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ORIGINAL ARTICLE

Validation of "The Parental Stressor Scale Infant Hospitalization modified, to Spanish" in a pediatric intensive care unit

Validación de "The Parental Stressor Scale Infant Hospitalization modificado, al español" en una unidad cuidados intensivos pediátricos

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Abstract

Introduction: Intensive care units are known as high-stress environments for family members, this can be higher when the patient is a son or daughter and the parents must face the disease along with everything that the hospital environment implies. The Parental Stressor Scale Infant Hospitalization (PSSIH) instrument is a tool used to measure stressors in Pediatric Intensive Care Units (PICU), however, the scale is not validated in Chile. The objective of this study is to culturally validate and adapt the instrument "the modified Parental Stressor Scale Infant Hospitalization" in mothers/fathers of hospitalized children in the PICU of a University Hospital. Method: Instrumental validation study. After translating and counter-translating the English version of the instrument, a group of 10 expert professionals evaluated the Spanish adaptation. Then, 10 parents of hospitalized children in the PICU evaluated the understanding of the instrument. The psychometric properties of the instrument were evaluated using exploratory factorial analysis and Cronbach's alpha. Results: The Chilean version of the "modified PSSIH" was applied to a sample of 221 parents, with minimal semantic modifications and the expert judges considered the instrument adequate, therefore, it was not necessary to delete any item. The 3-dimensional solution was chosen, which explained 48.89% of the total instrument variance. The Cronbach's alpha was 0.885, 0.902, and 0.703 respectively for each dimension. Con**clusion:** The modified PSSIH has proved to be a reliable and valid instrument in a sample of Chilean children hospitalized in a Pediatric Intensive Care Unit of a university hospital. The name in Spanish of the scale is "Escala de Evaluación de Estresores Parentales en niños hospitalizados en Unidades de Cuidados Intensivos Pediátricos" (EEEP - UCIP).

Keywords: Parental stress;

hospitalization; pediatric intensive care; parental stressors

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Introduction

The admission of a child to a Pediatric Intensive Care Unit (PICU) is a situation where parents experience anxiety and stress, altering their role at times when their child requires it most. Understanding and identifying which factors can facilitate the establishment and maintenance of a health team therapeutic intervention is an ethical imperative in the humanized care setting at PICU¹.

There are many causes of stress in a hospitalized child, his/her parents, and family that can be prevented such as ignorance about the implications of illness, medical procedures or rules, and routines in the hospital context. Currently, in Chile, there is still a time restriction in the PICU for parents or caregivers to be with the child 24 hours a day ².

A study carried out by Ramirez, Navarro, Clavería, Molina, and Cox³ on 217 parents of children admitted to a PICU in the Metropolitan Region identified the main parental stressors in that Unit, which were grouped into three dimensions: Clinical, Emotional, and Communication with the professional team, where the clinical dimension was the biggest stressor. These results correspond to the secondary analysis of the Educational Assistance Research Project # 201403 of the UC School of Nursing during the Instrument Validation process of The Parental Stressor Scale Infant Hospitalization in Spanish" (modified PSSIH).

This instrument was the only one found upon searching in scientific databases. The results were mostly instruments that evaluate stress in parents, but do not measure parental stressors. We found only one work that measures the hospitalization situation of a child, developed by Carter and Miles 4, called "The Parental Stressor Scale Infant Hospitalization" (PSSIH) made up of 28 items, grouped into six factors: a) appearance of the child, b) lights and sounds, c) procedures, d) communication with professional team, e) behavior and emotional response of the child, and f) parental role. This scale was modified by Saied⁵ in his doctoral thesis "Stress, Coping, Support, and Adjustment among Families of CHD Children in PICU After Heart Surgery" which incorporates the factor "Behavior of professionals" allowing to know and evaluate the relationship of clinical health personnel with parents⁶⁻¹¹, resulting in an instrument of seven factors and 37 items. This instrument was used in this research.

The objective of this study is to validate the instrument The Parental Stressor Scale Infant Hospitalization modified by Saied, for the Chilean population.

Methodology

Design

Validation of the modified measurement instrument "The Parental Stressor Scale Infant Hospitalization" ("modified PSSIH") for the Chilean population.

Adaptation and validation process of the modified PSSIH

Two independent translations into Spanish were done, followed by two counter-translations by native English speakers. After individual analysis by the members of the research team, the opinions were agreed upon in a final instrument that was sent to the expert professionals.

Once the scale was translated, the validation process was carried out in a sequential way: (1) content validity (2) linguistic adaptation (3) pre-test of the instrument's adapted version, and (4) construct validity and psychometric properties analysis.

Instruments and data collection

The modified PSSIH consists of 37 items grouped into seven factors, with a Likert like response modality: 1) appearance of the child; 2) images or sounds; 3) procedures or interventions; 4) behavior of the professional team; 5) communication of the professional team; 6) behavior and/or emotional response of the child; 7) role of the parents.

Content validity and linguistic adaptation

At this stage, the modified counter-translated PSSIH, was evaluated by ten expert professionals (three Pediatric Nurses, two Intensive Care Pediatricians, two Psychologists, one Anesthesiologist, one Neonatologist, and one Midwife Nurse) who answered a questionnaire regarding the adequacy of the item to the measured construct, comprehension, and writing. The data analysis considered the estimation of the Content Validity Coefficient (CVC) and the Lynn Index (LI) for each item, using as criteria for item adequacy a minimum of 0.6 for the CVC and 0.8 for the LI.

Subsequently, the changes suggested by the experts in writing were incorporated and the item "that a machine breathes for my child" is added to the factor "procedures and interventions" and an open question. Afterward, ten interviews were conducted with parents of children hospitalized at PICU and they were asked to assess the clarity of language, concepts, writing, and understanding of each question. With the suggestions, the instrument was modified to obtain the third version in Spanish, which was applied as a pilot in ten mothers/fathers of children hospitalized at PICU. In this last stage, the instrument had no modifications, obtaining the final version in Spanish of the Evalua-

tion Scale of Parental Stressors in PICU made up of 38 items plus an open question.

Validity and reliability study

The sample size was determined according to Brislin's criteria which indicates a minimum of five subjects for each item of the instrument. The study was conducted at the PICU of a University Hospital in the Metropolitan Region. The recruitment time was seven months (October 2015 - April 2016) to fulfill the required sample.

Construct validity

An exploratory factorial analysis was performed where the items were analyzed according to their asymmetry. 18 of the 38 items presented excessive asymmetry levels (asymmetry coefficient higher than 1 in absolute value) thus the factorial analysis was performed on a polychoric matrix, using the extraction method of unweighted least squares. To determine the number of optimal dimensions, the scree plot and Horn's parallel analysis were used, along with an analysis of the explained variance and the goodnessof-fit statistic Root Mean Square of Residuals (RMSR), considering a 0.0674 maximum for this indicator. To estimate the belonging of the items to the dimension, the oblimin rotation was used, since the dimensions correlated with each other (r higher than 0.4) and a minimum correlation of 0.3 was used as a criterion to incorporate an item to the dimension.

Reliability study

In order to evaluate internal consistency, Cronbach's Alfa was used, also incorporating a discriminatory capacity analysis of the items through the correlation of each one of the reagents with the score of each dimension of the instrument. It was considered for its interpretation that values between 0.60 and 0.69 represent acceptable reliability, from 0.70 to 0.79 a high reliability, and higher than 0.8 an optimal reliability.

Data analysis

For socio-demographic variables, descriptive statistics were calculated using the statistical software SPSS (SPSS for Windows, version 22, 2012; SPSS Inc., Chicago, IL, USA), while for factor analysis of the instrument, the statistical software FACTOR was used.

This project has been approved by the Catholic University of Chile's Medical Ethics Committee and the participants signed an Informed Consent.

Results

The study included a total of 221 participants

I. Evaluation of Content validity, linguistic adequacy, and piloting

The judges evaluated positively all the items of the instrument. The minimum CVC recorded for an item was 0.75 and for the LI was 0.85, concluding that no item was eliminated at this stage, only some minor changes were made in phrasing. Regarding linguistic adaptation, minor changes were registered in the following items: 1, 2, 3, 4, 5, 8, 9, 13, 20, 23, 25, 32. With respect to piloting, the average response time of the questionnaire was 25 minutes, without reporting problems with self-application. Table 1 shows the original instrument and the version subsequent to expert validation, linguistic adequacy, and piloting.

II. Evaluation of construct validity, reliability, discrimination, and homogeneity

Sample characterization: Characteristics of the child

Age of children from 0 to 18 years, with an average of 2.98 and a standard deviation of 4.3. (Table 2). Regarding hospitalization, 44% was the first time they were hospitalized, 34% had had three or more hospitalizations, and 61.5% had a scheduled admission. In relation to the causes, 60% correspond to heart problems, 14.2% to neurological problems, and the rest to oncological, respiratory, and other problems.

Caregiver Characteristics

Age between 18 and 61, with an average of 34.6. 61% are mothers, 62.7% have university education. Regarding marital status, 53.4% were married and 64.5% have another child in addition to the hospitalized one. 57.6% live in the Metropolitan Region (Table 3).

Factor analysis

The method of least-squares factor extraction was used in the FACTOR software for the analysis of polychoric matrices. The polychoric matrix adequacy estimated a Kaiser Meyer Olkin (KMO) from 0.866 > to 0.8 indicating optimal conditions for analysis. In addition, Bartlett's test gave a value of 4,498.4 associated with a p < 0.001, that is, the polychoric matrix to be analyzed is not an identity matrix, because the items do correlate with each other.

Regarding the number of factors, Horn's parallel analysis showed that three factors have a higher self-value than that provided at random. These factors explain 48.894% of the total variance of the instrument and are congruent with the scree plot as can be seen in the sedimentation graph (graph 1). The RMSR for this solution was 0.0627, lower than the criterion of 0.0674 which indicates an adequate fit of the resulting 3-dimensional factorial structure.

Table 1. Items in the instrument before and after validation and adaptation

Original items (english)

Below is a list of items that might describe your **Child's Appearance**. Using the following rating scale, circle the number that best express how stressful these things have been for you

- 1. Puffiness of my child
- 2. Color changes in my child (Pale, blue or yellow)
- 3. Child appearing cold

Below is a list of **Sights and Sounds** in an intensive care unit. Circle the number that best express how stressful each of these items has been for you

- 1. Seeing the heart on the monitors
- 2. The sound of monitors and equipment
- 3. The other sick children in the room
- 4. The sudden sounds of monitor alarms

Below is a list of **Procedures** that may have been done to your child. Circle the number that best express how stressful these procedures have been for you

- 1. Tubes in my child
- 2. Suctioning
- 3. Putting needles in my child for fluids, procedures or tests
- 4. Making my child cough and deep breath/pounding and clapping on my child's chest
- 5. Injections/ shots
- 6. Bruises, cuts, incisions on my child

Below is a list of items that relate to how **Professional staff** (doctors and nurses) may Communicate with you about your child's illness. Please indicate the stress level of these items

- 1. Explaining things too fast
- 2. Using words I don't understand
- 3. Tellingme different (conflicting) things about my child's condition
- 4. Not telling me what is definitely wrong with my child
- 5. Not talking to me enough

Below is a list of **Behaviors and emotional** responses that your child may have exhibited while in the intensive care unit. Using the same scale as above, how stressful were things for you?

- 1. Confusion
- 2. Rebellious or uncooperative behavior
- 3. Crying or whining
- 4. Demanding
- 5. Acting or looking as if in pain
- 6. Restlessness
- 7. Inability to talk or cry
- 8. Fright
- 9. Anger
- 10. Sadnessor depression

Below is a list of **Behaviors of the professional staff** (doctors and nurses) that you may have observed. Circle the number that best express how stressful these items have been for you

Modified items (spanish)

The following is a list of items that could be used to describe the **appearance of your child**. Using the following scale of measurement, circle the number which best describes how stressful these situations have been for you.

- 1. Seeing my child's swollen body.
- 2. Changes in the colour of my child's skin (pallid, blue or yellow) and/or visible bruising
- 3. It looked like my child was feeling cold

Below you will find a list of items that describes situations that you could have observed during the hospitalization of your child in the PCCU, such as **images or sounds**. Indicate how stressful each of the factors was for you.

- 1. Seeing the functioning of his body or organs on the monitors
- 2. The sound of the monitors and equipment
- 3. The presence of other sick infants in the unit
- 4. The sudden sounding of the alarms on the monitors

Below you will find a list of items that describe a series **of procedures or interventions** that could have been used to treat your child. Indicate how stressful these were for you

- 1. The presence of tubes and probes in my child's body
- 2. The aspiration of secretions or other fluids
- 3. The use of needles on my child to administer serums, transfusions, procedures or exams
- 4. Making my child to cough or inhale forcefully and deeply or performing chest compressions on my child
- 5. A machine was breathing for my child (new ítem)
- 6. Cuts or surgical wounds on my child's body
- 7. Injections/vaccinations

Below you will find a list of items that describes different situations in which the **Medical Team** (doctors and nurses) **communicated** with you about your child's condition. Indicate how stressful these were for you

- 1. They explained very quickly
- 2. They used words I did not understand
- I was given different (or contradictory) diagnoses of my child's condition
- 4. There was no definite diagnosis of my child's illness
- 5. They did not converse sufficiently with me

Below you will find a list of items that describes different ways of behaviour and/or emotional responses that your child may have demonstrated during their hospitalization in the PCCU. Indicate how stressful these were for you

- 1. Confused or disoriented
- 2. Rebellious or uncooperative behaviour
- 3. Crying and moaning
- 4. Needy (demanding a lot of attention)
- 5. Showing pain or making pain evident
- 6. Restlessness or lack of calm
- 7. Inability to speak or cry
- 8. Fear
- Anger
- 10. Sadness or depression

Below you will find a list of different types of **Behaviour by the Medical Team (doctors and nurses)** that you might have observed during the hospitalization of your child in the PCCU

Table 1. Items in the instrument before and after validation and adaptation (continuation)

Original items (english)

- 1. Joking, laughing, or talking loudly
- 2. Not talking to me enough
- 3. Toomany different people(doctors, nurses, staff) talking to me
- 4. Not telling me names or who they are

These items related to **Parental Roles**. How stressful have the following been for you?

- 1. Not taking care of my child my self
- 2. Not being able to visit my child when I wanted
- 3. Not being able to be with my crying child

Table 2 Chausetaulation of the Children

4. Not being able to hold my child

Using the same rating scale, how stressful, in general, has the total intensive care unit experience been for you?

Modified items (spanish)

- 1. Joking, laughing or speaking loudly.
- 2. They did not talk enough to me.
- 3. Several different people (doctors, nurses, other staff) talking to
- 4. Not telling me their names or who they were while treating my

The following list refers to the role of the parents. Indicate how stressful the following factors were for you

- 1. Not being able to take care of my child myself
- 2. Not being able to visit my child whenever I want
- 3. Not being able to be there when my child is crying
- 4. Not being able to hold my child in my arms or pick my child up

Using the same evaluation scale, how stressful in general has your experience in the Paediatric Intensive Care Unit been for you?

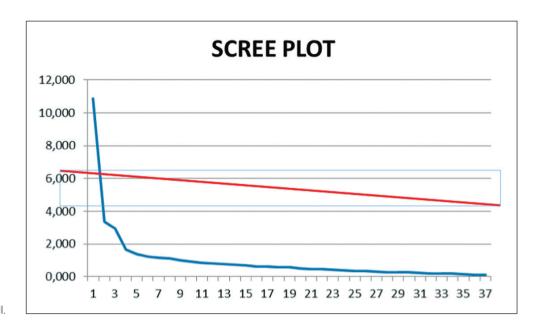
Is there any other situation that you found stressful and that has not been included in the questionnaire? Please describe it below: (new ítem)

Variable	Category	n	%
Gender	Male	115	53.2
	Female	101	46.8
	Total	216	100
Number of	1	96	44
hospitalizations	2	48	22
	3 or more	74	34
	Total	218	100
Admision	Programed	134	61.5
	Emergency	84	38.5
	Total	218	100
Area	Cardiology	115	68
	Neurology	24	14.2
	Oncology	10	5.9
	Respiratory	11	6.5
	Other	9	5.4
	Total	169	100

With respect to factorial loads, table 4 shows the result of the analysis using oblimin rotation.

In relation to discrimination and homogeneity, the observation of the items behavior shows that they all present adequate discrimination levels (correlations over 0.25 in their dimension), however, an ambiguous factorial load of the original scale is observed in the items: "Inability to speak or cry" of the "Emotional responses of the child" dimension; "Not being able to care

Variable	Category	n	%
Relation	Mother	133	61
	Father	85	39
	Total	218	100
Scholarity	Basic	7	3.2
	Medium	51	23.5
	Technical	54	24.9
	University	82	37.8
	Graduate	23	10.6
	Total	217	100
Marital status	Single	88	40.6
	Married	116	53.4
	Separated	13	6
	Total	217	100
Siblings	1	77	35.5
	2	71	32.7
	3 or more	69	31.8
	Total	217	100
Work	Independent	42	19.4
	Dependent	88	40.6
	House-wife	38	17.5
	Unemployed	4	1.8
	Medical leave	40	18.4
	Other	5	2.3
	Total	217	100
Zone	Urban	204	94
	Rural	13	6
	Total	217	100
Province	Metropolitan (capital)	125	57.6
	Other	92	42.4
	Total	217	100



Graph 1. Contrast criteria of fall.

		Dimension				Dimension	
	1	2	3	-	1	2	3
ITEM1F1		0.567		ITEM1F5	0.375	-	
ITEM2F1		0.484		ITEM2F5	0.625		
ITEM3F1		0.578		ITEM3F5	0.617		
ITEM1F2		0.567		ITEM4F5	0.555		
ITEM2F2		0.544		ITEM5F5	0.649		
ITEM3F2		0.627		ITEM6F5	0.654		
ITEM4F2		0.324		ITEM7F5	0.379	0.356	
ITEM1F3		0.692		ITEM8F5	0.872		
ITEM2F3		0.513		ITEM9F5	0.842		
ITEM3F3		0.511		ITEM10F5	0.822		
ITEM4F3		0.423		ITEM1F6		0.456	
ITEM5F3		0.422		ITEM2F6		0.828	
ITEM6F3		0.712		ITEM3F6		0.374	
ITEM7F3		0.763		ITEM4F6		0.675	
ITEM1F4			0.652	ITEM1F7	0.441	0.440	
ITEM2F4			0.583	ITEM2F7		0.550	
ITEM3F4			0.682	ITEM3F7	0.366	0.365	
ITEM4F4			0.677	ITEM4F7	0.585		
ITEM5F4			0.830				

F corresponds to the factors of the original instrument: F1: Child'Appearance; F2: Sights and sounds; F3: Procedures; F4: Professional staff; F5: Behaviors and emotional; F6: Behaviors of the professional staff; F7: Parental roles. 1: Emotional Dimension; 2: Clinical Dimension; 3: Dimension Communication with the clinical team.

Original scale dimension	Cronbach's alpha	Resultant dimension	Cronbach's alpha
Child's appearence	0.713	Clinical dimension	0.885
Sights & Sounds	0.767		
Procedures and Intervensions	0.848		
Professional staff behaviors	0.703		
Child's emotional responses	0.892	Emotional dimension	0.892
Professional staff communication	0.703	Comunicational dimension	0.703
Parents role	0.819	Clinical dimension	0.904
		Emotional dimension	0.902
Total scale			0.932

for my child myself" and "Not being able to be when my child is crying" of the "Role of parents" dimension that could affect the instrument homogeneity.

Regarding the factors proposed by the authors, compared to the one proposed in this work, it can be observed that the factors "appearance of the child", "images or sound", "procedures or interventions" and "behavior of the professional team" tend to be grouped into a single dimension, which will be called the "clinical dimension". The original factor "emotional behavior or responses of the child" and "role of parents" are loaded in the "emotional dimension" with respect to the role factor of parents. This decision was made with clinical criteria since the items of this factor also load in the Clinical dimension. The original factor "communication of the professional team" loads in the Communication of the professional team dimension, preserving the same name. Cronbach alpha was used to evaluate the reliability of the internal consistency dimension. Table 5 shows this indicator of the original factors and dimensions resulting from this analysis.

Likewise, it can be seen that the factor reliability analyses of the original instrument present an adequate level of internal consistency above 0.7. Analyzing the resulting three dimensions Clinical, Emotional and Communication, a clear increase in Cronbach's alpha is evident in the first two factors mentioned with an alpha of 0.885 and 0.902 respectively, while the third dimension since it remains intact, it presents the same level of internal consistency as in the original factorial structure (0.703).

Discussion

In general terms, the results of this research provide a validity analysis of the modified PSSIH instrument

for a sample of Chilean children treated in a PICU of a University hospital in the Metropolitan Region. The adaptations made met the standards suggested by specialized literature, considering linguistic and cultural differences of context. It was obtained an instrument made up of 38 items, grouped in three dimensions: 1. Clinic consisting of four original factors (appearance of the child; images and sounds; procedures or interventions, and team behaviors); 2. Communication with the clinical team, which includes an original factor (professional team), and 3. Emotional with two original factors (behavior and/or emotional responses and parental role). In addition, adequate reliability levels were observed in both the original factors and the dimensions resulting from this study.

Technological advances contribute effectively to the treatment of children at PICU, however, there is an increasingly automated professional-patient relationship, with restricted access to the family, focused on procedures and medical treatment¹². Therefore, the environmental assessment is essential, constituting a humanized care strategy. Literature¹³ refers to the implementation of activities that favor the relationship of professionals with the family and children, allowing for the establishment of spaces where technical efficiency is combined with the quality of care. From this perspective, validating an instrument that measures parental stressors responds to the health institutions' needs.

The dimensions addressed by this instrument agree with what is referred to in the literature as environmental stressors¹⁴. Involving the family in the care of a seriously ill child can optimize outcomes for the child, family, and the Institution¹⁵. Having a validated instrument allows the health team to assess their ability to communicate effectively, to identify what parents need to be involved in the decision-making process, and to participate in the care of their children.

It is also a support tool for the development of indicators to assess the quality of care and helps to identify and share good practices.

Regarding validation, two studies were found in which the factorial structure of the instrument is evaluated, a validation to the Portuguese language¹⁶ and another one carried out in a sample of caregivers in the United States ¹⁷.

In the case of the Portuguese¹⁶ validation, only 26 of the 37 items were added to the factorial analysis. The extraction method used was that of main components, a method criticized for not being considered a factorial analysis as such. However, the factorial structure presented is congruent with the resulting one in this study. Regarding the results of the study by Agazio and Buckley¹⁷, an analysis of main components was also carried out, testing solutions with 5, 6, 7 and 8 factors and the structure of 7 factors was chosen because it fit adequately with the original structure, however, the explained variance is not reported nor other criteria to delimit the number of factors, thus the comparison of results becomes difficult.

Finally, in relation to the internal consistency analyses, it was observed that in general, the original scale presents adequate reliability values^{18,19} that are congruent with those found in this study.

Study limitations

Application of the instrument in a single PICU and sampling was not random.

Conclusion

This study is not only a contribution to PICU research but also, the use of validated and reliable instruments is a tool for health teams that allows them to deliver safe and quality care to children and their parents. This is how the modified Parental Stressor Scale Infant Hospitalization instrument has proven to be reliable

and valid in a sample of Chilean children hospitalized in a Pediatric Intensive Care Unit of a university hospital, whose Spanish name is *Escala de Evaluación Estresores Parentales de niños hospitalizados en Unidades Cuidados Intensivos Pediátricos* (EEEP - UCIP), made up of 38 items, grouped into three dimensions: "Clinical Dimension", "Communication with the Clinical Team Dimension", and "Emotional Dimension", plus an open question.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Financial Disclosure

Authors state that no economic support has been associated with the present study.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Scale for the Evaluation of Parental Stressor in Pediatric Intensive Care Units (PICU)

(The Parental Stressor Scale: Infant Hospitalization (PSS:IH) Miles & col., modified by Saied, validated for Chilean population, IDA Project No. 15-096. School of Nursing. Faculty of Medicine Catholic University of Chile. Navarro-Tapia, S., Ramirez, M., Clavería, C., Molina, Y.)

It is of great interest for nurses and other professionals working in the PICU to know the effect that the **PICU** environment has on their experience as parents.

The following questionnaire includes a series of situations that can be considered stressful for parents during **their child's stay in the PICU**. We are very interested in knowing your perception or experience regarding the stress situations experienced by you, in the present hospitalization of your child.

We understand stressful situations, all those lived experiences that make us feel anxious, upset or tense.

In the following questionnaire, you are asked to circle the number that best represents how stressful this situation has been for you. In those items that are described below and that have not been part of your experience, you should check "Not Experienced" (0).

0 = Not experienced 3 = Moderately stressful 1 = It was not stressful 4 = Very stressful 2 = Minimally stressful 5 = Extremely stressful

CLINICAL DIMENSION

I. The following is a list of items that could be used to describe the <u>appearance of your child</u>. Using the following scale of measurement, circle the number which best describes how stressful these situations have been for you.

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Seeing my child's swollen body						
Changes in the colour of my child's skin (pallid, blue or yellow) and/or visible bruising						
1. It looked like my child was feeling cold						

II. Below you will find a list of items that describes situations that you could have observed during the hospitalization of your child in the PCCU, such as **images or sounds**. Indicate how stressful each of the factors was for you.

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Seeing the functioning of his body or organs on the monitors						
2. The sound of the monitors and equipment						
3. The sound of the monitors and equipment						
4. The presence of other sick infants in the unit						

III. Below you will find a list of items that describe a series of procedures or interventions that could have been used to treat your child. Indicate how stressful these were for you

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. The presence of tubes and probes in my child's body						
2. The aspiration of secretions or other fluids						
3. The use of needles on my child to administer serums, transfusions, procedures or exams						
4. Making my child to cough or inhale for- cefully and deeply or performing chest compressions on my child						
5. Injections/vaccinations						
6. Cuts or surgical wounds on my child's body						
7. A machine was breathing for my child (new ítem)						

IV. Below you will find a list of different types of **Behaviour by the Medical Team (doctors and nurses)** that you might have observed during the hospitalization of your child in the PCCU.

2.	They did not talk enough to me.	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Joking, laughing or speaking loudly						
2. They did not talk enough to me						
3. Several different people (doctors, nurses, other staff) talking to me						
Not telling me their names or who they were while treating my child						

DIMENSION COMMUNICATION WITH THE CLINICAL TEAM

V. Below you will find a list of items that describes different situations in which the <u>Medical Team</u> (doctors and nurses) <u>communicated</u> with you about your child's condition. Indicate how stressful these were for you.

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. They explained very quickly						
2. They used words I did not understand						
3. I was given different (or contradictory) diagnoses of my child's condition						
4. There was no definite diagnosis of my child's illness						
5. They did not converse sufficiently with me						

EMOTIONAL DIMENSION

VI. Below you will find a list of items that describes different ways <u>of behaviour and/or emotional responses</u> that your child may have demonstrated during their hospitalization in the PCCU. Indicate how stressful these were for you.

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Confused or disoriented						
2. Rebellious or uncooperative behaviour						
3. Crying and moaning						
4. Needy (demanding a lot of attention)						
5. Showing pain or making pain evident						
6. Restlessness or lack of calm						
7. Inability to speak or cry						
8. Fear						
9. Anger						
10. Sadness or depression						

VII. The following list refers to the role of the parents. Indicate how stressful the following factors were for you.

Items	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
Not being able to take care of my child myself						
2. Not being able to visit my child whenever I want						
3. Not being able to be there when my child is crying						
4. Not being able to hold my child in my arms or pick my child up						

VIII. Using the same evaluation scale, how stressful in general has your experience in the Paediatric Intensive Care Unit been for you?	Not experienced	It was not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
for you?						
IX. Is there any other situation that you found	d stressful and t	hat has not be	en included in the	questionnaire? Ple	ease describe it	below: (new item)

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