Factors associated with parental stress in a Neonatal Intensive Care Unit

Fatores associados ao estresse de pais em Unidade de Terapia Intensiva Neonatal

Factores asociados al estrés de padres en Unidad de Cuidados Intensivos Neonatales

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Abstract

Objective: To analyze the stress-related factors of parents of newborns hospitalized in a Neonatal Intensive Care Unit.

Methods: This is a cross-sectional study developed with 204 parents present in a Neonatal Intensive Care Unit in the state of Rio Grande do Sul. For data collection, we used an instrument to characterize participants and the Brazilian version of the Parental Stress Scale: Neonatal Intensive Care Unit. Data were analyzed using the Mann-Whitney and Kruskal-Wallis tests.

Results: The sociodemographic variables that were associated with higher levels of stress were sex, previous experience with neonatal unit, education and religion. And the clinical variables of newborns were hospitalization unit, respiratory and intravenous therapies and previous surgical procedure.

Conclusion: Female participants, who had no previous experience with a neonatal unit, with higher education and religion, had higher levels of stress, as well as those who had their children hospitalized in the high-risk unit, with respiratory support, use of two intravenous devices and with previous history of surgical procedure.

Resumo

Objetivo: Analisar os fatores associados ao estresse de pais de recém-nascidos internados em Unidade de Terapia Intensiva Neonatal.

Métodos: Estudo transversal desenvolvido com 204 pais presentes em uma Unidade de Terapia Intensiva Neonatal do estado do Rio Grande do Sul. Para a coleta dos dados, utilizaram-se um instrumento de caracterização dos participantes e a versão brasileira da *Parental Stress Scale: Neonatal Intensive Care Unit.* Os dados foram analisados por meio do teste de *Mann-Whitney* e *Kruskal-Wallis*.

Resultados: As variáveis sociodemográficas que se mostraram associadas a maiores níveis de estresse foram sexo, experiência anterior com unidade neonatal, escolaridade e religião. E as variáveis clínicas dos recém-nascidos foram unidade de internação, terapêuticas respiratória e intravenosa e procedimento cirúrgico prévio.

Conclusão: Os participantes do sexo feminino, que não possuíam experiência prévia com unidade neonatal, com maior escolaridade e religião apresentaram maiores níveis de estresse bem como os que tinham os filhos internados na unidade de alto risco, com suporte respiratório, uso de dois dispositivos intravenosos e com história prévia de procedimento cirúrgico.

Resumen

Objetivo: Analizar los factores asociados al estrés de padres de recién nacidos internados en Unidad de Cuidados Intensivos Neonatales.

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Conflict of interest: nothing to declare.

Métodos: Estudio transversal realizado con 204 padres presentes en una Unidad de Cuidados Intensivos Neonatales del estado de Rio Grande do Sul. Para la recopilación de datos, se utilizó un instrumento de caracterización de los participantes y la versión brasileña de la *Parental Stress Scale: Neonatal Intensive Care Unit*. Los datos fueron analizados mediante la prueba de *Mann-Whitney* y *Kruskal-Wallis*.

Resultados: Las variables sociodemográficas que demostraron estar asociadas a mayores niveles de estrés fueron sexo, experiencia anterior en unidad neonatal, escolaridad y religión. Y las variables clínicas de los recién nacidos fueron unidad de internación, terapia respiratoria e intravenosa y procedimiento quirúrgico previo.

Conclusión: Los participantes de sexo femenino, que no tenían experiencia previa en unidad neonatal, con mayor escolaridad y religión presentaron mayores niveles de estrés, así como los que tenían hijos internados en unidades de alto riesgo, con soporte respiratorio, uso de dos dispositivos intravenosos y con historia previa de procedimiento quirúrgico.

Introduction

It is estimated that 15 million premature infants are born annually worldwide, which means one in ten births.[1] From this, it is verified that there is a large population of premature newborns (NB) and their families to be welcomed by the health system, making prematurity an important public health issue.[1]

Moderate to extreme prematurity alone already entails the stay in the Neonatal Intensive Care Unit (NICU), which compromises the family dynamics and potentiates stress reactions in parents.[2] Studies show that the hospitalization of a child in this unit is considered stressful, since parents are not prepared for early hospitalization, besides leaving their child in the hospital, which generates insecurity and impotence.[3-5]

There are many aspects that can trigger stress in parents at NICU. Among them, we can mention the fact that they begin to experience parenting in an environment surrounded by constant noises, strong lights and strange people and often witness NBs being submitted to painful procedures.[2] Another factor is that parents need to give up their child's basic care, since these are performed by the health team.[4,5]

Thus, parents may present depressive conditions, anxiety disorders and sleep disorders resulting from the stress experienced in the NICU.[6] Studies reveal that the severe suffering of parents during hospitalization is linked to worse future results, both in relation to family interaction and cognitive and behavioral aspects of NBs.[2,7]

The family considers it important when there is interest by the team in their feelings, paying attention to both the needs of NBs and their own, which results in the opportunity to seek emotional support for that moment.[8] Fact that demonstrates the need to implement the precepts of family-centered care in the NICU, thus seeking to also meet the needs of family care, which minimizes parental stress and promotes bond consolidation.[9]

In this regard, it is essential to know the factors associated with the stress of parents in the NICU, which will allow, later, the implementation of strategies by health professionals to cope with them. Considering that, from a search in the scientific literature, it was identified the incipience of studies in the Brazilian scenario that reveal these factors, the study aimed to analyze the factors associated with stress in parents of NBs hospitalized in the NICU.

Methods

This cross-sectional study was developed with parents (father and/or mother) of NBs hospitalized in a NICU of a public hospital in the central region of Rio Grande do Sul. Inclusion criteria included parents should have visited their children at least three times before data collection and NBs should have been hospitalized for at least five days at the NICU. And the exclusion criterion was parents of NBs who hospitalized directly in the kangaroo unit.

The sample was delimited by the time of data collection, which took place from January to August 2017, in which all parents who were in the unit were invited to participate in the study, provided that the inclusion and exclusion criteria were met. During this period, 168 NBs were eligible, of which parents of 135 participated in the study. Data were collected by the first author of this article, assisted by a previously trained nursing student. The Brazilian version of the Parental Stress Scale:

Neonatal Intensive Care Unit (PSS: NICU) and a form of characterization of participants built for the study were used.

The characterization form was structured in two chunks: Chunk A – Parents' sociodemographic profile; and Chunk B - Clinical profile of NBs. The variables that constituted Chunk A were date of birth, sex, marital status, number of children, previous experience of child hospitalization in NICU, race/skin color, education, occupation, religion and place of residence. To characterize income and basic sanitation and housing conditions, the questionnaire from the Brazilian Association of Research Companies (ABEP - *Associação Brasileira de Empresas de Pesquisa*) was used. Chunk B comprised the variables date of birth, unit of hospitalization, days of hospitalization, sex, gestational age, birth weight, delivery, birth complications, 1st and 5th minute Apgar score, reason for hospitalization, respiratory, intravenous and nutritional therapies, use of phototherapy, congenital malformation, previous surgical procedure, use of sedation, drains, special covers and bladder probe.

The PSS: NICU was translated, adapted and validated for the Brazilian population in 2009 and aims to assess the stress experienced by parents of NBs in NICU. It consists of 26 items, distributed in three subscales – Sights and sounds, Baby looks and behaves and Changes in parental role – and organized on a Likert scale, with a score between 1 and 5, in which parents should indicate how stressful the experience described in each item was. Score "1" refers to non-stressing, "2" a bit stressing, "3" moderately stressing, "4" very stressing and "5" extremely stressing. Moreover, if parents had not gone through the situation described in a given item, they could choose the answer "NA" of "not applicable".[10] It is noteworthy that when the mean is greater than or equal to two indicates the presence of stress. With regard to its validity, PSS: NICU obtained Cronbach's alpha above 0.70 and a variance degree of 57.9%. Thus, it is a valid and reliable tool for assessing the stress of parents in NICU.[10]

Chunk A was filled out through an individual interview with parents in a place that offered privacy. Then the PSS: NICU was delivered and filled by parents in an average of ten minutes. It is noteworthy that for unliterate parents with some type of visual limitation, the scale was applied in the form of an interview. Chunk B was filled out with information obtained from the medical records and from nursing professionals.

Data were typed and organized in Epi-info® (version 7.2.1), under independent double typing. After verifying and correcting the inconsistencies, data analysis was performed using the R statistical program (version 3.4.2). The Stress Occurrence Level (Metric 1) was used for the analysis of PSS: NICU subscales, in which the denominator to obtain mean is the number of items experienced by parents. The Mann-Whitney Test (for two groups) and the Kruskal-Wallis Test (for three or more groups) were used to compare scores. When statistically significant differences were obtained, Dunn's Post-Hoc Test was applied in order to identify the groups. It was considered with significance level when $p<0.05$.

The study followed the ethical precepts of Resolution 466/2012 and has approval from the Research Ethics Committee, under Opinion 1,865,348 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 62641816.7.0000.5346.

Results

The study population consisted of 204 parents. There was a predominance of females (62.3%), mean age of 28.5 years (SD=7.6). Moreover, 67.2% lived in a stable union or with a partner), 57.3% studied less than 12 years and 47% belonged to socioeconomic strata C2 or D-E, which is equivalent to an estimated monthly household income of R$ 1,446.24 (US$262.95) and R$ 639.78 (US$116.32), respectively. They did not live in the city where the study was conducted (53.9%) and had no experience with previous hospitalization in the NICU (86.3%). Table 1 presents the means differences between the PSS: NICU subscales and parents' sociodemographic variables.

Table 1. Comparison of means of parents' sociodemographic variables according to the Parental Stress Scale: Neonatal Intensive Care (PSS: NICU) subscales

Variables	PSS: NICU subscales					
	Sights and sounds		Baby looks and behaves		Changes in parental role	
	Mean	p-value	Mean	p-value	Mean	p-value
Sex*		0.00		0.01		0.00
Female	2.31		3.00		3.68	
Male	1.94		2.54		3.11	
Age group**		0.74		0.37		0.45
≤ 18 years old	2.20		2.44		3.56	
19-25 years old	2.15		2.96		3.64	
26-35 years old	2.23		2.83		3.40	
> 35 years old	2.07		2.77		3.25	
Marital status*		0.26		0.99		0.06
With a partner	2.15		2.82		3.40	
Without a partner	2.33		2.82		3.93	
Number of children**		0.69		0.62		0.15
One	2.21		2.82		3.59	
Two	2.11		2.89		3.46	
Three	2.06		2.61		2.95	
Four or more	2.36		2.95		3.70	
Another child hospitalized in NICU*		0.43		0.32		0.03
Yes	2.02		2.64		2.95	
No	2.20		2.85		3.54	
Education**		0.03		0.09		0.77
Incomplete elementary school	2.10[a]		2.64		3.50	
Complete elementary school/incomplete high school	1.99[b]		2.69		3.39	
Complete high school/ incomplete higher education	2.28[c]		3.07		3.56	
Complete higher education	2.69[b]		2.83		3.23	
Religion*		0.11		0.01		0.92
Yes	2.23		2.93		3.47	
No	1.99		2.49		3.46	
Lives in the study setting city*		0.15		0.26		0.94
Yes	2.23		2.71		3.48	
No	2.13		2.92		3.45	
Socioeconomic stratum**		0.25		0.20		0.22
A	2.08		3.15		4.07	
B1	2.56		3.03		3.47	
B2	2.19		2.68		3.15	
C1	1.98		2.74		3.47	
C2	2.33		3.15		3.75	
D-E	2.05		2.64		3.45	

*Mann-Whitney nonparametric test. **Kruskal-Wallis nonparametric test and Dunn's Post-Hoc Test, if necessary. Means with the same letter have statistical difference between them.

According to Table 1, some parents' sociodemographic variables were identified with a statistically significant difference (p<0.05), such as sex, hospitalization of another child in the NICU, education and religion. Regarding sex, mothers had higher levels of stress in the three subscales "Sights and sounds" (mean=2.31), "Baby looks and behaves" (mean=3.00) and "Changes in parental role" (mean=3.68). Parents who had no previous experience of having a child in the NICU exhibited higher levels of stress related to the subscale "Changes in parental role" (mean=3.54). Regarding education, it was noticed that parents had higher levels of stress in the "Sights and sounds" subscale, and, in the comparison of the groups, there was a statistically significant difference between complete elementary school/incomplete high school (mean=1.99) and complete higher education (mean=2.69). It was also identified that parents who had a religion showed higher levels of stress in the "Baby looks and behaves" subscale (mean=2.93).

Table 2. Comparison of means of birth variables of newborns according to the Parental Stress Scale: Neonatal Intensive Care (PSS: NICU) subscales

Variables	PSS: NICU subscales					
	Sights and sounds		Baby looks and behaves		Changes in parental role	
	Mean	p-value	Mean	p-value	Mean	p-value
Gestational age*		0.94		0.07		0.06
Premature	2.18		2.73		3.36	
Full term	2.15		3.04		3.71	
Birth weight*		0.47		0.65		0.26
< 2,500 g	2.21		2.80		3.39	
≥ 2,500 g	2.11		2.87		3.58	
Childbirth*		0.46		0.84		0.56
Vaginal	2.25		2.86		3.55	
Caesarean section	2.15		2.82		3.44	
Twin pregnancy*		1.00		0.67		0.63
Yes	2.27		2.94		3.38	
No	2.16		2.81		3.47	
Need for neonatal resuscitation*		0.59		0.29		0.35
Yes	2.19		2.74		3.38	
No	2.15		2.91		3.57	
Congenital malformation*		0.90		0.73		0.35
Yes	2.27		2.90		3.76	
No	2.16		2.81		3.43	

*Mann-Whitney nonparametric test.

In means comparations between the PSS: NICU subscales and the birth variables of NBs were not found statistically significant differences (Table 2). In Table 3, the clinical variables of NBs with a statistically significant relationship (p<0.05) are described, which were hospitalization unit, respiratory therapy, type of intravenous therapy and previous surgical procedure.

Table 3. Comparison of means of clinical variables of newborns according to the Parental Stress Scale: Neonatal Intensive Care (PSS: NICU) subscales

Variables	PSS: NICU subscales					
	Sights and sounds		Baby looks and behaves		Changes in parental role	
	Mean	p-value	Mean	p-value	Mean	p-value
Inpatient unit**		0.57		0.08		0.04
High risk	2.25		3.14		3.79[a]	
Intermediate care	2.09		2.66		3.40[b]	
Isolation	2.33		2.96		3.51[c]	
Kangaroo	2.16		2.67		3.04[a]	
Length of stay**		0.61		0.08		0.74
≤ 10 days	2.12		2.71		3.43	
11-20 days	2.17		3.07		3.51	
21-30 days	2.14		2.44		3.26	
> 30 days	2.61		3.10		3.73	
Respiratory therapy*		0.04		0.11		0.18
Yes	2.40		3.06		3.66	
No	2.10		2.75		3.40	
Type of respiratory therapy**		0.26		0.56		0.57
None	2.10		2.75		3.40	
Nasal catheter	2.21		3.08		3.49	
CPAP	2.48		3.00		4.04	
Mechanical ventilation	2.41		3.03		3.62	
In the incubator	3.16		3.58		3.66	
Intravenous therapy*		0.12		0.24		0.41
Yes	2.26		2.90		3.53	
No	2.06		2.72		3.37	
Type of intravenous therapy**		0.15		0.06		0.02
None	2.06		2.72		3.37[b]	
Peripheral catheter	2.21		2.78		3.47[b]	
PICC	2.16		2.80		3.36[b]	
Umbilical catheter	2.50		2.62		4.00[a]	
Two intravenous devices	2.80		3.71		4.42[b]	
Nutritional therapy**		0.88		0.66		0.79
Absence of diet	2.50		3.50		4.57	
Oral administration	2.15		2.81		3.44	
Oral and probe administration	2.15		2.68		3.57	
Probe administration	2.15		2.76		3.43	
Parenteral administration	2.41		3.22		3.77	
Enteral and parenteral administration	2.12		2.79		3.29	
Phototherapy*		0.46		0.30		0.54
Yes	2.37		3.37		3.92	
No	2.17		2.81		3.45	
Previous surgical procedure*		0.03		0.01		0.28
Yes	2.64		3.50		3.80	
No	2.12		2.75		3.43	
Sedation*		0.05		0.07		0.64
Yes	2.78		3.49		3.75	
No	2.14		2.79		3.45	
Special coverage*		0.29		0.53		0.33
Yes	2.32		2.94		3.59	
No	2.14		2.80		3.44	
Bladder probe*		0.25		0.18		0.05
Yes	2.54		3.35		4.29	
No	2.16		2.80		3.43	

CPAP - Continuous Positive Airway Pressure; PICC - peripherally inserted central catheter. *Mann-Whitney nonparametric test. **Kruskal-Wallis nonparametric test and Dunn's Post-Hoc Test, if necessary. Means with the same letter have statistical difference between them.

Regarding the inpatient unit, higher levels of stress were found in the "Changes in parental role" subscale. When comparing the groups, there was a statistically significant relationship between the high-risk unit (mean=3.79) and the kangaroo unit (mean=3.04). It was also found that the parents in which their children were using respiratory therapy had higher stress levels in the "Sights and sounds" subscale (mean=2.40). However, in the variable of type of respiratory therapy, there was no statistically significant difference (p>0.05). Regarding the type of intravenous therapy, parents exhibited higher levels of stress in the "Changes in parental role" subscale. Comparing the groups, there were statistically significant differences between none (mean=3.37), peripheral catheter (mean=3.47) and PICC (mean=3.36) with the use of two intravenous devices (mean= 4.42). The previous surgical procedure was associated with higher levels of stress in parents with regard to the "Sights and sounds" (mean=2.64) and "Baby looks and behaves" subscales (mean=3.50).

Discussion

In the present study, a statistically significant relationship was identified between stress and some parents' sociodemographic variables and the clinics of NBs. Among the sociodemographic variables, we mention sex, education, previous experience with hospitalization of a child in the NICU and religion.

Regarding sex, it was observed that mothers had the highest means in the three PSS: NICU subscales, which corroborates other studies,[11-13] when mentioning that mothers have higher levels of stress when compared to parents. This can be explained since culturally and by the right to maternity leave are mothers who act essentially in the care of a child after their birth.

In the comparison of means between the subscales and education, it was identified that parents with higher education had higher levels of stress than those who had completed elementary

school or incomplete high school, with regard to the "Sights and sounds" subscale. This result is consistent with another study, which found that higher education is associated with higher levels of stress in the "Sights and sounds" subscale.[14] More educated parents may have higher levels of stress because they have a better perception of their child's health status.

The fact that most parents had never had another child hospitalized in the NICU justifies the higher levels of stress presented by them in the "Changes in parental role" subscale, as they possibly did not expect children to need to be hospitalized in this unit. Spirituality has been pointed out by parents as a strategy to face the situation of hospitalization of a child in the NICU, providing feelings of strength, hope and comfort to overcome this difficult time.[15,16] This differs from what was found in this study, since parents who had a religion showed higher levels of stress in the "Baby looks and behaves" subscale.

When relating the birth variables of NBs to the PSS: NICU subscales, no statistically significant differences were found. This finding corroborates a meta-analysis study, in which variables such as gestational age and birth weight were not associated with parental stress.[13]

Hospitalization in the NICU is enough to cause high levels of stress in parents, regardless of the degree of prematurity and birth weight. This unit is seen by mothers as an environment in which NBs are very serious, with imminent risk of death, which arouses fear, doubts and suffering in the face of the possibility of their children not surviving.[17]

Regarding the clinical variables of NBs, a statistically significant relationship was found between the means of the PSS: NICU subscales with hospitalization unit, respiratory therapy, type of intravenous therapy and previous surgical procedure. Parents in which NBs were hospitalized in the high-risk unit were more stressed when compared to parents in the kangaroo unit regarding the "Changes in parental role" subscale, which may be a result of the differences between the two units. The kangaroo unit is an environment with physical and material structure that allows the mother to stay with the NBs 24 hours a day to perform the kangaroo method.[18] Unlike the high-risk unit, in which parents' contact with NBs is often limited, due to the intense routine, clinical fragility and technological complexity present, in addition to the fact that they rarely perform simple day-to-day activities, or even they even hold their child, making them not feel effectively parents. Higher stress levels were found in parents who could not hold their child in their lap.[19]

The use of respiratory therapy by NBs was also associated with higher levels of stress in parents in the "Sights and sounds" subscale. This result corroborates the study that found that when NBs were using respiratory support, whether by mechanical ventilation or CPAP, parents had a higher level of stress.[2]

Parents had higher levels of stress on the "Changes in parental role" subscale when NBs had two intravenous devices compared to none, PICC or peripheral catheter. This can be explained by parents' fear of touching or picking up NBs using so many devices, since they believe they can hurt them or even because of carelessness they end up removing the venous access.

Higher levels of stress were also observed in parents when children needed to undergo some type of surgical procedure, both in the "Sights and sounds" and "Baby looks and behaves" subscales. The need for surgery ends up being a potentiator of the stress already experienced by parents in the NICU, as they have to deal with the risks associated with anesthesia and surgery, the postoperative complications and the pain of NB.[20]

Thus, in addition to the factors already described in the scientific literature, this study highlights new aspects such as religion not having previous experience with NICU, hospitalization in a high-risk unit and use of two intravenous devices and as factors associated with higher levels of stress in parents of neonatal intensive care. The limitations of the study are related to the fact that it was developed only in one NICU in the central region of Rio Grande do Sul, it did not include all the parents of hospitalized NBs during the data

collection period and the statistical analysis did not allow establishing a relationship of causality. There is a need for further studies that can expand the understanding of the stress experienced by parents in other NICUs in Brazil.

Conclusion

In this study, the sociodemographic factors associated with higher levels of stress were female, no previous experience with NICU, higher education and religion. And clinical factors, hospitalization in the high-risk unit, respiratory support, use of two intravenous devices and previous surgical procedure. In this sense, it believes that it is necessary to think of strategies to minimize the stress experienced by parents in the NICU, including their participation in the care and decision-making related to the care of their children, organization of parent groups, provision of constant and clear information, better sleep conditions and rest. Furthermore, there is the need for an awareness of the hospital institutions themselves, which need to create favorable working conditions so that professionals can adequately assist families in the NICU.

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Collaborations

Kegler JJ, Neves ET, Silva AM, Oliveira DC and Zamberlan KC declare that they contributed to the project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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