2014;70(9):1970–9.
- Skene C, Gerrish K, Price F, Pilling E, Bayliss P. Developing family-centred care in a neonatal intensive care unit: an action research study protocol. *J Adv Nurs*. 2016;72(3):658–68.
- Tobiano G, Marshall A, Bucknall T, Chaboyer W. Patient participation in nursing care on medical wards: an integrative review. *Int J Nurs Stud*. 2015;52(6):1107–20.
- Ferreira CA, Balbino FS, Balieiro MM, Mandetta MA. Family presence during cardiopulmonary resuscitation and invasive procedures in children. *Rev Paul Pediatr*. 2014;32(1):107–13.
- Reis CA, Andrade AC, Manzo BF, Couto DL, Duarte ED. The family-centered care practices in newborn unit nursing perspective. *Esc Anna Nery*. 2015;19(4):629–34.