



Sleep characteristics of the parents of children admitted to a pediatric intensive care unit: risk factors and repercussion on their daily life activities



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ABSTRACT

Objective: to analyze the sleep characteristics of the parents of children admitted to a pediatric intensive care unit (PICU), the possible risk factors and impact of sleep quality on their daily life activities.

Methods: Parents of children admitted to PICU for at least 48 h filled in a survey. Demographic data, sleep characteristics before and during admission and its impact on daily life activities measured by the FOSQ-10 questionnaire, were collected.

Results: 100 surveys from parents of 53 children admitted to the PICU were collected. Most children (74%) were cardiac patients. 55% of them had had previous PICU admissions. 45% of parents lived in a different city. They spent a median of 14 h a day (IQR 12–16) at the hospital and 89.2% did not attend work. Parents had significantly worse subjective sleep quality ($p = 0.001$), less sleeping hours/day ($p = 0.001$), more difficulty falling asleep ($p = 0.001$) and more night arousals ($p = 0.001$) during PICU admission than before. 77% of parents also had a bad FOSQ-10 score. Perceived sleep quality and FOSQ-10 score had a good correlation ($p = 0.00$, Kappa 0.43). Significant risk factors were living in a different city ($p = 0.03$), programmed admissions ($p = 0.001$), previous PICU admissions ($p = 0.001$), prolonged PICU length of stay ($p = 0.03$) and longer distance from home ($p = 0.03$).

Conclusions: Three quarters of the parents of children admitted to PICU suffer from sleep disorders, which negatively affects their personal lives. Perceived sleep quality had a good correlation with FOSQ-10 score. Institutional support is needed to optimize parents' resting conditions during their child's hospitalization.

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1. Introduction

A child's hospitalization generates great anxiety and stress for parents, especially if they are admitted to the pediatric intensive care unit (PICU) [1–5].

There are two main stress-causing factors during a child's PICU admission: fear and concern about the child's health, which is usually proportional to the severity of illness and to the invasiveness of the procedures, and uncertainty about the outcomes.

Families with previous hospitalizations are at high risk of reliving bad experiences, which increases even more anxiety and stress.

Parents spend many hours and nights at the hospital, disturbing completely their daily life activities and sleep. Sometimes families will need to face additional problems, as reorganizing the care of other children, moving to another city (with all the economical and accommodation challenges that it involves), frequent commutes to the hospital, work absenteeism ...

This emotional stress and change of daily habits interferes with sleep quality, leading to daytime sleepiness, fatigue, bad mood and difficulty to perform efficiently and effectively in their daily responsibilities, both at work and during leisure time [6–8].

Sleep is a basic human necessity and has many important biological functions. It is regulated by the sleep–wake cycle [9,10].

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Multiple factors can affect sleep quality and the sleep–wake cycle: age, psychological problems, diseases, hormonal, environmental, sociocultural, or economic changes [11,12]. People affected by an impaired sleep–wake cycle can experience physical and psychological disorders. The most prevalent symptoms are concentration problems, tiredness, daytime sleepiness, irritability and headache. Social and family life can also be affected by sleep disorders [13].

Sleep quality is important for every parent, but especially for those whose children are in hospital, as their physical and emotional health affects their ability to cope with their child's illness, to support their child and other family members during the process, to participate in decision-making and to maintain their relationships with family and friends [8].

The objectives of our study were to analyze the sleep characteristics of the parents of children admitted to the PICU and to compare them with their previous quality of sleep; to investigate the most important risk factors that lead to sleep and rest impairment; and to assess its impact on their daily life activities.

2. Methods

A descriptive observational study was performed at the pediatric intensive care unit (PICU) of the Gregorio Marañón University Hospital, a tertiary hospital in Madrid (1300 beds), Spain, for 2 years (from January 2018 to December 2019). This PICU is composed of 17 beds. It is an open ward, where parents are allowed to be present 24 h a day. However, it lacks a specific family room for parents and proper rest areas. When parents stay overnight at the PICU, they sleep in an armchair next to their child's bed. No other similar studies had been previously performed in our country.

The study was approved by the Ethics Committee of the General Gregorio Marañón University Hospital.

A voluntary survey was filled in by the parents of children admitted to the PICU for at least 48 h (Appendix A), with no other exclusion criteria. After a proper explanation of the study to parents, a verbal informed consent was achieved. Although many parents were offered to participate, not all of them returned the completed survey back to us, mainly because they forgot it due to the stress or concerns about their children. There was not any cost or gift given for participation.

The survey consisted of 5 sections: the first part collected demographic data of the patient (age, gender, diagnosis, severity of illness (PRIMSIII score) and previous admissions to the PICU). The second part was related to demographic data of the parents and family (marital status, number of children, age of siblings, city of residence, employment situation). The third section included questions about parent's sleep characteristics in their life before hospital admission. In the fourth section there were similar questions about sleep characteristics and resting time during their child's PICU admission. Finally, the fifth section corresponded to the FOSQ-10 questionnaire [14–16], which is an objective evaluation of sleep quality and it evaluates the excessive daytime sleepiness and its impact on daily life activities. The original FOSQ questionnaire consists of 30 questions divided into 5 subscales: general productivity (8 items), activity level (9 items), vigilance (7 items), social outcomes (2 items) and intimacy and sexual relationships (4 items). We have used the short version called FOSQ-10 [14–16], where each question can be punctuated from 0 to 4. To obtain the total score, a mean-weighted item score was first computed for those subscales with more than one item. This approach prevented the distortion of the score resulting from missing responses. The total score was derived by calculating the mean of the subscale scores and multiplying that mean by 5. A final score lower than 18 corresponds to bad sleep quality. The questionnaire was translated into Spanish by a native English speaker, following the indications

of previous publications that used a Spanish version of the FOSQ questionnaire [16].

Data were analyzed with the IBM SPSS Statistics 22 package. To compare qualitative variables, Chi Square test and Fisher's exact test were used (when percentage of expected frequency minor than 5 exceeded 20%), with a confidence interval of 95%. The Kolmogorov–Smirnov test was applied to test for a normal distribution of quantitative variables. Student's t-test and Mann–Whitney's U test were used to compare these variables according to their Kolmogorov–Smirnov distribution results. Correlation between quantitative variables was calculated with non-parametric Spearman Rho test. To compare sleep characteristics before and during PICU admission, statistical tests for paired samples were used. To evaluate the statistical concordance between subjective self-reported sleep quality and the results from the FOSQ-10 questionnaire, we used the Kappa index as coefficient of intra-class correlation. A p-value of <0.05 was considered to be statistically significant.

3. Results

3.1. Characteristics of the parents

100 surveys from the parents of 53 children (48% fathers and 52% mothers) with a median age of 38 years (IQR 34–43) were analyzed. 95% of them were married or lived as a couple and they had a median of 2 children (IQR 1–3) (55% of the parents had, at least, another child apart from the one in the PICU).

Their residence was in the same city as the hospital in 55% of the cases, but the remaining 45% of parents were displaced from their homes. A temporary accommodation was offered to 73.3% of them by a non-governmental association. Parents spent a median time of 20 min (IQR 15–45) on each journey from their place of residence to the hospital. 25% of the parents did not have any support from their families or friends during their child's stay at the PICU.

75.5% of parents had a regular job, working a median of 8 h a day (IQR 6–8). 18.5% were self-employed workers. Most of the parents (89.2%) did not attend work during their child's admission. None of the parents that continued working during the child's admission were self-employed.

Parents stayed a median of 14 h a day (IQR 12–16) at the hospital.

3.2. Characteristics of the patients

The median age of patients was 16 months (IQR 4–95) and the most frequent diagnosis was heart disease (74%), followed by respiratory (12%) and infectious (6%) diseases. 49% were programmed admissions for scheduled surgery. 55% of the children had a previous admission to PICU, 65.5% of which had more than one. Median PRISM-III score was 8 (IQR 5–11), and by the time parents filled in the surveys, children had been admitted for a median of 7 days (IQR 4–15).

3.3. Comparison of parents' sleep characteristics before and during PICU admission

Table 1 shows the comparison between sleep characteristics of the parents before and during their child's PICU admission. Sleep characteristics of parents significantly decreased during their child's PICU admission: they slept fewer hours per day and had more night arousals, and the percentage of parents experiencing difficulty falling asleep, night arousals or difficulty falling back asleep after those arousals increased.

During PICU admission, parents slept significantly fewer hours per day, had more night arousals, difficulty falling asleep, and difficulty falling asleep after those arousals.

Table 1

Comparison of sleep characteristics before and during PICU admission.

SLEEP CHARACTERISTICS	BEFORE	PICU ADMISSION	p
Sleeping hours/day (Mean (SD))	6.8 (1.0)	5.0 (1.3)	0.001
Difficulty falling asleep (% parents)	50.8	69.7	0.003
Night arousals (% parents)	71.4	85.9	0.003
Number of night arousals (Mean (SD))	2.1 (1.0)	3.7 (1.8)	0.001
Difficulty falling asleep after arousals (% parents)	30.5	56.7	0.001
Daytime naps (% parents)	24.2	19.4	0.607

Fig. 1 compares parents' perception of their sleep quality before and during PICU admission, which was significantly worse during the latest.

3.4. Sleep treatment and stimulants

Only 5% of the parents were under medical treatment for sleep disorders during the PICU admission, all of which already had it beforehand ($p = 1$).

No significant differences were found in the consumption of stimulants or energy drinks before and after PICU admission (46% vs 57.6%; $p = 0.375$). The most common beverage was coffee (83.9%), followed by cola drinks (32.1%), tea (12.5%) and energy drinks (12.5%).

3.5. FOSQ-10 scores, comparison and concordance between perceived sleep quality and FOSQ-10 questionnaire during PICU admission

FOSQ-10 score was <18 points in 77% of the parents, which corresponds to bad sleep quality and excessive daytime sleepiness, which negatively affects their daily life activities.

FOSQ-10 score had a good correlation with the subjective perception of sleep quality: 87.8% of parents who felt they had bad sleep quality also had a bad FOSQ-10 punctuation ($p = 0.001$, Kappa 0.433) (Table 2).

3.6. Risk factors for bad sleep quality and FOSQ-10 scores

Table 3 shows personal and family factors related to sleep quality. Parents who lived in another city, those who were admitted for programmed interventions and those who had experienced previous PICU admissions had significantly worse sleep quality.

Table 4 shows the correlations between the number of sleeping hours, total FOSQ-10 score and other family features during PICU admission.

Table 5 shows perceived sleep quality during admission and FOSQ-10 scores according to some patient and family features.

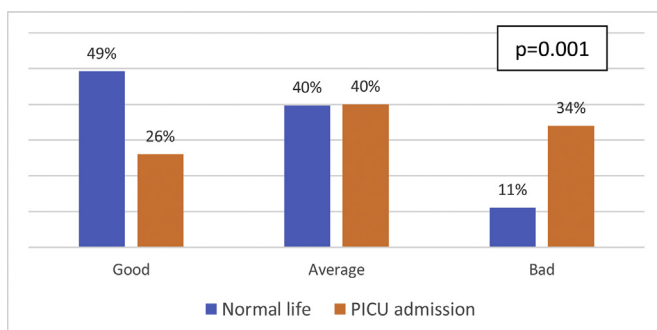


Fig. 1. Comparison of sleep quality before and during PICU admission. Parents had a significantly worse quality of sleep during PICU admission.

Table 2

Concordance between perceived sleep quality and FOSQ-10 questionnaire during PICU admission.

Perceived sleep quality	FOSQ-10		Total
	Bad <18	Good ≥ 18	
Bad	65	9	74
Good	12	14	26
Total	77	23	100

$p = 0.001$, Kappa 0.433

FOSQ-10 score had a good correlation with the subjective sleep quality perception of parents during admission.

Sleep quality was significantly worse in longer admissions and FOSQ-10 scores were better in families with more children.

Significant risk factors for poor sleep quality and bad FOSQ-10 scores were living in another city, programmed admissions, previous PICU admissions, longer PICU length of stay, long home-to-hospital distance and the number of nights spent at the PICU.

4. Discussion

This is the first study to assess sleep and rest quality of the parents of children admitted to the PICU, comparing its characteristics before and during hospitalization. This is also the first study that correlates different personal and family risk factors with sleep disturbances and its impact on daily life activities.

Some authors have studied some risk factors for the development of anxiety and depression in these situations, but they did not correlate those findings with sleep disorders [2,3]. Stremmler et al [7,8]. Described sleep disorders and some risk factors in parents of critically ill hospitalized children, but those results were not compared with their prior life conditions.

Our results show that a very high percentage of parents suffer from bad sleep quality when their children are admitted to the PICU. A pediatric intensive care unit is a special environment, where multiple factors can trigger the onset of sleep problems. Some of these stressful factors include the physical and emotional stress of dealing with severely ill children, emotionally overwhelming situations concerning patients and their families, the permanent menace of the onset of life-threatening situations, procedures or techniques at any time, high light and noise intensity even at night, etc. Stremmler et al. [8] described a list of influencing factors for sleep disruption that parents created, which included: child's condition, being at the bedside, difficult thoughts and feelings, changes to usual sleep, caring for self and family, the hospital environment and access to sleep options.

4.1. Patient characteristics and risk factors

We found that having previous admissions to the PICU (no matter how much time had passed) and programmed admissions were significant risk factors for poor sleep quality. This is probably due to the parents' anticipatory anxiety, nervousness and reliving previous negative experiences. Perceived quality of sleep worsened as the

Table 3
Risk factors for bad sleep quality and FOSQ-10 during PICU admission.

Risk factors		Poor sleep quality (% parents)	p	Poor FOSQ-10 (<18) (% parents)	p
Cardiopathy	Yes	78.4	0.12	75.3	0.59
	No	21.6		24.7	
Usual residence	Madrid	48.6	0.03*	55.8	0.76
	Others	51.4		44.2	
Work during admission	Yes	10	0.70	8.6	0.26
	No	90		91.4	
Programmed admission	Yes	55.4	0.004*	57.1	0.001*
	No	44.6		42.9	
Parent	Father	48.6	0.83	44.2	0.16
	Mother	51.4		55.8	
Previous PICU admissions	Yes	56.8	0.001*	53.2	0.001*
	No	43.2		46.8	

Living in another city, programmed admissions and previous PICU admissions were significant risk factors for poor sleep quality.

Table 4
Correlations between the number of sleeping hours during the PICU admission, total FOSQ-10 score and other family features.

	Sleeping hours/day		Total FOSQ-10 score	
	P	Correlation coefficient	p	Correlation coefficient
Patient age	0.76		0.75	
PRISM III score	0.20		0.62	
PICU length of stay	0.03*	0.28	0.17	
Time since last PICU admission	0.8		0.46	
Home-hospital distance	0.03*	-0.28	0.01*	-0.35
Number of nights in PICU	0.02*	-0.31	0.02*	-0.25
Number of children	0.74		0.09	
Sleeping hours/day			0.03*	0.276

Significant risk factors for bad sleep and bad FOSQ-10 score were long duration of PICU admission, long home-hospital distance and the number of nights at the PICU.

Table 5
Sleep quality and FOSQ-10 score according to other family/patient characteristics.

	Sleep quality			FOSQ-10		
		Mean (SD)	p		Mean (SD)	p
PRISM III	Bad	9.05 (6.2)	0.99	Bad	8.94 (6)	0.98
	Good	8.33 (3.7)		Good	8.67 (4.2)	
Patient age (months)	Bad	53.32 (60.5)	0.55	Bad	53.7 (61.4)	0.44
	Good	45.65 (59.6)		Good	43.35 (55.9)	
Parent age (years)	Bad	37.61 (7.3)	0.83	Bad	37.11 (7.3)	0.19
	Good	37.88 (6.2)		Good	39.64 (5.6)	
Length of stay (days)	Bad	14.46 (15.8)	0.01*	Bad	14.17 (15.9)	0.15
	Good	8.54 (8.9)		Good	8.74 (7.1)	
Number of children	Bad	1.76 (0.9)	0.18	Bad	1.73 (0.9)	0.03*
	Good	2 (0.9)		Good	2.13 (0.7)	
Time since last PICU admission (months)	Bad	33.74 (51)	0.32	Bad	31.46 (48.4)	0.93
	Good	31 (46.3)		Good	37.68 (54.2)	

Sleep quality was significantly worse in longer admissions and FOSQ-10 score was better in families with more children.

length of stay increased, although parents seemed to sleep more hours per day in longer admissions.

4.2. Family characteristics and risk factors

Some studies [2,7] show that fathers and younger parents had the worst sleep quality. However, we did not find any significant differences in the quality of sleep between both parents or age. Families with more children had better FOSQ-10 scores but no differences were found in the perceived quality of sleep. This is important because the patient's siblings can feel dislodged and abandoned, and parents will need to reorganize their schedules to take care of them.

We agree with Stremler's studies about the importance of home location and distance to hospital [7,8]. Almost half of our patients came from a different city, which involved that their parents had to find a temporary accommodation during their child's admission, and 27% of them did not receive any help from any non-

governmental associations. We found that these parents had significantly worse sleep quality. Sometimes parents needed to commute long distances on each home-hospital journey. Our study showed that there is a significant inverse correlation between the home-hospital distance, sleeping hours per day and FOSQ-10 score.

An important family issue was the parents' employment situation, which was also highlighted by Stremler et al. [7]. Only 11% of the parents continued working during the PICU stay, but none of them were self-employed workers. No significant differences were found in sleep quality or FOSQ-10 results between self-employed-workers and normal workers or in the attendance to their jobs during PICU admission.

4.3. Parents' sleep characteristics

Parent's sleep characteristics significantly worsened during PICU admission: they slept fewer hours per day, had more difficulty falling

asleep, more frequent arousals and more difficulty in falling asleep after those arousals. There were no significant differences in daytime naps, probably because parents spent many hours at the hospital and they did not have the option to take naps. These results are consistent with other authors' findings.

Half of the parents had spent at least one night at the PICU, and there was a significant inverse correlation between the number of nights they spent at the PICU and the number of sleeping hours per day and FOSQ-10 score.

Surprisingly and contrary to the previous mentioned studies, despite parents' sleep disorders, only 5% of them took medication to help them sleep and relax, all of which were already taking such medication before PICU admission. The same happened with stimulating or energy drinks: no significant differences were found before and after PICU admission.

4.4. FOSQ-10 scores, comparison and concordance between the perceived quality of sleep during PICU admission and FOSQ-10 questionnaire

The FOSQ-10 questionnaire has also been used in a study conducted in an adult ICU to assess sleep quality and daytime sleepiness. In our study, a high percentage of parents had a bad FOSQ-10 score, which is consistent with the results of other studies [7,8].

4.5. Current parents' life conditions at hospitals and our recommendations

Ballufi et al. [5] described that traumatic stress symptoms are common among parents whose children are in the PICU, so pediatric intensive care units are developing interventions to provide support for parents and help them to experience lower stress and participate in children's medical care [1]. These interventions are designed to support parents in coping with the hospitalization via communication, empathy and education, and improve parent's emotional health. Many PICUs still lack a proper family room or space where parents can have a rest, naps, meals, or just wait while any procedure is taking place in the unit.

Sleep disorders have a profound impact on daily life. Studies show that lack of sleep and poor-quality sleep have negative cognitive and behavioral effects. It impairs attention, alertness, concentration, reasoning and problem solving, and leads to daytime sleepiness and poor overall performance [10,13].

It is necessary to develop awareness campaigns for parents of PICU patients in order to raise consciousness about the importance of good sleep quality and its impact on daily life activities and emotional situation. New protocols, prevention programs and strategies should be adopted to optimize the resting time of parents [1]. Nowadays, many hospitals lack a well-conditioned rest room for parents or flexible timetables to accompany their children as long as possible, despite previous evidence of better sleep quality when parents sleep next to their children [7,8]. In the same way, there are some non-governmental associations which help parents with difficult social or economic situations, but their funds are usually not sufficient to offer all the support they require. We recommend creating flexible visiting schedules, rest rooms for families, offering psychological support to parents and developing support interventions to help them cope with the situation. Improving environmental conditions is also important to promote circadian rhythm adaptation (lights, noise ...).

5. Conclusions

In conclusion, over three quarters of the parents of children admitted to the PICU suffer from sleep disorders, which has a

significant impact on their personal and social lives. The subjective sleep quality has a good correlation with FOSQ-10 scale. A greater institutional support is needed to optimize parent's accommodation conditions during their child's hospitalization, in order to improve their resting time.

6. Limitations

This is a single-center study, so our sample was exposed to the same PICU environment. Hence, more studies, including other pediatric intensive care units, are necessary to confirm our results.

Participation rate was very high in our study, but the sample size was rather small for some of the items, which can limit the statistical power of some analysis.

We must keep in mind that this is a descriptive study based on a survey and there may be many uncontrolled factors.

Finally, this study was conducted in a PICU with no family room and difficult accommodation conditions for parents. It would be interesting to develop a similar study in another hospital with more optimal conditions for parents to contrast our results.

CRediT authorship contribution statement

Miriam García: Conceptualization, Methodology, Funding acquisition, Formal analysis, Writing - original draft, Validation. **Gema Manrique:** Methodology, Funding acquisition, Formal analysis, Writing - original draft. **Sarah N. Fernández:** Writing - original draft. **Yolanda Puerta:** Data curation. **Patricia Paredes:** Data curation. **Alba M. Corchado:** Data curation. **Ana B. García-Moreno:** Data curation. **Brian Jiménez:** Data curation. **Santiago Mencía:** Conceptualization, Methodology, Funding acquisition, Formal analysis, Writing - original draft, Validation.

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Conflict of interest

None.

The ICMJE Uniform Disclosure Form for Potential Conflicts of Interest associated with this article can be viewed by clicking on the following link: <https://doi.org/10.1016/j.sleepx.2020.100020>.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.sleepx.2020.100020>.

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