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ORIGINAL ARTICLE

Perioperative stress and anxiety in parents of children operated on for congenital heart disease

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KEYWORDS
Parental stress;
Parental anxiety;
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Pediatric cardiac surgery;
Renal surgery

Abstract

Introduction: Levels of stress and anxiety suffered by parents of children with congenital heart disease (PCUCS) during their children's admission for cardiac surgery may be higher than those suffered by other parents who go through the same experience.

Objective: General objective of this study was to measure the stress and anxiety suffered by PCUCS and parents of children undergoing renal surgery (PCURS) in relation to the intervention of their children. The specific objective of the quantitative study was to compare global stress and anxiety according to sex, time of the perioperative period, and cohort. The general objective of the qualitative section is to explore the experience that PCUCS and PCURS have during their hospital stay and to identify the specific factors that influence the genesis of stress and anxiety.

Method: A cohort study was carried out in which PCURS and PCUCS were included. The quantitative part was performed by comparing the scores of three questionnaires that measure stress levels (PSS-14), state anxiety (STAIE) and trait anxiety (STAIR) throughout three perioperative moments. At the same time, a qualitative study was carried out with semi-structured interviews and collection of diaries on which a descriptive phenomenological analysis was carried out, according to Munhall. The analysis of the text was carried out according to Colaizzi.

Results: Stress and anxiety levels were significantly higher in PCUCS compared to PCURS. Mothers in the cardiac cohort were those with the highest scores on all scales. In the qualitative

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study, four themes emerged: ''stress and anxiety from the moment of diagnosis'', ''surgical intervention as a critical moment'', ''harshness of the postoperative period in the Intensive Care Unit'' and ''joy and gratitude versus dependence and fear for the future''.
Conclusions: PCUCS suffer higher levels of stress and anxiety than PCURS, being the mothers of the cardiac cohort those who suffer these disorders with greater intensity. This study can constitute a starting point to develop strategies that cover these parental needs.

PALABRAS CLAVE
Estrés psicológico;
Ansiedad;
Cardiopatías congénitas;
Cirugía cardíaca

Estrés y ansiedad perioperatorios en padres de niños intervenidos de cardiopatías congénitas

Resumen

Introducción: Los niveles de estrés y la ansiedad que sufren los padres y madres de niños con cardiopatía congénita (PMNCC) durante el ingreso para cirugía cardíaca de sus hijos pueden ser más elevados que los que sufren otros padres y madres que pasan por la misma experiencia.
Objetivo: El objetivo general de este estudio fue medir el estrés y la ansiedad que sufren los PMNCC y los padres de niños sometidos a cirugía renal (PMNCR) en relación con la intervención de sus hijos. El objetivo específico del estudio cuantitativo fue comparar el estrés y ansiedad global en relación al sexo, momento del periodo perioperatorio y cohorte. El objetivo general del apartado cualitativo es explorar la vivencia que tienen los PMNCC y PMNCR durante su estancia hospitalaria e identificar los factores específicos que influyen en la génesis del estrés y la ansiedad.
Método: Se realizó un estudio de cohortes en el que se incluyeron los PMNCC y los PMNCR. La parte cuantitativa se realizó comparando las puntuaciones de tres cuestionarios que miden los niveles de estrés (PSS-14), ansiedad estado (STAIE) y ansiedad rasgo (STAIR) a lo largo de tres momentos perioperatorios. Paralelamente se hizo un estudio cualitativo con entrevistas semiestructuradas y recogida de diarios sobre los que se realizó un análisis fenomenológico descriptivo, según Munhall. El análisis del texto se realizó según la propuesta de Colaizzi.
Resultados: Los niveles de estrés y ansiedad fueron significativamente más altos en los PMNCC respecto a los PMNCR. Las madres de la cohorte cardíaca fueron las que presentaron las puntuaciones más altas en todas las escalas. En el estudio cualitativo emergieron cuatro temas: ''estrés y ansiedad desde el momento del diagnóstico'', ''intervención quirúrgica como momento crítico'', ''dureza del postoperatorio en la Unidad de Cuidados Intensivos'' y ''alegría y agradecimiento versus dependencia y temor ante el futuro''.
Conclusiones: Los PMNCC sufren mayores niveles de estrés y ansiedad que los PMNCR, siendo las madres de la cohorte cardíaca las que sufren estos trastornos con mayor intensidad. Este estudio puede constituir un punto de partida para desarrollar estrategias que cubran estas necesidades parentales.

What is known

Studies conducted in other countries indicate that parents of children with congenital heart disease undergoing cardiac surgery experience high levels of stress and anxiety. Although in some studies these levels were significantly higher in fathers and mothers of patients undergoing cardiac surgery compared to other control groups, in other studies there are no such differences.

What it contributes

This is the first national study to assess levels of stress and anxiety in parents of children with heart disease conducted in our country. Furthermore, the use of quantitative and qualitative methodology is new in this field and allows us to quantify stress and anxiety, determine the causes, and learn the experiences of the parents of children undergoing heart surgery for the first time and who have no previous coping strategies, during the perioperative period.

Implications of the study

This study allows us to determine the family groups that are more susceptible to perioperative stress and anxiety, the times when their vulnerability is greatest, and what the causes are. The most important implication of this study for clinical practice is that it will help implement information and psychological support measures for parents during the perioperative period, and strategies to help family coping in children undergoing heart surgery.

Introduction

Congenital heart disease is the most common congenital malformation. In Spain, the incidence is 13.6 cases per thousand live births.[1]

Paediatric admissions associated with serious disease or surgery cause parental stress.[2] The psychological[3,4] and physiological[5,6] aspects of perioperative stress have been studied in children undergoing surgery. However, the level and evolution of stress and anxiety experienced by parents throughout the perioperative process and the particular situations that trigger them have been little studied. There are studies that indicate that some of these parents suffered post-traumatic stress disorder in the postoperative period following their children's surgery[7] and up to half presented symptoms of depression and/or anxiety in relation to the surgical process.[8] This study, novel in our country, was conducted in PCUCS and PCURS, in a tertiary hospital with IHAN certification (Baby Friendly Hospital Initiative) that provides a model of family-centred care and in which parents play a fundamental role in the ongoing care of their children. The parents of these children, admitted to the PICU and inpatient units during the perioperative process and having gone through similar experiences despite having different factors exposing them to stress and anxiety, may have high levels of stress and anxiety during their children's stay in hospital, which need to be addressed. This study helps us determine the first experience of PCUCS and PCURS during the perioperative period, when they have no previous coping strategies. Knowledge of the causes of these disorders will help us to establish appropriate coping strategies.

The overall aim of this study is to measure the stress and anxiety experienced by PCUCS and PCURS in relation to their children's intervention. The specific aim of the quantitative study is to compare overall stress and anxiety according to sex, time of perioperative period, and cohort. The aim of the qualitative section is to explore the experience of PCUCS and PCURS in relation to their children's perioperative period and to identify the factors that trigger stress and anxiety.

Our questions are:

1. Do PCUCS have higher levels of stress and anxiety than PCURS?
2. Can we, by analysing these parents' experience during the perioperative process, identify the causes triggering stress and anxiety?

Method

We designed a mixed-method study. We also conducted a quantitative and analytical cohort study and, in parallel, a qualitative descriptive phenomenological study. All PCUCS and PCURS whose children were admitted and underwent surgery for the first time between January/2014 and July/2017 in a tertiary hospital in Madrid were included. The children of parents in both cohorts may have severe associated conditions, requiring care in PICU and subsequent stay in inpatient units, and therefore it is possible that the parents of these children will go through the same experience. There are more parents of children admitted for other reasons who may be going through the same situation, but including a wider variety of patients and types of surgery would have made the sample more heterogeneous and therefore it would have been more difficult to analyse the data. The sample size was 74 PCUCS and 76 PCURS (Fig. 1). All participating parents signed the informed consent form. Parents who did not understand Spanish, had a mental disorder, had another child with a chronic illness or disability, had gone through more surgeries, and those who died during the perioperative process were excluded from the study.

We collected a series of the parents' socio-demographic variables (Table 1) and the children's clinical variables (Table 2), which includes, among other data, the Aristotle Score (a system for classifying heart disease by points according to potential risk factors for each procedure, potential morbidity, mortality, and expected surgical difficulty).

Quantitative data on the parents' stress and anxiety were obtained from the responses to three validated questionnaires, the PSS-14 (Parental Stress Score) in its Spanish version[9] and the STAI,[10] in its state (STAIs) and trait (STAIt) versions. These questionnaires were to be completed at three points in time: admission, immediate postoperative period, and pre-discharge.

The PSS-14 is a reliable and valid instrument to assess stress with high internal consistency and a Cronbach's alpha value of .81.[9,11,12] It consists of fourteen items scored from 0 to 4, a higher score indicates greater stress. The maximum score is 56 and the cut-off point distinguishing pathological stress was set at 28.[13]

The STAI is a self-report scale that assesses anxiety as a transitory state (STAIs) and as a latent personality trait (STAIt).[14] The maximum score is 80 and the pathological cut-off score for the STAIt is 26 for fathers and 33 for mothers, and for the STAIs 29 for fathers and 32 for mothers.[4] Both tests have high internal consistency, between .90–.93 for the STAIs and between .84–.87 for the STAIt.[15]

The questionnaires to be completed on admission, in the immediate postoperative period, and at discharge were

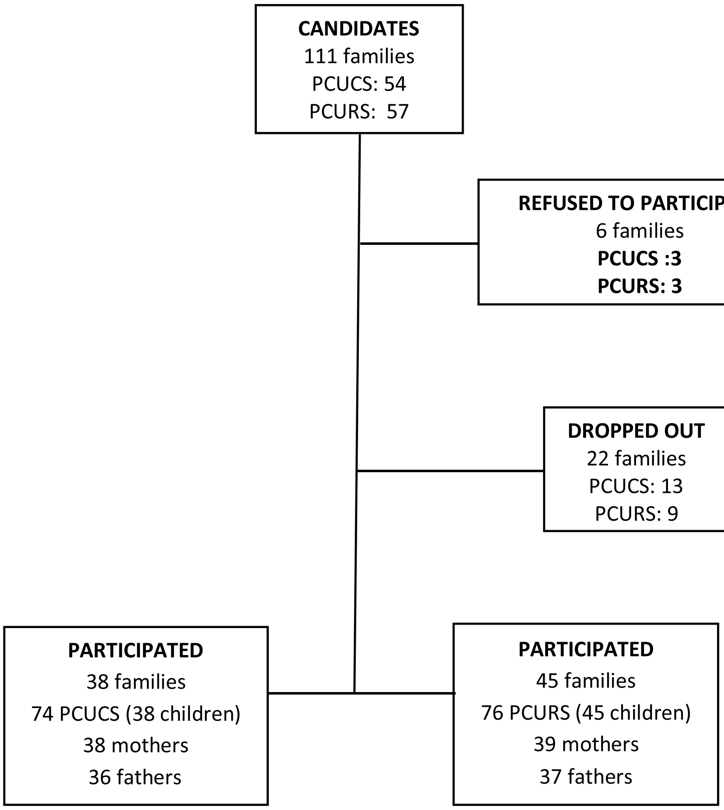

Figure 1 Flow chart of participants.

Table 1 Sociodemographic characteristics of the parents.

	Cardiac cohort (n = 74)		Renal cohort (n = 76)	
	Fathers (n = 36)	Mothers (n = 38)	Fathers (n = 37)	Mothers (n = 39)
Age (years)				
<25	0	1 (3%)	0	0
26–35	12 (33%)	18 (47%)	9 (24%)	13 (33%)
36–45	21 (58%)	18 (47%)	27 (73%)	26 (67%)
>45	3 (9%)	1 (3%)	1 (3%)	0
Active employment status	31 (86%)	21 (55%)	36 (97%)	28 (72%)
Coming from another AC	16 (44%)	18 (47%)	5 (13%)	4 (10%)
Level of education				
Primary	5 (14%)	6 (16%)	2 (5%)	3 (8%)
Secondary	18 (50%)	18 (47%)	13 (35%)	15 (38%)
University	13 (36%)	14 (37%)	22 (60%)	21 (54%)

Data are expressed as n (%).
AC: autonomous community.

given to the parents by a member of the research team the day before the intervention after providing them with information about the study. The cardiac surgeons and paediatric urologists provided information regarding the type and risks of surgery.

All statistical analyses were performed with SAS© software, version 9.4 for Windows. Quantitative variables were tested for normality using the Kolmogorov–Smirnov test. Qualitative variables were described as absolute and relative frequencies. Quantitative variables were described by the mean and standard deviation (SD). The correlation between continuous variables was studied using Pearson's correlation coefficient. Comparisons of quantitative variables between more than two groups made through analysis of variance (ANOVA) due to their normal distribution. Significant effects were followed by pairwise comparisons with Bonferroni correction. In the case of qualitative variables, frequency analysis was performed with the χ^2 test. In all analyses a p-value <.05 was considered statistically significant.

Table 2 Characteristics of the children.

	Cardiac cohort (n = 37)	Renal cohort (n = 45)
Age (months)	6 [1–36]	25 [7–36]
Admission to PICU	37 (100)	14 (31)
Stay in PICU (days)	8.7 ± 21.8	.5 ± .6
Hospital stay (days)	18.3 ± 40.0	2.3 ± 1.5
Sex (M/F)	17/20	40/5
Type of heart disease		
Septal defects (ASD, VSD, AV canal)	14 (38)	
Coarctation of the aorta	8 (22)	
Conotruncal anomalies	7 (19)	
Anomalous pulmonary venous return	3 (8)	
Valvulopathy	2 (5)	
Univentricular heart	2 (5)	
Vascular ring	1 (3)	
Aristotle score	6.8 ± 2.6	
Aristotle class		
Level 1 (1–5.9)	12 (32)	
Level 2 (6–7.9)	7 (19)	
Level 3 (8–9.9)	13 (35)	
Level 4 (10–15)	5 (14)	
Type of urological intervention		
Hypospadias		15 (33)
Nephrectomy		13 (29)
Pyeloplasty		8 (18)
Penile surgery		6 (14)
Ureteroneocystostomy		2 (4)
Cystectomy		1 (2)
Corrective/palliative surgery	33 (89)/4 (11)	
Medication on admission	9 (24)	12 (27)
Medication at discharge	25 (68)	27 (60)
Postoperative complications	11 (27.7)	1 (2)
Infectious	6 (16.2)	1 (2)
Pulmonary	4 (10.8)	0 (0)
Recovery	1 (2.7)	0 (0)

Data are expressed as n (%), mean ± standard deviation or median [interquartile range].
ASD: atrial septal defect, AV canal: atrioventricular canal, M/F: male/female, PICU: Paediatric Intensive Care Unit, VSD: ventricular septal defect.

In the qualitative section, a descriptive and analytical phenomenological analysis was carried out following Munhall's methodology,[16] seeking knowledge of lived experiences and associated feelings. To this end, the principal investigator conducted purposive sampling from the database generated for the quantitative component and conducted five semi-structured interviews with parents from each cohort at a time close to discharge. The interviews were conducted, and recorded, in a hospital ward. An interview guide, elaborated by the research team according to the thematic areas proposed in the questionnaires presented in the quantitative section, was followed, asking about the personal situation of the parent before the admission of their child, the parent-child relationship throughout the admission, the effect of the admission on family life, the relationship with the hospital environment, and the future perspectives regarding the clinical situation of their child. In addition, three mothers provided field diaries that they had written voluntarily. The interviews were recorded and subsequently transcribed. The text analysis was traditional according to Colaizzi's proposal[17] (Fig. 2), two readings were made of the recorded transcription and a series of codes elaborated according to the proposed objectives. The resulting codes were grouped into a list of themes and the results found were then described, including the associated verbatims. Qualitative results were obtained under the criteria of frequency and intensity in the codes and themes. Data saturation was found from the fourth interview of each cohort, at which point it was observed that the capacity to produce codes and themes relevant to the object of study

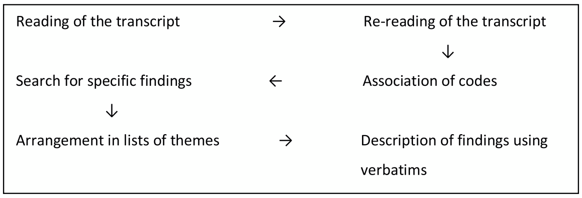

Figure 2 Colaizzi's method.

Table 3 PSS-14, STAIs, and STAIt test results segmented by cohort and sex.

Cohort	Time	Score per cohort	Sex	Time	Score per sex
PSS-14 (Cut-off score for pathological stress = 28 points)					
CARDIO	Admission	26.5 ± 8.4[a]	Mothers	Admission	28.9 ± 8.8[c]
	Postoperative period	27.1 ± 9.2[a]		Postoperative period	29.4 ± 9.1[c]
	Discharge	25.7 ± 8.9[a]		Discharge	28.4 ± 8.2[c]
			Fathers	Admission	23.7 ± 7.2
				Postoperative period	24.3 ± 8.6
				Discharge	22.6 ± 8.8
RENAL	Admission	22.0 ± 8.3	Mothers	Admission	22.8 ± 8.9
	Postoperative period	21.7 ± 7.5		Postoperative period	22.2 ± 7.9
	Discharge	21.1 ± 7.8		Discharge	21.6 ± 8.6
			Fathers	Admission	21.2 ± 7.7
				Postoperative period	21.1 ± 7.1
				Discharge	20.5 ± 6.9
STAIs (State anxiety cut-off score: mothers = 32 points, fathers = 29 points)					
CARDIO	Admission	54.5 ± 11.7[a]	Mothers	Admission	58.5 ± 11.5[c]
	Postoperative period	50.7 ± 13.9[b]		Postoperative period	52.6 ± 12.5[d]
	Discharge	38.29 ± 9.2 **NS**		Discharge	38.9 ± 9.8 **NS**
			Fathers	Admission	49.7 ± 10.3
				Postoperative period	48.3 ± 15.3
				Discharge	37.5 ± 8.4
RENAL	Admission	46.5 ± 11.0	Mothers	Admission	49.5 ± 11.6
	Postoperative period	45.2 ± 11.5		Postoperative period	48.0 ± 12.2
	Discharge	39.4 ± 9.0		Discharge	40.5 ± 10.1
			Fathers	Admission	43.2 ± 9.3
				Postoperative period	42.2 ± 10.2
				Discharge	38.1 ± 7.5
STAIt (Trait anxiety cut-off score: mothers = 33 points, fathers = 26 points)					
CARDIO	Admission	43.7 ± 11.2[a]	Mothers	Admission	47.6 ± 11.3[c]
			Fathers	Admission	39.2 ± 9.3
RENAL	Admission	36.6 ± 9.8	Mothers	Admission	39.1 ± 10.0
			Fathers	Admission	34.0 ± 8.8

Data expressed as n (number of observations) and mean ± standard deviation.

[a] p < .001 for comparison between cardiac and renal cohorts.

[b] p < .01 for comparison between cardiac and renal cohorts.

[c] p < .05 for comparison between cardiac mothers and other groups (cardiac fathers, renal mothers, and renal fathers).

[d] p < .01 for comparison between cardiac mothers and renal fathers.

diminished, thus, continuing from the fifth interview of each cohort no longer made sense because they were becoming redundant.

The results obtained in this study were validated by the respondents, during the interview and later, after sending them the audio, the transcript, and the results obtained to ensure the veracity of the information. The methodologies were triangulated as another quality criterion in this work, using quantitative and qualitative methodologies to observe the same object of study from different angles. The Ethics Committee of the hospital approved the study (number 13/211).

Results

One hundred and eleven families from the two cohorts were asked to participate. Fifty-four PMNCC and 57 PMNCR families. Six declined to participate from the start (5.4%) and 22 families (19.8%) dropped out later. A total of 150 parents eventually participated in completing the questionnaires, 74 in the PMNCC (38 families) and 76 in the PMNCR cohort (45 families) (Fig. 1). The description of the sociodemographic and clinical data of parents and children is shown in Tables 1 and 2.

Quantitative study

Parental stress, PSS-14 questionnaire (Table 3)

Parental stress scores were significantly higher in the cardiac cohort than in the renal cohort at all three time points, admission (26.5 ± vs 22.0 ± 8.3), immediate postoperative (27.1 ± 9.2 vs 21.7 ± 7.5) and pre-discharge (25.7 ± 8.9 vs 21.1 ± 7.8). Only the mothers in the cardiac cohort exceeded the pathological cut-off score for this test (28 points) and their scores were statistically significantly higher than each of the other 3 groups (cardiac parents and PCURS) at all three time points studied (admission 28.9 ± 8.8, postoperative 29.4 ± 9.1, and near discharge 28.4 ± 8.2). Stress levels were stable throughout the hospital stay in all groups.

Table 4 Characteristics of the interview participants.

Code	Cardiac mothers	Cardiac fathers	Renal mothers	Renal fathers	Interview duration (min:s)	Employment situation	Coming from[a]	Level of education
COD 01	31 years	–	–	–	52:20	Leave of absence	Other A.C.	University
COD 02	34 years	–	–	–	59:30	Unemployed	Other A.C.	Secondary
COD 03	33 years	–	–	–	37:14	Unemployed	C.A.O.	Secondary
COD 04	–	35 years	–	–	20:53	Active	Other A.C.	University
COD 05	–	37 years	–	–	60:12	Active	Other A.C.	University
COD 06	–	–	32 years	–	20:52	Unemployed	C.A.O.	Secondary
COD 07	–	–	29 years	–	31:37	Active	C.A.O.	University
COD 08	–	–	33 years	–	29:07	Unemployed	C.A.O.	Secondary
COD 09	–	–	–	35 years	34:09	Active	Other A.C.	Secondary
COD 10	–	–	–	33 years	46:26	Active	Other A.C.	Secondary

[a] Coming from: A.C.O. Autonomous Community of Origin: without moving from their Autonomous Community of Origin. The respondent is living in their usual place of residence. O.A.C. Other Autonomous Community. The respondent is living away from their usual place of residence.

State anxiety, STAIs (Table 3)

The level of state anxiety was higher than the cut-off score in the fathers and mothers of both cohorts, at all three measurement points. The level of state anxiety was higher in the PCUCS cohort than in the PCURS cohort on admission and in the immediate postoperative period (54.5 ± 11.7 y 50.7 ± 13.9 vs 46.5 ± 11.0 y 45.2 ± 11.5, respectively), but not at discharge. Again, it was the mothers in the cardiac cohort who had significantly higher scores than the other three groups for admission and than the fathers in the renal cohort in the immediate postoperative period (58.5 ± 11.5 and 52.6 ± 12.5, respectively). Regarding the time course of state anxiety, scores decreased statistically significantly in both cohorts from admission to discharge ($p < .0001$).

Trait anxiety, STAIt questionnaire (Table 3)

The level of trait anxiety was above the cut-off score in both cohorts. Also in this questionnaire, mothers in the cardiac cohort had significantly higher values at admission (47.6 ± 11.3) compared to the other three groups.

Neither stress nor anxiety levels correlated with severity of heart disease (Aristotle score), type of surgery, presence of postoperative complications, being from another autonomous community, length of hospital and PICU stay, or need for medication at discharge in the PCUCS cohort. There was also no correlation with any of the sociodemographic variables of the parents. It should be noted that more of the mothers in the cardiac cohort were not in active employment than in the other groups ($p < .0001$).

Qualitative study

Data on age, sex, cohort, interview duration and sociodemographic data are given in Table 4. 5 interviews were conducted for each cohort. The sampling was intentional and purposeful. Data saturation was established when there was a decrease in identification of relevant themes and sub-themes with regard to the established objectives. Feelings and sensations, grouped into personal, family/social, and institutional spheres, as well as emerging concerns and needs to be met are shown in Table 5. The most relevant feelings extracted from the interviews and diaries written by the parents related to stress and anxiety and validated by the interviewees themselves are shown below.

''Stress and anxiety from time of diagnosis''

The prenatal diagnosis of a cardiac or renal anomaly involved an initial moment of stress and anxiety in both cohorts, although more marked in the PCUCS cohort.

> ''At week 28, they found a heart almost bigger than the foetus, so even an ignoramus like me saw that something was wrong, because it was a huge heart'' (COD 2).
>
> ''Then the words heart disease and then... you say... oh, goodness, this doesn't look good but (....) Then you see the seriousness, (...) you have to go to... to a tertiary level centre, is that what they say? Tertiary level, then well, you have to go to Madrid, and then all that, I remember it was all like a haze, what he told me'' (COD 3).
>
> ''I will never forget that sentence. ''This child has a heart condition'', (...) And my husband the same... worse, he almost turned white. And then we stayed in that room, and he went away and left us there, I suppose, as you know... what there is, so that we could have our moment to... to take it in, to cry, whatever. And then, well, from then on it was horrible, it was horrible'' (COD 4).

The diagnostic tests, an indeterminate hospital stay, health services provided by strangers, being away from their homes, work problems, and financial outlay meant added stress and anxiety.

> ''From the minute they're born, you have a hard time. Then there are the tests that have to be done, the needles and IVs... horrible! I mean, I see hospitals and I dread them'' (COD 6).

Table 5 Sensations, feelings and needs to be covered.

POSITIVE FEELINGS AND SENSATIONS
  - Grateful for the involvement of health professionals.
  - Confidence in the institution and in the professionals.
  - Joy at the satisfactory outcomes.
  - Joy at being reunited with their child after the operation.
  - Feeling useful during the process.
  - Hope.
  - Capacity for resilience throughout the process.

NEGATIVE FEELINGS AND SENSATIONS
- At personal level:
  - Stress.
  - Anxiety.
  - Sadness.
  - Anguish.
  - Helplessness.
  - Loneliness
  - Fatalism.
  - Loss of sense of time.
  - Despair at slow postoperative progress.
  - Difficulty understanding and coming to terms with the situation.
  - Suffering.
  - Fear and uncertainty about death or postoperative sequelae.
  - Feeling of being held hostage in hospital.
  - Impotence.
  - Personal collapse due to what has been experienced and what remains to be experienced.
  - Feeling of being on an emotional rollercoaster.
- At family/social level
  - Self-imposed isolation.
  - Abandonment by other family members.
  - Family stress.
  - Family disorganisation.
  - Creation of a parallel life to the one they had.
  - Being distanced from their place of residence.
  - Uncertainty about the future of the family.
  - Search for family and social normalisation.
- About the hospital
  - Aggressive environment.
  - Dependence on hospital care.
  - Feeling that they are currently living surrounded by health personnel.

NEEDS TO BE MET
  - Psychological support.
  - Clear and comprehensible information.
  - Being physically at their child's side.

''It means (crying) giving up your life, because..., I had to come here with a suitcase, not knowing what awaited me and leaving behind everything I had thought out, planned, because everything had been broken (...), with enormous anxiety and stress because you don't know what's going to happen and you have to set up a life parallel to the one you had at home and, of course, out of your environment, without your people, without your family, without your friends. I've felt very lonely.'' (COD 3).

''Everything has cost us a lot of money, we've had to rent a flat here, lots of travelling. Thanks to having a lot of family who have come to help us, otherwise we would have had to hire a person to be at home with my other child while I was here in the ICU, while my husband was working... Family logistics become very complicated.'' (COD 2).

''The surgical intervention as a critical moment''

The imminence of the intervention was expressed by most parents as a particularly emotionally challenging time. The preparation for the operating theatre, the waiting during the operation, the uncertainty about the outcome, including the possibility of losing their child, involved high levels of stress and anxiety.

> ''At 6:30 we were up, at 7:15 in the morning we were here and nothing, we were with her until she went up to the operating theatre. We were then waiting... anxiety, obviously anxiety'' (COD 4).
>
> ''But of course, you see him, in that cot, we went with him to the operating theatre, and you feel a pain, something ... You say, 'will I see him again when he comes out of the operating theatre?''' (COD 3).
>
> ''Well, looking at the clock every 10 minutes... or less, to see if the time's passing, to see if the time's passing, to see if the time's passing, to see if the time's passing, and to be, well, thinking that it will pass, thinking that it will pass, thinking that it will pass, everything will be fine, they will be... they'll have done it already, they'll have anaesthetised him... and looking at the clock, looking at the clock, looking at the clock, looking at the clock and crying... and looking at the clock and crying'' (COD 1).

''The harshness of the postoperative period in the PICU''

Regarding the stay in PICU the parents showed as fundamental causes of their stress and anxiety the initial feeling of coldness, the noise contamination through the sounds of the machines, associated with initial disorientation, nerves, worries, and fears of the unknown and of the clinical situation, and the external appearance of their children.

> ''You start to see everything that comes with the operation. Then you see the frenetic pace of the ICU, which you're not used to, or anything on the first day. Drugs here, bring this, bring him that... and you see your little boy there... And then the image that I can't forget... all bloody, oh God!'' (COD 3).
>
> ''And they started to put everything on him... all the equipment and put in the IV here, put in the IV there, put in I don't know what kind of monitoring, I don't know what kind of screen, bah, I left the PICU and went to... to the delivery room, where M was, to tell her where they had taken her son. And with sadness and anxiety we went up to the room. A sadness...and a silence...well...sepulchral. We entered a ward with children, with...moans and cries of...other babies...but us without a baby. And it was a situation that was...well...hard.'' (COD 2).

The need to use highly invasive techniques, such as extracorporeal membrane oxygenation (ECMO), was a factor that markedly increased levels of stress and anxiety during the parents' stay in the PICU, because of the visual impact of the situation and the potential negative consequences of their use.

> ''We were left with the ECMO, with the machine, the extracorporeal machine, I mean, ''just don't let him come out with the ECMO, just don't let him come out with the ECMO!'' (COD 5).
>
> ''Very stressful because also, there are also a lot of risks with the extracorporeal machine, apart from it not working again.... and the fear of kidney dysfunction...which doesn't usually happen, but...but that's what I thought...'' (COD 1).
>
> ''Then I went to talk to the surgeon, ''look, since you have told me this, that it was difficult to remove the extracorporeal machine, if this has any repercussions on the postoperative period, if it's going to be longer, if I'm going to be longer, if it's going to have... any repercussions.... on the organs''. Of course, after processing the information I said: ''Oh, my goodness! And will there be any problems, will there be any sequelae in any organ?'' (COD 3).

Furthermore, being physically distant from their children, not knowing if they needed them, and not having updates on their physical condition triggered notable anxiety and stress throughout the child's admission.

> ''I couldn't go to bed, impossible, I couldn't, but I couldn't because of the anxiety of being away... maybe he's crying and needs me and I'm not there... it created... such anxiety that I said, ''I can't go to bed!'' (COD 1).
>
> ''You go a month without holding him... Yes. A month, ah, well, look, going back, you asked me before what was the best moment in the ICU and I told you when we... when we left, well, I've just remembered another one too, which was when... when they let me hold him, which was almost at the end. (COD 3).

The torpid clinical evolution in some cases, the impossibility to continue with their life prior to diagnosis, or have a clear vision of their personal, family, and work future, produced high levels of stress and anxiety in the postoperative period.

> ''It's that this is never going to change.... because I'm going get a tattoo of the phrase ''little by little''. Because it's true that you can't talk about time when you come here, but you have a life. You can put many things on hold, but some things you can't'' (COD 2).
>
> ''Yes, I mean, seeing that... we saw light at the end of the tunnel, because I always see this, I've always seen it with a lot of darkness, I mean, yes, little by little, but all dark, never seeing .... well, look, the end is there. No, you don't see it, you don't see the end, you don't see what the end will be like, or when.'' (COD1)

''Joy and gratitude versus dependence and fear for the future''

Impending discharge, dependence on hospital care and fear of providing inadequate or insufficient care for their child after discharge generated high anxiety and stress in the parents in both cohorts, more marked in the discourse of the PCUCS.

> ''Well, I'm on the ward and I miss the PICU (...). When you leave there, you realise that you're not going to have a great doctor, glued to your child for life, or a nurse to solve the situation'' (COD 2).
>
> ''That's my fear...the thickness of the bubble that my child has to have. Because of course, I say to them, what are we going to do if my child catches something? And they tell me: ''try not to let him catch something''. But

of course, he has a brother, a brother who goes to school, who is going to come with a cold... and he's going to catch it, because I can't banish my older son, I can't say to him: ''you're sick aren't you? ... you go to your grandparents!''. (COD 1).

''I don't know what's going to happen when... being with my son at home, I don't know how he's going to limit us, I don't know what special care he's going to need, I don't know what his life is going to be like, I don't know, it's a question mark, because the child's whole life, he's been here, in hospital, he's three months old'' (COD 5).

''And how do you see the future at home again? Ah, well, it's already very good, I can already see myself with the pushchair over there. Sometimes I get a bit of the jitters, of (...) a bit of fear. Although I try to be very optimistic, I can tell you that when .... I get overwhelmed, I prefer not to think about it... I live for the moment and day by day'' (COD 3).

''I think when I go home, I'm going to feel like...like I've been taken hostage. The other day I was thinking about it, I've been here so long that I became disconnected from everything... from everything, I don't know how the world is going, I don't know what's happened in these three months, I don't know, I don't know, I don't...no...when I go home again it's going to be super...shocking and I'm even afraid that I'm going to paralyse me because it's going to be a situation.... very, very... different to what I have experienced over these three months, which has been reduced to hospital life, from home to hospital, hospital to hospital... talking to doctors, being with... nurses, nurses... this is... my life, so when I go home then... I don't know...'' (COD 4).

Discussion

A significant percentage of the PCUCS have psychological disorders in relation to the care that their children require due to their illness.[18,19] These disorders are accentuated at critical times such as the perioperative period of cardiac surgery. In one study, up to 30% of PCUCS were diagnosed with post-traumatic stress disorder[7] and between 25%–50% presented symptoms of depression and/or anxiety.[8,20]

In our series, the PCUCS had higher levels of stress than the PCURS. There are controversial studies in the literature in this regard; in some, PCUCS have higher levels of stress than controls,[21,22] while in others there are no substantial differences.[25] In the study by Diffin et al.,[21] levels of anxiety and depression in parents of newborns with congenital heart disease during admission to PICU at 6 months and at one year were compared with those of a control group of parents of healthy children, and the scores for anxiety and depression were significantly higher in the cardiac cohort during admission to PICU. However, stress and anxiety levels showed no significant differences between the cardiac and control cohorts at 6 and 12 months after surgery. In our study, postoperative levels of stress and anxiety were also higher in the PCUCS cohort in the PICU admission period compared to the PCURS cohort. Similarly, in the study by Sarajuuri et al.[22] parents of children with univentricular heart presented higher levels of stress when compared to healthy children at 18 months of age. In our series, the PCUCS with children with univentricular heart were rare and our measurement was different, although we also found significant differences between the groups. On the other hand, the study by Golfenshtein et al.[25] studied stress levels in a group of fathers and mothers of children undergoing surgery for congenital heart disease at discharge from surgery, at 3, 6, 9, and 12 months after surgery and found that scores on the stress scale remained at the 50th percentile from 3 months after discharge from surgery, with no excessively high scores in these periods, which differs from our results at hospital discharge.

In the present study, the mothers of the children who underwent cardiac surgery had the highest scores on the stress scale (at admission 28.8 ± 8.8, immediate postoperative period 29.4 ± 9.1, and at discharge 28.4 ± 8.2. Table 3), and were the only ones to score above the cut-off considered pathological (28 points). This is a finding that is repeated in most studies on parental stress associated with cardiac surgery and may be because mothers are usually the main caregivers of their children in the hospital setting.[7,20–23]

Regarding the surgical risk associated with the complexity of the heart disease (Aristotle score and Aristotle class)[24] in our series, there were no significant differences in stress levels according to the complexity of the intervention or whether the surgery was corrective or palliative. This is a finding that is repeated in other studies.[23,25–27] Only parents of children with hypoplastic left heart syndrome or univentricular heart have shown higher levels of stress than those with other types of heart disease,[22,28–30] but this type of patient was very rare in our series.

Regarding state anxiety, our study shows a level above the cut-off scores in both cohorts (29 for the fathers and 32 for the mothers) and it is higher in the PCUCS cohort than in the PCURS cohort. Again, the mothers in the cardiac cohort had the highest scores in line with most series in which mothers had higher levels of anxiety[21,31,32] and there was a statistically significant difference compared to the other three groups at admission and in the immediate postoperative period (Table 3). Unlike stress levels, which were stable throughout admission, state anxiety levels progressively decreased from admission to discharge. Regarding the time course of anxiety after surgery, the data in the literature varies. In some studies anxiety levels decreased over time,[21,26] while in others anxiety levels remained above controls for up to 3 years after surgery.[29,33]

The value of adding a qualitative study to the quantitative study is the ability to determine and analyse the most important causes at each moment of the perioperative period of stress and anxiety in parents. Knowing these causes will help us to design strategies to combat them in the future.

When we describe the causes of these parents' stress, we find that it starts at the time that the heart disease is diagnosed. As reported in other studies, at this time the parents reported feeling in a state of shock, overwhelmed, ''broken hearted''.[34] This shock is experienced regardless of whether the diagnosis is made prenatally or postnatally, and regardless of the type of heart disease.[34,35] Our findings indicate that the stress parents experience when their child's condition is diagnosed generally begins long before birth, and the use of terms such as ''heart disease'' can trigger a state of stress, anxiety, and even associated shock in parents, prolonged over time. Many of these parents suffer from stress and anxiety from 26 to 28 weeks' gestation onwards, and therefore may have high levels of stress and anxiety at the moment of their child's admission to hospital. This is in line with the quantitative data.

During admission, parents perceive hospital as a ''hostile environment'' where they are unfamiliar with the spaces and staff caring for their children. As reported in the study by Thomi et al.,[35,36] parents feel as if they are suddenly thrust into an unknown and unpredictable world in which they have to learn to cope. Our results indicate that they enter a world in which they do not know anyone, they do not know the environment, they have to change their residence, and even move to a different autonomous community to ensure adequate care for their child. They have to leave their place of comfort, which can cause individual and family dysfunction because the logistics of their life change at family, economic, and social level, from an individual and/or nuclear family perspective, and they are often alone. Kosta et al. also highlight these aspects.[37]

The day of surgery is uniformly noted in most studies as a critical time. The separation after taking the child to the operating theatre and the waiting during surgery have been described in other studies as ''sitting on pins and needles''[34] or as a ''time of darkness''[35] when they did not know what was happening to their child, and generated great uncertainty especially in parents of children undergoing cardiac surgery having to face the possibility of their child's death.[34,36,38] Similarly, in our study, waiting for their child to enter the operating theatre and waiting during the surgical procedure, along with the uncertainty that this period entailed, generated very high levels of stress and anxiety in the parents. The scarcity of information received during the surgery, the uncertainty about what was happening in the operating theatre, and the fear of receiving bad news exacerbated these feelings.

During admission to the PICU, the noises, alarms, and the ''high-tech'' environment are a cause of increased parental stress, as well as their feeling of inability to help their child.[35] The transient loss of parental role was frustrating for the parents during their stay in PICU. This is aggravated when the postoperative course is torpid because this transitory loss of parental role is too prolonged. During the postoperative period in the PICU, the parents feel that they can only wait to see what happens to their child, leaving him/her in the hands of strangers, they feel alone, far from their children and in an environment that is unfamiliar to them, sometimes referred to as ''initially cold''. Despite being surrounded by health personnel at the time of admission to the PICU, the parents feel lonely, and the distance from their children rather than physical, is related to not being able to meet their children's needs. In addition, the use of ECMO was highlighted by the parents as very stressful and anxiety-generating, due to the real situation of danger that the technique implies.

On the other hand, after this initial cold period, the PICU environment gave most of the parents a sense of security regarding their child's care, as they established a relationship and gained confidence. The postoperative care provided by the PICU staff may mean that transition to the ward, the process of discharge home, and the move to a new hospital setting with different staff trigger increased stress and anxiety, because a situation of care dependency has been created. Discharge from hospital also generated stress and anxiety because it marks the moment when the parents, after a period in which they have relinquished their parental role in caring for their children, have to resume that role. They expressed concerns about their ability to adequately care for their children, and this generated stress and anxiety. The parents interviewed reported that the return home was not going to be easy, because it was full of challenges, and they considered themselves insufficiently prepared to fulfil the parental role. In line with other studies, in our work we see that at this point the parents' joy at returning home converges with uncertainty regarding the care and needs of their child.[35,36]

One of the limitations of this study is that patients in the cardiac cohort had a higher percentage of PICU admissions, longer length of stay, and were more often from other autonomous communities (44% fathers and 47% mothers) compared to the renal cohort (13% fathers and 10% mothers). This may have contributed to higher levels of stress and anxiety in the cardiac cohort. The fact that stress levels did not change over time, unlike anxiety levels which did, may mean that the PSS-14 questionnaire is not sensitive enough to detect changes over a short period of time.

Based on the results of our study, future lines of research could be considered to study the usefulness of some nursing interventions aimed at reducing the stress and anxiety of parents during the admission of their children.

Conclusions

The PCUCS experienced higher levels of stress and anxiety than the PCURS, and the mothers of the cardiac cohort experienced more intense levels.

Analysis of the perioperative experience of these parents shows many positive as well as negative feelings and sensations in the personal, family/social, and hospital spheres.

Positive feelings include gratitude and trust in the professionals and the institution. Negative feelings range from stress, anxiety, anguish, helplessness, or personal powerlessness to abandonment by other members of the family, disorganisation, or uncertainty about the future in the family/social sphere. Regarding the hospital, on the one hand the parents experienced it as an aggressive environment, but on the other, they expressed their dependence on it for the care of their child.

The parents also mentioned a number of needs to be met such as psychological support, more information, or being able to spend more time with their children.

Based on these feelings and needs, nursing interventions should be designed to reduce parents' stress and anxiety in relation to their child's surgery.

Conflict of interest

The research team behind this article declares that we have no conflict of interest.

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