

# Parental participation in care during Neonatal Intensive Care Unit stay: a validation study

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## Abstract

**Introduction:** Although the Neonatal Intensive Care Units (NICU) can offer lifesaving care for vulnerable newborns after birth, separation from the parents, pain, sleep disruptions, and environmental stressors can be traumatic experiences for these critically ill newborns. At the same time, the new parents can experience a situation they are not prepared for, such as separation from the newborn, and fear of the unknown, which, together disrupt the family ties, which are created and strengthened right during the moment of birth. Evaluating the participation of the parents in neonatal care during their children's stay in the NICU allows health professionals to highlight possible gaps in the correct management of the babies by the parents, intervening where it is necessary, with proper education and support.

**Aim:** To validate the Italian version of "The Scale of Parental Participation in Care: Neonatal Intensive Care Unit" (PPCS: NICU).

**Methods:** The study was conducted in a 22-bed mixed (medical and surgical) NICU of a public hospital. The study participants comprised parents whose infants were admitted to the NICU from April to August 2022.

**Results:** A total of 128 parents were included in the study. Exactly half of the sample was female, and the average age was 33.43 ± 6.51 years; 31.25% (n=40) of the sample already had a first child. Those who had a history of previous abortion were 25% (n=32). Additionally, 3.12% (n=4) of parents experienced a previous death of their child. About the type of delivery, 54.69% (n=70) of the sample experienced vaginal birth, 17.19% (n=22) of them underwent an elective cesarean, and 28.12% (n=36) underwent an emergency cesarean. Item analysis was performed on all 16 items. The corrected total item correlation coefficients for the scale items were adequate between 0.408 and 0.821. Cronbach's alpha was 0.926.

**Conclusion:** The Italian version of the PPCS: NICU shows high reliability and therefore, it can be used in the context of Italian NICUs to assess the degree of parental participation in neonatal care, allowing early identification of critical issues by parents in

the care of newborns admitted to NICU.

**Keywords:** Parenthood, Neonatal Intensive Care Unit, Parental Participation, Nurses.

## Introduction

Although Neonatal Intensive Care Units (NICU) can offer lifesaving care for vulnerable newborns after birth, separation from the parents, pain, sleep disruptions, and environmental stressors may represent traumatic experiences for these critically ill newborns<sup>1</sup>. At the same time, the new parents can experience a situation they are not prepared for, such as separation from the newborn, and fear of the unknown, which, together disrupt the family ties, which are created and strengthened right during the moment of birth<sup>2</sup>. The first thirty days of a child's life represent a necessary period for correct psychophysical development; furthermore, the parents' strong knowledge and adequate and responsible behavior are fundamental in improving outcomes and providing a more effective relationship with the healthcare services<sup>3</sup>. Family-Centered care is one of the strategies that can help infants and parents to cope with these traumatic experiences in the NICU<sup>4</sup>. Parental participation in care has positive outcomes for both infants and parents<sup>5,6</sup>. Indeed, involvement in neonatal care reduces parents' stress levels, increasing their self-esteem and interaction with the baby<sup>4</sup>, thus reducing parents' anxiety levels and improving their problem-solving skills<sup>7</sup>. Evaluating the participation of parents in neonatal care during their children's NICU hospitalization allows healthcare professionals to highlight any gaps in the correct management of the baby by the parents, intervening, where necessary, with proper education and support.

This study aims to validate the Italian version of "The Scale of Parental Participation in Care: Neonatal Intensive Care Unit" (PPCS: NICU)<sup>8</sup>.

## Methods

This is a cross-cultural validation study using a back translation and monolingual test<sup>9</sup>. In the first phase, after formal authorization from the author of the original version of the tool, a back translation using two translators was performed. The draft of the Italian version was evaluated by an expert panel composed of five NICU nurses for face and content validity. In this phase, each expert rated all items of the translated tool as "essential," "useful but

not necessary," or "useless." In the second phase, an evaluation of the psychometric properties was carried out.

## Setting and Population

The study was conducted in a 22-bed mixed NICU (medical and surgical) of a public hospital. The study participants comprised parents whose infants were admitted to the NICU from April to August 2022 and agreed to participate. During data collection, parents were allowed to enter the NICU twice a day, for a maximum of two hours, due to visiting limitations related to COVID-19.

## Data Collection

The newborns' clinical data and the parents' socio-demographic data were collected on a personal data sheet. Parents were assisted and observed for three days after admitting the newborn. On the third day, parental participation in neonatal care was evaluated, and the assessment was carried out by the nurse who was in charge of the newborn and who assisted the parents entering the ward.

## Description of the instrument

A previous review of the literature showed the need for validated tools to measure parents' participation in care<sup>8</sup>. For this reason, Ceylan and colleagues (2021) designed the PPCS: NICU, an instrument consisting of one dimension and 16 items<sup>8</sup> (Fig. 1). In this study, the corrected item-total correlation coefficients were between 0.48 and 0.78, and cronbach's alpha level was 0.93. The intraclass correlation level was 1.000 ( $p = <0.001$ ). The response categories were as follows; 3 = always, 2 = sometimes, 1 = never. The total score of the scale ranges from 16 to 48, with higher scores indicating higher involvement of the parent in the care. No cut-off points have been provided by the authors<sup>8</sup>.

Content validity was performed using Davis' method<sup>10,11</sup>. Cronbach's alpha reliability level and item-total score reliability were used to evaluate the translated scale's reliability.

## Statistical Analysis

EXCEL<sup>®</sup> was used to store the data. Descriptive

statistics were reported as appropriate after testing continuous variables for normality of the distribution by the Shapiro-Wilk test. Frequency and percentage were reported for nominal variables, whereas average and standard deviation (SD) were calculated for quantitative variables. A  $\chi^2$  test was performed to compare categorical variables. Analysis of variance was performed to estimate the size of the association between parents' features and total scale scores. Statistical significance was set to a p-value lower than 0.05. Statistical analysis was performed using IBM® SPSS Statistics software version 22.0.

### Ethical issues

The study was conducted by the principles of the original Declaration of Helsinki and subsequent amendments. Written informed consent was obtained from all participants. Data were stored and managed in accordance with current Italian legislation on data protection. Data were collected and analyzed in anonymous and aggregated form. The Institutional Review Board of the hospital where data collection was performed approved this study.

### Results

A total of 128 parents were included in the study. Exactly half of the sample was female, and the average age was  $33.43 \pm 6.51$  years; 31.25% (n=40) of the sample already had a first child. Those who had a history of previous abortion were 25% (n=32). Additionally, 3.12% (n=4) of parents experienced a previous death of their child. Concerning the type of delivery, 54.69% (n=70) of the sample experienced vaginal birth, 17.19% (n=22) of them underwent an elective cesarean, and 28.12% (n=36) underwent an emergency cesarean. Among the newborns, 14.07% (n=9) were twins. The average gestational age of newborns was  $35.62 \pm 4.31$  weeks, whereas the average weight at birth was  $2638.67 \pm 968.83$  grams.

### Scale Proprieties

The five panelists judged face validity as appropriate. The content validity index (CVI) was 0.976 (Table 1). Item analysis was performed on all 16 items. The item-total correlation coefficients for the scale items were between 0.408 and 0.821. Cronbach's alpha was 0.926. Therefore, no item was removed from the translated scale (Table 2). The items of the final tool are reported in Table 3.

Tab 1 - Rating of the 16-items tool by five panelists; CVI: content validity index

Question	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Item CVI
1	✓	✓	✓	✓	✓	1
2	✓	✓	✓	✓	✓	1
3	✓	✓	✓		✓	0.6
4	✓	✓	✓	✓	✓	1
5	✓	✓	✓	✓	✓	1
6	✓	✓	✓	✓	✓	1
7	✓	✓	✓	✓	✓	1
8	✓	✓	✓	✓	✓	1
9	✓	✓	✓	✓	✓	1
10	✓	✓	✓	✓	✓	1
11a	✓	✓	✓	✓	✓	1
11b	✓	✓	✓	✓	✓	1
12	✓	✓	✓	✓	✓	1
13	✓	✓	✓	✓	✓	1
14	✓	✓	✓	✓	✓	1
15	✓	✓	✓	✓	✓	1
16	✓	✓	✓	✓	✓	1
CVI						0.976

Tab 2 - Item Analysis and internal consistency of the translated version; SD: standard deviation

N	Mean	SD	Corrected Item total correlation	Cronbach's alfa if item deleted
1	2.49	0.575	0.613	0.922
2	2.70	0.583	0.623	0.922
3	2.66	0.506	0.807	0.917
4	2.93	0.257	0.502	0.926
5	2.84	0.365	0.715	0.921
6	2.93	0.257	0.554	0.925
7	2.68	0.546	0.821	0.916
8	2.70	0.462	0.693	0.920
9	2.56	0.529	0.672	0.921
10	2.66	0.551	0.799	0.917
11	2.94	0.301	0.408	0.927
12	2.09	0.620	0.697	0.920
13	2.19	0.585	0.642	0.922
14	2.67	0.549	0.714	0.919
15	2.37	0.573	0.429	0.928
16	2.53	0.614	0.666	0.921
Total scale score			41,95 ± 5.58	
Alfa di Cronbach			0.926	

Legend: SD - standard deviation.

Table 3 - Items of Italian version of the Scale of Parental Participation in Care: Neonatal Intensive Care Unit

N.	ITEM
1	Il genitore comunica con il personale sanitario
2	Il genitore pone domande riguardo l'assistenza ed il trattamento di suo/a figlio/a
3	Il genitore è disponibile a partecipare ad addestramenti erogati nella Terapia Intensiva Neonatale
4	Il genitore desidera visitare il/la proprio/a figlio/a
5	Il genitore desidera avere contatto fisico con il/la figlio/a (accarezzare, tenere le mani, ecc...)
6	Il genitore usa termini affettuosi con suo/a figlio/a
7	Il genitore desidera tenere in braccio il/la figlio/a
8	Il genitore prova a calmare il/la proprio/a figlio/a (cullandolo, cantando, ecc...)
9	Il genitore è attento a posizionare il/la figlio/a in una posizione comoda e consona
10	Il genitore partecipa all' alimentazione del figlio/a
11a	La mamma è disposta ad allattare al seno (per le madri)
11b	Il papà supporta la mamma affinché il figlio/a riceva latte materno (per i padri)
12	Il genitore partecipa alle cure igieniche del figlio/a
13	Il genitore si accorge di qualsiasi peggioramento nelle condizioni generali del figlio/a
14	Il genitore desidera eseguire il contatto pelle a pelle o desidera partecipare alla Kangaroo care con suo figlio/a
15	Il genitore supporta suo figlio/a durante procedure dolorose
16	Il genitore esterna le proprie emozioni e i propri pensieri.

### Tool Scores according newborns' characteristics

There was no statistical difference between the average total score of the scale across mothers and fathers. Parents of first children reported significantly greater participation in care ( $p=0.007$ ), compared to their counterparts. At the same time, previous deaths ( $p = 0.014$ ) and abortion ( $p= 0.039$ ) emerged as early barriers to parental participation in care. Difference emerged according to the type of delivery with a lower participation by those underwent emergency cesarean ( $p < 0.001$ ) (Table 4).

### Total scores of the scale according to newborns' characteristics.

The average scores obtained by the parents about the medical devices placed on their children at the time of the survey were detailed in Table 5. We found that the greater the criticality of the child, the lower was the participation in care by the parents. Parents of children who underwent high-frequency ventilation ( $p < 0.001$ ), tracheal tube ( $p<0.001$ ), and arterial catheter ( $p = 0.016$ ) reported significantly lower participation in care. Furthermore, the parents of children undergoing phototherapy, which does not allow for the free manipulation of children, also reported lower scores ( $p = <0.001$ ), with respect to their counterparts.

Table 4 - Mean Scores according sample's characteristics

Characteristics	Average $\pm$ SD	P Value
Parent		
Mother	42,75 $\pm$ 4,85	0.103
Father	41,14 $\pm$ 6,16	
First Child		
Yes	42,83 $\pm$ 4,31	0.007
No	40,00 $\pm$ 7,38	
Previous abortions		
Yes	40,19 $\pm$ 6,65	0.039
No	42,53 $\pm$ 5,08	
Deceased children		
Yes	35,25 $\pm$ 5,90	0.014
No	42,16 $\pm$ 5,46	
Delivery		
Vaginal	42,83 $\pm$ 5,49	
Elective Cesarean	43,77 $\pm$ 2,68	0.001
Emergency Cesarean	39,11 $\pm$ 6,10	
Twins		
Yes	41,68 $\pm$ 3,16	0.826
No	41,99 $\pm$ 5,91	

Legend: SD - standard deviation.

Table 5 - Mean Scores according medical device placed on children

Device	(N) Average ± SD						P Value
	Yes			No			
Peripheral venous access	(77)	42,87	± 5,17	(51)	40,55	± 5,93	.021
Caval epicutaneous catheter	(16)	40,31	± 4,60	(112)	42,18	± 5,69	.212
Umbilical venous catheter	(64)	39,61	± 6,48	(64)	44,28	± 3,12	< .001
Continuous infusions	(110)	41,37	± 5,73	(18)	45,44	± 2,59	.004
Arterial catheter	(8)	37,38	± 3,96	(120)	42,25	± 5,55	.016
High flow nasal cannula	(20)	43,35	± 5,18	(108)	41,69	± 5,64	.222
Non Invasive Ventilation	(8)	39,25	± 5,12	(120)	42,13	± 5,58	.159
Tracheal tube	(36)	37,61	± 6,70	(92)	43,64	± 3,98	< .001
High frequency Ventilation	(10)	35,10	± 5,93	(118)	42,53	± 5,17	< .001
Gastric tube	(54)	39,52	± 5,55	(74)	43,72	± 4,93	< .001
Cerebral Function Monitor	(6)	41,17	± 4,75	(122)	41,98	± 5,64	.728
Bladder catheter	(10)	37,90	± 3,78	(118)	42,29	± 5,58	.016
Temperature probe	(57)	38,58	± 5,94	(71)	44,65	± 3,42	< .001
Phototherapy	(22)	35,50	± 6,54	(106)	43,28	± 4,31	< .001
CO <sub>2</sub> sensor	(32)	36,44	± 6,16	(96)	43,76	± 3,97	< .001

Legend: SD - standard deviation.

## Discussion

The Italian version of the PPCS: NICU is composed of 16 items, which is similar to the original scale<sup>8</sup>. No items were eliminated during the cross-cultural validation of the scale. The Cronbach's alpha coefficient of 0.926 reflects a strong reliability of the instrument. This scale can be used within the Italian NICUs to detect the level of parental participation in neonatal care and highlight those situations of need that require health education interventions to improve the process of caring for their newborns. Parents who have experienced previous abortions obtained a lower score than those who have suffered the loss of a previous child. These results can be related to the fears and insecurities of the parents resulting from their past experience. According to the type of birth, the parents who obtained a lower score are those who underwent emergency caesarean; this represent an unscheduled and disrupting surgical event they are often not prepared for, thus subjected at a higher risk of insecurities and need for support. Also, when a baby is admitted to NICU, periods of separation may result, and depending on the mother's physical health, these periods can be significantly long. The impact of separation from the child may reflect a reduction in mother-child

interactions<sup>12</sup>.

There was a statistically significant difference between those who already had a child, and those who gave birth to their firstborn; notably, this latter group reported higher scores compared to those who already had this experience. Indeed, the poor availability of babysitting services for other children may represent a barrier to parenting in NICU, as described in a previous study<sup>13</sup>. Furthermore, this difference could be attributed to the restricted visiting policy due to COVID-19 regulations that have reduced the times of visits and stays of parents with hospitalized newborns. We observed how greater parental participation in care is detected in the presence of minimally invasive or commonly used devices in the NICU setting, such as a high-flow nasal cannula, epicutaneous venous catheters, and the presence of continuous infusion. Lower participation in care was detected in the presence of invasive devices and instruments typical of a critical condition, such as the presence of the tracheal tube, arterial catheter, and high-frequency oscillatory ventilation. The only exception is represented by phototherapy, which negatively influences the participation in care despite being a non-invasive device, but this could be linked to the peculiarity

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of this instrumentation which does not allow the mobilization of the child in the parents' arms. Implementing the PPCS: NICU in neonatal care may help promoting an early detection of parents in need of support, and may provide important information regarding which medical device aids most and influence parental participation in neonatal care, being able to intercept and educate parents already at the time of placing the specific devices on newborns.

### **Limitations**

As reported in a previous study<sup>9</sup>, there is no perfect translation technique, and multiple methods would have probably ensured higher accuracy. However, the sample size complies with the suggestion to follow lower minimum ratios between participants and items (5:1 or 10:1)<sup>14</sup>.

### **Conclusions**

The present study demonstrates that the translated tool shows high reliability and could be used in the context of Italian NICUs to assess the degree of parental participation in neonatal care, allowing early identification of critical issues by parents in the care of newborns admitted in NICU. The issues found in newborn care can be the subject of targeted health education interventions, aimed at empowering parents and making them independent in the common care activities and parenthood of their children. The systematic use of the tool could index parents based on their characteristics, being able to predict which categories need more support and health education. At the same time, it could predict which parents will need support based on the medical devices placed on the newborn.

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