

PARENTAL NEEDS AND STRESS IN NEONATAL INTENSIVE CARE UNITS: EFFECT OF DATA COLLECTION PERIOD

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ABSTRACT

The assessment of parental needs and stress is essential for the implementation of quality family-centred care in Neonatal Intensive Care Units (NICUs). Therefore, we aim to assess the effect of data collection period on self-reported needs and stress among parents of very preterm infants hospitalized in level III NICU, comparing those interviewed 8-14 days after child's admission with those interviewed 15-22 days after that event. Between January and September 2013, parents filled the NICU Family Needs Inventory and the Parental Stress Scale in NICU. Needs of assurance and proximity were the most valued, independently of the time of interview. A tendency for attributing a higher relevance to support needs and to stress levels regarding change in parental role was observed throughout the hospitalization.

KEY-WORDS: NEEDS ASSESSMENT; STRESS, PSYCHOLOGICAL; PARENTS; INTENSIVE CARE UNITS, NEONATAL

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INTRODUCTION

This short report takes advantage of an opportunity that emerged during fieldwork conducted within a mixed-method, observational study about parenting roles and knowledge in Neonatal Intensive Care Units (NICUs).¹ A draft of the research protocol proposed the second week of infant's hospitalization (8 to 14 days after admission) as the period for assessing parental needs and stress through surveys. However, data obtained during ethnographic observation, conducted before the administration of the questionnaires, indicated the possibility to post pone the assessment 15 to 22 days after child's admission for minimizing the burden to participants.

Considering that parental perceptions of needs and stress may change across child's hospitalization² and researchers must be aware of potential effects of decisions regarding the moment of data collection on the interpretation of results,³ the research team needed to address the following question: how does the moment of data collection influence the self-report of parental needs and stress in NICU?

Thus, this study aims to assess the effect of data collection period on self-reported needs and stress among parents of very preterm infants hospitalized in NICU, by comparing those interviewed 8 to 14 days after child's admission with those interviewed 15 to 22 days after that event.

METHODS

Participants were parents of very preterm infants (<32 weeks of gestation) born between January and September 2013 and hospitalized in the level III NICU with the largest number of very preterm infants in the North of Portugal. The study protocol was previously described.¹

Parents with infants still hospitalized at the time of the interview were consecutively invited to participate in the study by a health professional. Parents with serious illness that precluded NICU visitation (e.g. cancer), families who were absent in NICU during the hospitalization period, and parents whose infants were transferred to other hospital were excluded.

There were 35 pairs of parents of very preterm infants, and 28 were eligible and invited to integrate the study. Parents of infants born between 1st January and 15th May 2013 were interviewed 8 to 14 days after their child's admission, while parents of infants born between 16th May and 30th September 2013 were interviewed 15 to 22 days after child's birth. From 16 eligible pairs invited 8 to 14 days after admission, 12 accepted to participate, being included 10 mothers and 9 fathers. All the pairs invited 15 to 22 days after the birth of the infant accepted to participate (n=12), being included 12 mothers and 8 fathers.

Trained interviewers were responsible for conducting individual face-to-face interviews, using structured questionnaires. Data on demographic and socioeconomic characteristics, personal medical history and gynecologic and obstetric history were collected through self-report. Clinical records were reviewed to retrieve data on pregnancy complications, mode of delivery and neonatal characteristics. Additionally, parents filled validated Portuguese versions of the NICU Family Needs Inventory⁴ and the Parental Stressor Scale: Neonatal Intensive Care Unit.⁵ The NICU Family Needs Inventory is a self-administered scale, consisting in 56 statements designed to measure the importance of family needs and grouped into 5 subscales: "assurance", "proximity", "information", "comfort" and "support". Each item ranges from 1 (not important) to 4 (very important). The Parental Stressor Scale: Neonatal Intensive Care Unit measures parental perception of sources of stress arising from the environment of

the NICU. It is a self-administered scale, with 26 items that cover 3 dimensions - “Sights and Sounds”, “Baby Looks and Behaves” and “Change in Parental Role”, and each is rated in a five-point scale, ranging from 1 (not at all stressful) to 5 (extremely stressful). Statistical analysis was performed using Stata 11.0 (College Station, TX, 2009). Needs and stress subscales were presented as medians and interquartile range (IQR) and compared using the Mann-Whitney test.

RESULTS

The mean (standard deviation) time of infants’ hospitalization at the moment of interview was, in the first period of data collection, 9.2 (0.9) days and 18.0 (2.3) days in the second one. There were no statistically significant differences between parents who participated in the two moments regarding demographic and socioeconomic variables, personal medical history, gynecologic and obstetric history and neonatal characteristics.

Parents classified, on average, all items of NICU Family Needs Inventory as important or very important (Table 1). Needs of assurance and proximity were the most valued, independently of the time of interview. Parents interviewed 15 to 22 days after their child’s admission tended to attribute higher importance to almost all needs, in particular to support. Despite the lack of statistical significance, higher levels of stress were observed among parents interviewed 15 to 22 days after their child’s admission, when compared with those interviewed 8 to 14 days, especially on subscale change in parental role.

DISCUSSION

The results revealed that, independently of the time of interview, needs of assurance and proximity were the most valued by parents of very preterm infants hospitalized in NICU. These findings are supported by other studies,⁶ and seem to align with the parents’ attempt to develop a sense of meaning about a new reality shaped in an unknown sociotechnical environment,⁷ through confidence in the care provided to their child, involvement in decision-making and caregiving activities,⁸ and trust on the accuracy of the information about infants’ health status.⁹

A tendency for attributing a higher relevance to support needs and to stress levels regarding change in parental role was observed throughout the hospitalization. It may reflect a growing parental search for assistance, either from healthcare professionals to learn and practice skills for taking care of their infant,⁹ and from family and friends for assistance with household tasks,⁸ care of other children and emotional support.⁹ In the first two weeks of child’s hospitalization in NICU, infant priorities and protection may mask parents’ own needs of support.⁸ The physical and symbolic barriers for touching and holding the child and the continuous noise, characteristic smells and lights of NICU,¹⁰ along with the impossibility to protect the child from harm and performing caregiving activities⁸ and feelings of self-blame and guilt⁷ contribute to explain the higher stress levels regarding change in parental role.

This short report reveals some tendencies regarding the potential effects of the moment of data collection on the interpretation of results in studies

TABLE 1 PARENTS’ NEEDS AND STRESS PERCEPTION, ACCORDING TO THE TIME OF INTERVIEW.

	Interview after admission		p
	8 to 14 days	15 to 22 days	
NICU Family Needs Inventory			
Subscales	Median (IQR)	Median (IQR)	
Assurance	3.9 (3.9-4.0)	3.9 (3.7-4.0)	0.055
Proximity	3.8 (3.6-3.9)	3.9 (3.7-4.0)	0.578
Information	3.7 (3.5-4.0)	3.8 (3.5-3.9)	0.854
Comfort	3.3 (3.1-3.7)	3.4 (3.1-3.7)	0.932
Support	3.1 (2.9-3.6)	3.3 (3.2-3.8)	0.122
Parental Stress			
Subscales	Median (IQR)	Median (IQR)	p
Sights and Sounds	2.5 (2.0-3.0)	2.7 (2.1-3.2)	0.410
Baby looks and behaves	3.4 (2.6-4.0)	3.6 (2.6-4.5)	0.583
Change in parental role	3.7 (3.0-4.3)	4.5 (4.0-4.7)	0.082
Overall Stress	4.0 (3.0-5.0)	4.0 (3.0-5.0)	0.787

that involve parents' self-reported data on needs and sources of stress in NICU. The lack of refusals in the second moment of data collection, as well as a deeper awareness of parents-centered needs (support

and comfort) and change in parental role may support the idea that the third week of hospitalization may constitute an appropriate moment for data assessment for research purposes.

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