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Research paper

Development of a screening measure of stress for parents of children hospitalised in a Paediatric Intensive Care Unit



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ABSTRACT

Background: Having a child admitted to intensive care is a highly stressful experience for parents; however there is a lack of screening instruments of parental stress in that context, which would be useful for both, research and clinical purposes.

Objectives: (1) To validate a brief measure of parental stress based on the Parental Stressor Scale: Paediatric Intensive Care Unit (PSS:PICU), (2) to study which environmental factors of the PICU are more stressful in a sample of Spanish parents, and (3) to study which variables are related to higher levels of stress among this group.

Method: 196 Spanish parents completed the Abbreviated PSS: PICU (A-PSS:PICU) and a general stress scale (the *Perceived Stress Scale*) upon their child's discharge to test the convergent validity of the tool. Three months later, they were assessed anxiety and depression using the *Hospital Anxiety and Depression Scale*, and posttraumatic stress with the *Davidson Trauma Scale* in order to test the predictive validity of the A-PSS:PICII

Results: Two factors emerged from Confirmatory Factor Analyses, (1) stress due to child's condition and (2) stress related to PICU's staff. The A-PSS:PICU showed adequate reliability and convergent and predictive validity. The most stressful aspects were the behaviours and emotional responses of their child and the loss of their parental role. Age, gender, child's condition, length of admission, spiritual beliefs, and mechanical ventilation were associated to parental stress scores.

Conclusion: The A-PSS:PICU is a reliable and valid measure. Parental stress should be screened during a child's PICU admission to identify parents at risk of post-discharge distress.

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1. Introduction

Having a child admitted to a Paediatric Intensive Care Unit (PICU) has long been recognised as a highly stressful experience for parents. ^{1–3} This is understandable if we take into account that children under intensive care are usually acutely ill or injured, and consequently they are at increased risk of death. Furthermore, the PICU's environment itself, with its rapid pace, noises, bright lights,

Some previous studies have explored what are the sources of parental stress during their child's hospitalisation in the PICU.^{4–6} Commonly identified parental stressors included the loss of the parenting role, uncertainty over the child's outcome, being separated from their child, a feeling that the quality of care the child was receiving was poor, not being able to understand medical information^{4–6} or having communication problems with the medical staff,⁷ feelings of uncertainty and helplessness,⁸ and seeing their child in pain and discomfort. Also, parents can become distressed as a result of their exposure to other paediatric patients' life threatening conditions, traumatic procedures, and death.⁹

Some studies have used interviews to detect parental sources of stress^{4,5}; however most of them have used questionnaires. The best known measure to assess parents' responses to stress in the PICU is the Parental Stressor Scale: Paediatric ICU (PSS:PICU).^{10,11} The

and crisis-focused interventions presents a great challenge for parents who are already stressed.

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original 79-item scale was developed by Carter, Miles, Buford, and Hassanein. ¹⁰ Following factor and item analysis, Carter and Miles ¹¹ revised the scale, reducing it to 37 items measuring the following seven dimensions in the ICU environment: Child's appearance, Sights and sounds, Painful procedures conducted on the child, Alteration in parenting role, Behaviours and emotional responses, Staff's behaviour and Staff's communication.

The PSS:PICU was based Selye's theory on stress, ¹² Lazarus's cognitive-phenomenological theory on stress, ¹³ Roy's adaptation model of nursing ¹⁴ and Moos's theory on coping with illness. ¹⁵ These authors support the idea that the stress response is the result of a complex interaction between multiple variables such as environmental stimuli, characteristics of the situation, personal factors and the perception of the individual of the power of the stressors. So, while a child is hospitalised in a PICU, a multiplicity of environmental stimuli could be sources of parental stress. Some personal/family variables (such as age of the parent) and situational factors (such as child's illness) can also interact with these stimuli to affect their overall stress response. ^{16,17} Based on that idea, the PSS:PICU was developed to measure the environmental stressors of the PICU.

The PSS:PICU has shown reliability, validity, and stability in numerous research studies^{10,11,18} and has proved its efficacy to measure the effect of interventions to reduce parental stress in the PICU.^{19,20} It has shown adequate psychometric properties when used in a variety of populations, such as Indian,²¹ Spanish,²² Malay²³ and Chinese.²⁴

In spite of the fact that the PSS:PICU is a reliable and valid measure, it is not free of limitations. First, although a total stress score can be calculated in addition to seven subscale scores, no confirmatory factor analysis has been conducted to test the adjustment of a model with a second order factor. Second, with regard to the Spanish validation, the small sample size (N=20) is an important limitation, as it should have been five times larger as the power analysis revealed. Third, and most important, it takes around 30 minutes to complete the PSS:PICU, which makes it not practical to use on a daily basis²⁵ if we consider the difficulty of the situation that these parents are experiencing, and the high burden of work and consequently the lack of time – of staff working in critical care. Instead, in the context of the PICU, professionals need to have effective and fast screening tools to measure parental stress, which are not available currently. If we had these shorter measures, parents with a high level of disturbance could be detected for an early intervention. A shorter measure would be useful for research purposes too, as a way of reducing the demand on participants' time.

In previous studies, stress assessed through the PSS:PICU has been found to be related to several psychological variables, such as general stress, ²⁶ anxiety^{11,24,27,28} depression²⁸ and posttraumatic stress.^{7,29} Thus, these variables could be used as external criterion to test the validity of the new tool. PSS:PICU scores have also found to be related with some medical and sociodemographic variables, such as child's mechanical ventilation^{6,23,30,31} unexpected admission,³² higher severity of the child's condition,^{21,23} lack of previous PICU's experience,²³ prior parental psychological problems³² or parental socioeconomic difficulties³³ which are associated with higher stress.

Even when, as it has just been described, there is a wide body of using the PSS:PICU, this measure has some problems, mainly its length. Therefore, the purposes of this study were the following: (1) to develop a short questionnaire based on the PSS:PICU that could be used with parents of critically ill children as a screening measure of the degree and sources of stress produced by the PICU environment, (2) to study which are the most stressful aspects of the PICU in our sample of Spanish parents, and (3) to study which variables are related to higher levels of stress in our Spanish sample.

2. Method

2.1. Sample

Participants were parents whose child had been discharged in the previous 48 hours from a PICU in Madrid, Spain. The PICU is located in a tertiary level hospital and has 16 beds, 8 physicians and a total of 49 nursing staff. The nurse-to-patient ratio is 2:1. Regarding psychosocial services provided at the PICU, there is a Social Worker who attends families at request for the entire paediatric ward where the PICU is located. A psychologist from an NGO provides psychological support to the children with heart conditions and their families two times a week.

The parents were excluded from eligibility in the study if they did not speak sufficient Spanish to complete a questionnaire, if they were admitted for less than 12 hours in the PICU or if child abuse or neglect was suspected as a precipitant to the admission. A total of 196 parents of 130 children agreed to participate, 61.2% women and 38.8% men. Their average age was 37.80 years (SD: 6.58) for the parents and 56.58 months (SD: 61.92) for the children. The primary reasons for admission were planned surgery (65.3%), emergency medical treatment (16.8%), accidental injury and emergency surgery (11.1%) and relapse of a chronic disease (6.6%). The more prevalent diagnoses were heart conditions (26.2%), cancer (16.2%) and respiratory conditions (12.3%). The average length of admission was 6.12 days. Three months after the child' discharge 158 parents completed the following-up assessment.

2.2. Materials

Abbreviated Parental Stressor Scale for Paediatric Intensive Care Unit (A-PSS:PICU). In order to develop this scale, two psychologists summarised the content of each of the seven subscales of the Spanish version of the Spanish PSS:PICU²² in one item for each subscale. To do so, for example, instead of asking how stressful were 6 different medical procedures, with an item for each procedure, we asked in one item how stressful were medical procedures conducted on the child in general, and we gave them some examples of such procedures, so six items were reduced to one. Thus, the brief scale designed contains 7 items (one for each of the seven subscales of the PSS:PICU). The response format is a 5 point Likert scale ranging from 1 "Not stressful" till 5 "Extremely stressful", or 0 "Not experienced". It was developed in Spanish language and it is included in Appendix A along with its English translation. To translate it to English, two native Spanish-speaking bilingual psychologists translated it independently and agreed on a final common translation. The Spanish version was first administered to 4 parents (2 mothers and 2 fathers) in order to test whether understanding difficulties emerged. With this purpose, we asked these 4 parents to complete the measure and also to indicate whether they had had any difficulty in understanding each of the items. As none of them reported any difficulty, we administered the scale to the 196-parents sample above described with the aim of assessing its psychometric properties.

Perceived Stress Scale (PSS).³⁴ The PSS is a global measure of stress that was developed with the aim of measuring the degree to which situations in one's life are appraised as stressful. We used the European Spanish version.³⁵ This is a 14-item questionnaire that demonstrated adequate reliability (internal consistency, $\alpha = .81$, and test–retest, r = .73), concurrent validity, and sensitivity.

Davidson Trauma Scale (DTS).³⁶ It is a 17-item measure that assesses the 17 DSM-IV symptoms of PTSD. It was adapted to Spanish language³⁷ showing high internal consistency (α = .90) and test–retest reliability (ICC = 87).

Hospital Anxiety and Depression Scale (HADS).³⁸ It is a 14-item scale that contains two 7-item Likert scales, one for anxiety and

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