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Uncertainty Associated to Parents of Preterm Infants Hospitalized in Neonatal Intensive Care Units

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Objective. This work sought to determine the factors associated to uncertainty in parents of preterm newborns hospitalized in neonatal intensive care units (NICU). **Methods.** This was a cross-sectional analytic study with 117 parents (79 mothers and 38 fathers) of preterm newborns hospitalized in three NICUs of Cartagena (Colombia). Sociodemographic information was included; the biophysical profile of the preterm infant (PTI) and the results from the Mishel Uncertainty in Illness Scale. **Results.** A high level of uncertainty was found in 49.3% of the mothers and 52.6% of the fathers. The OR lower limits the variables of the parents that were associated to uncertainty were: OR = 2.5 not having a partner and OR = 2.3 having secondary education, plan OR = 2.8 belonging to socioeconomic levels 1 and 2. In the PTI variables, the following were related to uncertainty: weight <1500 gr and mechanical ventilation care, with lower limits of the OR of 1.9 and 1.3, respectively. **Conclusion.** Nurses must incorporate in the care plan the evaluation and intervention of uncertainty in fathers and mothers of PTIs hospitalized in NICU.

Key words: uncertainty; infant, premature; parents; intensive care, neonatal.

Incertidumbre asociada a padres de recién nacidos pretérmino hospitalizados en las Unidades de Cuidado Intensivo Neonatal

Objetivo. Determinar los factores asociados a la incertidumbre en padres de recién nacidos prematuros hospitalizados en Unidades de Cuidado Intensivo Neonatal (UCIN). **Métodos.** Estudio analítico de corte trasversal, en 117 padres (79 madres y 38 padres) de recién nacidos prematuros hospitalizados en tres UCIN de Cartagena (Colombia). Se incluyó información sociodemográfica, el perfil biofísico del recién nacido pretérmino (RNPT) y los resultados de la Escala de incertidumbre de Mishel. **Resultados.** Se encontró un nivel de incertidumbre alto en el 49.3% de las madres y en el 52.6% de los padres. Los límites inferiores de las OR de las variables de los padres que se asociaron

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con la incertidumbre fueron: OR = 2.5 no tener pareja; OR = 2.3 tener escolaridad secundaria, y OR = 2.8 pertenecer al estrato socioeconómico 1 y 2. En las variables del RNPT se relacionaron con incertidumbre el peso <1500 gr y la asistencia ventilatoria mecánica, con límites inferiores de las OR de 1.9 y 1.3, respectivamente. **Conclusión.** Las enfermeras deben incorporar en el plan de cuidados la valoración y la intervención de la incertidumbre en padres y madres de RNPT hospitalizados en UCIN.

Palabras clave: incertidumbre; prematuro; cuidado intensivo neonatal.

Incerteza associada a pais de recém-nascidos prematuro hospitalizados nas Unidades de Terapia Intensiva Neonatal

Objetivo. Determinar os fatores associados à incerteza em pais de recém nascidos prematuros hospitalizados em Unidades de Terapia Intensiva Neonatal (UTIN). **Métodos.** Estudo analítico de corte transversal, em 117 pais (79 mães e 38 pais) de recém nascidos prematuros hospitalizados em três UTIN de Cartagena (Colômbia). Se incluiu informação sócio-demográfica, o perfil biofísico do recém nascido prematuro (RNPT) e os resultados da Escala de incerteza de Mishel. **Resultados.** Se encontrou um nível de incerteza alto em 49.3% das mães e em 52.6% dos pais. Os limites inferiores das OR das variáveis dos pais que se associaram com a incerteza foram: OR = 2.5 não ter parceiro e OR = 2.3 ter escolaridade secundária, e OR = 2.8 pertencer à classe socioeconómica 1 e 2. Nas variáveis do RNPT se relacionaram com incerteza o peso <1500 gr e a assistência ventilatória mecânica, com limites inferiores das OR de 1.9 e 1.3, respectivamente. **Conclusão.** As enfermeiras devem incorporar no plano de cuidados a valorização e a intervenção da incerteza nos pais e mães de RNPT hospitalizados na UTIN.

Palavras chave: incerteza; prematuro; padres; país; terapia intensiva neonatal.

Introduction

The birth of a newborn (NB), although considered a positive occurrence, brings along a series of changes that alter the daily routine of the parents. When the delivery occurs prior to the expected time and a preterm infant (PTI) is born or with a congenital pathology, it may be even more difficult for the parents to confront this new situation.[1] It is a fact that hospitalization of the NB is an event that involves all those who in one way or another field identified with the infant; this is the moment in which the parents often feel the abrupt rupture of the project they had forged in relation to the child they had imagined, given that the distance between what they expected to feel and what they indeed feel is enormous, with the onset of feelings of sadness, fear, confusion, rejection, guilt, and uncertainty among others.[2] Regarding uncertainty, nursing proposes Medium Range Theory (MRT), which seeks to conceptually support the care offered to patients and their families, who because of their situation of illness anguished and in a state of confusion. This theory was proposed by Mishel[3], who indicates it as a cognitive state in which individuals are not capable of understanding the meaning of the facts or events that occur due to the illness. Uncertainty emerges the moment the parents cannot adequately structure or categorize the events produced during the hospitalization of their children; the previously mentioned, is derived from the lack of stimuli and information, fear of the unknown, ambiguity, and complexity of the hospitalization, illness, and treatment.[3]

During the care practice and experience developed by the nursing professional in neonatal intensive care units (NICU), it has been observed that fathers and mothers confront the hospitalization of a child in different manners; the father in the experience within the unit is the first person who confronts the hospitalization, he arrives accompanied by a burden of concern related to the mother's state of health and the uncertainty about their child's situation. The mother, on the other hand, often bears a sense of guilt for not

having completed the gestation period of her child. Due to this, reactions may appear, like negation, projection, and irritability. The purpose of the study was to determine the factors associated to uncertainty in fathers and mothers of preterm newborns hospitalized in three neonatal intensive care units in Cartagena, Colombia. Nursing care in NICUs has centered on carrying out strictly care activities, which are of high complexity and require continuous training by the healthcare staff; however, given the professional, ethical, and legal commitment, it is pertinent and absolutely necessary to question and investigate on a daily basis on the different needs of patients and their family nucleus, among these, the uncertainty generated in parents by the hospitalization of a premature child.

This study seeks to strengthen the nursing discipline upon identifying from the point of view of care the situation of uncertainty of the parents of preterm newborns hospitalized in NICUs and, from there and from the nursing MRT propose to address situations of uncertainty, so that new conditions may be found to favor the relationship and the care offered to patients and their families.

Methods

This was a quantitative correlational cross-sectional study; the population was comprised by the parents of 98 PTI between 24 and 36 weeks of gestation, hospitalized in three NICU of Cartagena during a trimester. This study had the participation of 38 fathers and 79 mothers. The project was approved by the research committee of the Faculty of Nursing at Universidad de Cartagena by the participating institutions. Ethical aspects of the research were supported by Resolution 008430 of 1983,[4] from the Colombian Ministry of Health and the Nursing Code of Ethics;[5] the study was considered of minimum risk for the participants. Informed consent was contemplated along with voluntary participation and confidentiality of the information. Authorization was requested from the author and rights were paid to use the scale. To collect the information, a 12-item sociodemographic survey was used, along with the biophysical profile of the PTI (5 items) and Mishel's scale on perception of uncertainty in parents upon the illness of their children.[3] This scale obtained a Cronbach's alpha of 0.9 in different studies[3,6] and 0.79 in this study; it has 31 questions, which inquire about the feelings of parents with hospitalized children. It measures uncertainty against the diagnosis and treatment, relationships between parents and care providers, and proposals for the future. Each question has a Likert-type response pattern from 1 to 5, where 1 corresponds to totally agree and 5 to undecided. The minimum score is 31 and the maximum is 155. The following cut-off points will be worked to determine the level of uncertainty (LU); low LU = < 61 points, regular LU = 61-89 points, and high LU = > 89 points.

The three instruments were separately applied to each father and mother of the hospitalized PTI. The data obtained by applying the instruments were incorporated onto a Microsoft Excel matrix. The Statistical Package for Social Sciences (SPSS) program, version 19.0 was used for data analysis with which frequencies and statistical measurements were generated for their presentation. Odds Ratio and multivariate analysis were used to estimate associations among the variables.

Results

Of the 117 parents (79 mothers and 38 fathers) of PTI hospitalized in three of the NICU in Cartagena, it was found that in 80.6% of them the father or the mother were surveyed and in 19.4% both parents were surveyed. With respect to age of the parents, in mothers the interval from 19 – 25 years prevailed with 41.8% (33), and the fathers were mostly, 57.9% (22), between 26 and 35 years of age. In 65.8% (52) of the mothers and 63.2% (24) of the fathers in this study, common-law union is the prevalent marital status. Regarding schooling, 39.2% (31) of the mothers were high school graduates and 29.1% (23) reached a basic level of schooling (primary);

likewise, it is worth highlighting that 2.5% (2) of the mothers were illiterate; as per academic formation of the fathers, it was found that 26.3% (10) had undergone higher education, 23.7% (9) had technical formation, and 10.5% (4) of the fathers were illiterate. According to socioeconomic level, 83.6% of the mothers and 68.4% of the fathers belonged to levels 1 and 2; regarding their affiliation to the General Health Social Security System, 77.2% of all the mothers and 52.6% of the fathers were in the subsidized regime. Among the study participants, 74.7% of the mothers and 76.3% of the fathers stated being Catholic, followed by 17.7% belonging to the Evangelist religion.

Of the PTI hospitalized in NICU, 42.9% were female, with a mean gestational age of 31.6 weeks; 41.8% of the newborns hospitalized were between 33 and 37 weeks, and 54.1% of these registered weight below 1500 gr. Respiratory distress syndrome was the most frequent pathology upon admission for 57.1%, followed by neonatal sepsis in 26.5%. A total of 65.3% of the PTI hospitalized required mechanical ventilation care (Table 1).

Table 1. Biophysical characteristics of the 98 PTI

Characteristic	n	%
Gender		
Female	42	42.5
Male	56	57.5
Weeks of gestation		
24 – 28	25	25.5
29 – 32	32	32.7
33 – 37	41	41.8
Weight		
500 - 1000 gr	16	16.3
1001 - 1500 gr	37	37.8
1501 - 2000 gr	21	21.4
2001 - 2500 gr	24	24.5
Pathologies		
Respiratory Distress Syndrome (RDS)	56	57.1
Sepsis	26	26.5
Neurological	3	3.1
RDS + Sepsis	1	1.0
RDS + Neurological	1	1.0
Other	11	11.2
Ventilation care		
Yes	64	65.3
No	34	34.7

According to the level of uncertainty of mothers and fathers, it was found that 49.3% and 52.6% of them, respectively, presented high level of uncertainty; only 2.5% of the mothers and 2.6% of the fathers had low level of uncertainty (Table 2).

Table 2. Level of uncertainty in fathers and mothers

Level	Mothers		Fathers	
	N	%	n	%
Low	2	2.5	1	2.6
Regular	38	48.1	17	44.7
High	39	49.3	20	52.6
Total	**79**	**100.0**	**38**	**100.0**

These were the lower limits of the OR the variables of the parents associated to uncertainty: OR = 2.5 not having a partner, OR = 2.3 having secondary schooling, and OR = 2.8 belonging to socioeconomic levels 1 and 2. In the PTI variables, the following were related to uncertainty: weight <1500 gr and mechanical ventilation care, with OR lower limits of 1.9 and 1.3, respectively (Table 3).

Table 3. Association between uncertainty and economic and family factors, and biophysical characteristics of the PTI

Variables	OR	$CI_{95\%}$ OR	
		Lower limit	Upper limit
Not having a partner	52.0	2.5	1 100.4
Having only one child	0.2	0.0	1.3
Having secondary schooling	12.2	2.3	65.2
Socioeconomic levels 1 and 2	91.3	2.8	2 943.1
Subsidized regime	0.8	0.2	3.9
Rural area	1.3	0.2	8.1
Male PTI	0.5	0.1	2.3
PTI < 32 weeks	0.3	0.0	3.2
PTI < 1500 gr	37.5	1.9	725.4
PTI with RDS	0.3	0.1	1.7
PTI with mechanical ventilation	6.2	1.3	30.4

Discussion

Upon analyzing the information obtained from the parents of PTI hospitalized in the NICU, about their level of uncertainty with the hospitalization of their children and the factors that determine this feeling to greater extent, it was found that per the sociodemographic characteristics of the study participants the marital status that most prevailed in both parents was common-law union; with respect to socioeconomic level, levels 1 and 2 obtained the highest percentages. Likewise, basic secondary schooling was the prevailing educational level, data similar to that found by Moreno[7] in a study conducted with 128 parents of newborns hospitalized in NICU, where 72% of those surveyed manifested living in common-law union; with respect to socioeconomic level, 6 of every 10 parents belonged to level 1. As per level of schooling, 30% completed primary, 61% had secondary schooling, 6% were at technical level, and 1% had university education. An individual's years of schooling are generally interpreted as a

mean of their potential cognitive ability; hence, parents with a low degree of schooling or who are illiterate will have less tools to process the information offered by the healthcare providers with respect to their child's situation.[7]

The type family most prevalent among the study participants was the nuclear family, unlike that found by López *et al.,*[8] who reported that 57.8% of the participants belonged to the extended family typology, where the parents lived with close relatives, like aunts and uncles, cousins, and grandparents. With respect to age, it was found that the most evident age interval in the mothers was from 19 – 25 years, and in the fathers from 26 – 35 years; in terms of economic activity, the occupation variable evidenced a high percentage of mothers as housewives (32.9%), whose income was lower than the current minimum wage, which agrees with data reported by Lizarazo *et al.,*[9] where the mean age of the group of mothers and fathers was 25.9 and 27.6 years, respectively; this study had the participation of 264 mothers, with 71% being housewives and their income was below the current legal minimum wage; notwithstanding the new economic requirements generated by the birth of a preterm infant and the low income of the parents, this variable was not found associated to the level of uncertainty.

According to the biophysical characteristics of the PTI, the mean gestational age was 31.6 weeks, with 54.1% of them weighing under 1500 gr, which differs from the study by López *et al.*,[8] who found a mean gestational age of 33.6 weeks and average weight at birth of 2005 gr. For parents of newborns, the infant's weight is a characteristic they relate to normal infants and is part of the child desired, a condition that was not present in the newborns in the present study and which generated in them pain, anger, and guilt. Pérez *et al*.,[10] stated in their study that the most frequent pathology for the PTI was – in the first place – respiratory distress, followed by neonatal sepsis; a result similar to that found in this study, given that the most frequent pathology on admission to NICU was the infant respiratory distress syndrome, followed by early neonatal sepsis, where 65.3% of the NB required ventilation support in the NICU, impacting greatly on the parents of the hospitalized newborn children.

As for the level of uncertainty of fathers and mothers from this study, 49.3% of the mothers and 52.6% of the fathers presented high levels of uncertainty, which agrees with the findings by Duran,[11] who reported that uncertainty was the most frequently found feeling and in highest levels in parents of NB hospitalized in NICU; upon these situations, Mishel[3] states that uncertainty tends to increase in contexts with patterns of ambiguous symptoms or when they lack familiarity with the event, as is the case of parents of PTI hospitalized in NICU, who often are not in the capacity to process the information offered them with respect to the diagnosis, treatment, prognosis, and special care their child receives; additionally, when the parents have expectations on their child improving and this does not occur, or if the predictions on the infant's evolution are unknown, uncertainty may even be evaluated as danger.

Data from the present study reports that uncertainty in fathers and mothers of PTI hospitalized in NICU was significantly associated to three factors inherent to their sociodemographic characteristics (being from socioeconomic levels 1 and 2, not having a partner, level of schooling) and two factors appertaining to the PTI's biophysical profile (low birth weight < 1500 gr and requiring mechanical ventilation support). On the factors related to the parents, it was found that belonging to socioeconomic levels 1 and 2 was significantly associated (minimum OR = 2.8) with the development of uncertainty; this contradicts data published by Nájera,[6] where socioeconomic level had no association with uncertainty. Not having a partner is another predisposing factor (minimum OR = 2.5), which represents a high risk of presenting uncertainty due to not being supported by a stable spouse. In this aspect, Mishel[3] considers that social support, in this case that which could be provided by a stable spouse, bears a direct effect upon uncertainty because it reduces the complexity perceived; it would also have an indirect effect due to its influence upon the

predictability of the typology of symptoms. Under this circumstance, nursing professionals are the resource of highest participation because they are closest to the fathers and mothers; thereby, through adequate strategies, they may offer step by step the necessary information and support. With respect to the third factor associated, it was found that parents with academic formation up to secondary education had diminished cognitive capacity due to the low degree of schooling (minimum OR= 2.3); consequently, parents with low degree of schooling or illiteracy will have less possibilities of understanding the information offered by healthcare providers with respect to their child's situation. The behavior of these last two factors investigated in this study is similar to that found by León *et al*.,[12] who report that the parents of children admitted to NICU experience higher levels of anguish and uncertainty, compared to those of healthy children; likewise, the psychosocial health of the parents is influenced by age, low schooling, lack of social support, and lower family function.

Regarding factors related to the biophysical characteristics of the PTI and upon associating the PTI's weight < 1500 gr to uncertainty (minimum OR= 1.9), given that for the parents the infant's weight is a trait they relate to normal infants and which is part of the child desired and when facing the real low-weight preterm infant, somehow alters the preconceived image they had of their child, generating in them emotional responses, like pain, shock, negation, anger, guilt, and uncertainty.[13] Another predisposing factor related to the PTI is the need for mechanical ventilation care (minimum OR 1.3), a situation similar to that found in other studies.[14-16] Peculiarities in the child, like weight, gestational age, and respiratory support (mechanical ventilation) provoked uncertainty in the parents; Roberts *et al*.,[15] expressed that it is caused by seeing the child surrounded by monitors, or paralyzed and subjected to mechanical ventilation. Miles *et al*.,[16] coincide with the aforementioned upon stating that the child's appearance with endotracheal tubes, enduring painful procedures – according to the parents – is one of the main sources of uncertainty. This image is quite strong for the parents and it is difficult for them to assume it positively; they feel removed from their child, perceiving the situation as aggressive and expressing pain. Parents of PTI who required mechanical ventilation support have higher levels of uncertainty. The uncertainty inherent to the treatment of these children leads to great emotional impact in the parents who go through emotional swings that exhaust and overwhelm them. Hence, uncertainty, as a perception variable, hinders clear assessment of events and limits coping, a condition that requires the ability by nursing, as a credible authority, to solve or diminish the levels of uncertainty the hospitalization generates in the parents and to achieve better coping and adaptation to their situation.

To conclude, this study stems from the results that reveal the panorama of fathers and mothers of PTI hospitalized in NICU, given that enduring the experience of having a preterm child hospitalized means to them being submerged within an unknown and aggressive context, inasmuch as it is a setting saturated by monitors, mechanical ventilators, visual and auditory warning alarms where professionals work at the rhythm of established parameters. In the participants of the current study the following were prevalent: common-law unions, belonging to socioeconomic levels 1 and 2, type of nuclear family, subsidized health regime, and academic formation up to the secondary level of education. Higher degrees of schooling permit developing the potential cognitive ability for fathers and mothers to interpret the information offered to them on the status of their child's health. With respect to the level of uncertainty, it was found that most of the fathers and mothers present regular or high levels of uncertainty, a situation that requires of nursing – as a credible authority – accompaniment to offer the necessary support to fully understand the course of the disease and their child's health situation. Specifically, five factors were associated to these levels of uncertainty: three elements related to the characteristics of the parents (being from socioeconomic levels 1 and 2, not having a partner, degree of schooling,) and 2 peculiarities

of the PTI's biophysical profile (low birth weight < 1500 gr, and requiring mechanical ventilation support); when the parents have to confront situations they do not manage to understand they cannot establish a pattern, which leads to confusion and insecurity on the progress of the treatment, further causing higher levels of uncertainty.

In spite of their low income and of the new economic impositions generated by the birth of a preterm child, the variable of earning less than the minimum wage was not found associated to the level of uncertainty.

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