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Sleep Quality, Emotion Regulation and Parenting Stress in Children with Congenital Heart Disease

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Abstract

The aim of this study is to evaluate parental perceptions of parent-infant bedtime interactions and quality of sleep, after hospital discharge, in a group of children diagnosed at birth with congenital heart disease (CHD), as compared with the perceptions of parents in a control group of children who were healthy at birth. More specifically, we evaluated the associations between parental stress, parental perceptions of infant emotion regulation, and infants' bedtime and sleep routines in each of the two groups. Fifty Italian intact two-parent families (23 boys) of toddlers ageing from 11 to 36 months (M= 23.42, SD=7.10) were recruited. 20 families of CHD children group were recruited from the Department of Cardiology at the Bambino Gesù Children's Hospital in Rome, Italy; 30 families of the healthy children group were recruited from two childcare units. Parents completed Emotion Regulation Checklist (Shields & Cicchetti, 1997), Parent-Child Sleep Interaction Scale (PSIS; Alfano et al., 2013), Parent-Stress Index-Short Form (PSI-SF; Abidin, 1990) and ad-hoc semi-structured interview on child's sleep quality. The independent-samples t-test evidenced that parents of healthy children reported significantly higher scores on children's emotion regulation compared with the CHD group Specifically CHD children and healthy children's emotion regulation reported both by mothers (respectively CHD children's mothers: M= 26.11, SD= 2.9; healthy children's mothers: M= 28.85, SD= 2.71; t(37) = 3.10, p= .004) and fathers (respectively CHD children's fathers: M=25.76, SD= 2.79; healthy children's fathers: M= 27.37, SD= 2.02; t(31)= 2.71, p= .010). Main correlational findings showed in the CHD children's group that parenting stress total scores were positive related to difficult parent-infant bedtime interactions both for mothers (r=.58, p < .01) and fathers (r= .70, p < .01). Results show significant differences in emotion regulation between the two groups. The results of this research will show to the clinicians the aspects of parent-infant bedtime interactions to be addressed in parents of children with CHD.

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1. Introduction

The gradual establishment of appropriate sleep-wake regulation patterns is a complex developmental process that can pose challenges for parents during the first years of the child's life. Sleep disturbances such as bedtime resistance, prolonged night awakenings or night-time fears are frequently brought to the attention of paediatricians or other child-care professionals (Mindell, Telofski, Wiegand, & Kurtz, 2009). Nevertheless, the origin of sleep disturbances in infancy is still unclear; yet advancing our understanding of the factors that contribute to disruption of sleep patterns bears key implications for both research and clinical practice (Alfano, Smith, Reynolds, Reddy, & Dougherty, 2013). Variability in sleep-wake patterns is influenced by the interaction of multiple dimensions (Galland, Taylor, Elder, & Herbison, 2012; Settineri, Frisone, Alibrandi, & Merlo, 2019) such as the child's temperamental dispositions, clinical issues affecting the child from birth, or cultural, social and familial factors. Routine parenting practices and parental expectations about bedtime are closely associated with sleep patterns, this relationship is bidirectional (Galland et al., 2012; Sadeh, Tikotzky, & Scher, 2010). The role of mothers in establishing their children's sleep patterns has been extensively investigated in the literature; in contrast, few studies have examined the role of paternal involvement. Nonetheless, fathers' characteristics and the father-child relationship are known to be related to developmental outcomes throughout childhood (Barker, Iles, & Ramchandani, 2017). A number of authors have identified specific paternal factors that may influence children's sleep patterns (Palmstierna, Sepa, & Ludvigsson, 2008; Sadeh et al., 2010; Tikotzky, Sadeh, & Glickman-Gavrieli, 2011). For example, Tikotzky and colleagues (2011) found that a higher level of paternal involvement was related to fewer night awakenings at 1 and 6 months; Bell and Belsky (2008) observed more frequent mother-reported sleep problems for children with absent fathers.

Difficulties in establishing regular sleep-wake regulatory patterns are a common feature of health conditions that arise at birth and require infants to be admitted to intensive care units. Some authors have reported that the prolonged hospitalizations, surgical interventions, and medical complications frequently associated with such clinical conditions can considerably alter sleep (Gögenur, Wildschiøtz, & Rosenberg, 2008; Mulkey et al., 2015; Ter Horst, Mud, Roofthooft, & Bos, 2010). For example, infants with congenital heart disease (CHD) typically develop a regular sleep-wake cycle later than healthy peers (Barbeau & Weiss, 2017). Infants with CHD are often reported to be sleepy and sleep issues are frequently flagged to paediatricians and health professionals by the parents of children with CHD (So, Buckley, Adamson, & Horne, 2005).

To date, Italian populations have never been investigated in relation to sleep quality, parental stress and (both) parents' perceptions of infants' emotion regulation in children born with congenital heart disease.

1.1 Sleep quality, emotion regulation, and parenting in children with congenital heart disease

Congenital heart defects are the most common congenital anomaly, affecting around 1% of live births; recent medical advances have led to significantly increased chances of survival for a growing population (Krasuski & Bashore, 2016; van der Bom et al., 2011).

However, very few studies in recent decades have investigated the peculiarities and criticalities of sleep-wake patterns in early childhood in this clinical population.

Changes in sleep quality in children with congenital heart disease are not limited to the hospitalization period itself (Jack, 2004; Upham & Medoff-Cooper, 2005), but are also evident in the first months following their discharge from hospital (Matthey, 2001; Spence, Swinsburg, Griggs, & Johnston, 2011).

The presence of pathological conditions at birth, such as the diagnosis of a congenital heart disease, represents a risk factor for psychological well-being and for the quality of life of the entire family system (Bevilacqua et al., 2013; Kaugars, Shields, & Brosig, 2018).

Studies with parents whose children are affected by a life-threatening clinical condition from birth indicate that they experience greater stress and adaptation difficulties than do the parents of children who are born healthy. Specifically, the parents of children born with major clinical issues report significantly more physical health complaints as well as higher levels of depression, stress, anxiety, and emotional distress than do the parents of healthy infants (Aite et al., 2016; De Stasio et al., 2018; Gatta et al., 2017; Grunau et al., 2009; Linden, Cepeda, Synnes, & Grunau, 2015; Miller, Gordon, Daniele, & Diller, 1992).

Despite previous research showing that sleep patterns are a definite concern for parents (Armstrong, Quinn, & Dadds, 1994), Spence and colleagues (2011) reported that the mothers of neonates who had cardiac surgery were not bothered by their infants' sleep patterns. This may have been thanks to the time they spent in the NICU getting to know their baby and its sleep behaviours. During their time in the neonatal nursery, mothers get to know their infants and learn to differentiate between the baby's normal cues (e.g., hunger) and those due to its cardiac condition (e.g., respiratory distress).

In keeping with the findings of Spence and colleagues (2011), other studies suggest that the parents of infants with a congenital cardiac anomaly do not always experience higher levels of stress compared to the parents of healthy peers (Doherty et al., 2009). The degree of stress and anxiety reported by parents in a clinical group can vary according to the type or severity of the child's clinical condition (De Stasio et al., 2018). Finally, as described by Lee and colleagues (2007), parental stress can be mitigated by protective factors, including social support, parental information, and understanding of the infant's clinical condition.

Infant sleep development is thought to be also influenced by intrinsic infant characteristics (Sadeh et al., 2010) Specifically, emotion regulation is defined as the ability to decrease, maintain or increase emotional arousal to facilitate engagement with the context (Molina et al., 2014). It plays a fundamental role in affective, social and cognitive development (Kim Spoon, Cicchetti, & Rogosch, 2013) and its negativity, the emotional lability, relates to unmodulated changes in behavioral and neuroendocrine functioning associated with too intense and too long responses to stimuli (Keenan, 2000). Individual differences in emotion regulation processes can contribute to sleep difficulties in children so, children's emotional functioning could be a factor underlying sleep problems (El-Sheikh & Buckhalt, 2005). For example, El-Sheikh and Buckhalt (2005) found that higher levels of child emotional intensity were predictive of child-reported sleep and wake problems with a general poorer quality of sleep. Emotional arousal and difficulties in regulating negative emotionality (children are less adaptable to changes) can both directly influence sleep problems and stoke family processes in which parents do things that maintain a sleep problem to avoid child distress (Staples & Bates, 2011). According to Torowicz and colleagues (2010), as compared to healthy peers, infants affected by congenital heart anomalies may be perceived by their parents as more challenging, difficult to soothe, irritable, and negative in mood; furthermore, irritability in infants has been related to parental fatigue, discontentment, feelings of inadequacy and finding it challenging to provide everyday care, such as feeding (Torowicz et al., 2010). In addition, mothers may express a lack of self-confidence, because they feel unable to clearly distinguish between needs that are specifically related to their baby's cardiac condition and its ordinary developmental needs (Soulvie, Desai, White, & Sullivan, 2012; Uzark & Jones, 2003). To date, no studies conducted with Italian samples have specifically compared children with congenital heart anomalies and healthy peers in relation to parental stress, parental perceptions of infant emotion regulation, and infant bedtime routines.

In order to validate existing observations on challenging bedtime routines and parenting stress, we require greater understanding of how routine bedtime interaction and parental factors might be impacted when infants are born with health risks. Thus, the current study was designed to

advance understanding of the specific difficulties and needs of both children born with a risk condition and their parents, with a view to informing intervention programmes for enhancing parental resilience and preventing parental psychosocial.

1.2 Objectives

The present research examined parental perceptions of parent-infant bedtime interactions and quality of sleep, after hospital discharge, in a group of children diagnosed at birth with congenital heart disease, as compared with the perceptions of parents in a control group of children who were healthy at birth. More specifically, we evaluated the associations between parental stress, parental perceptions of infant emotion regulation, and infants' bedtime and sleep routines in each of the two groups.

2. Method

2.1 Participants and procedure

Fifty Italian intact two-parent families (23 boys) of toddlers ageing from 11 to 36 months (M= 23.42, SD=7.10) were enrolled in our study. 30 families of the healthy children group were recruited from child care units located in Rome, Italy. 20 Families of CHD children group were recruited from the Department of Cardiology at the Bambino Gesù Children's Hospital in Rome, Italy. The group of children born with congenital heart disease presented various diseases, among which Tetralogy of Fallot, ventricular septal defect, coarctation of the aorta, pulmonary stenosis, transposition of the great arteries and atrioventricular canal defect. All parents received the questionnaires and completed all the measures at home or in hospital. Mothers were specifically asked to also complete a questionnaire concerning demographic characteristics of the family, the child's medical and developmental history and the ad-hoc questionnaire about children's sleep quality. The study was approved by the Ethics Committee of Bambino Gesù Hospital, in compliance with the Helsinki Declaration. All mothers gave their informed consent to the anonymous use of their data for this study.

2.2 Measures

The Parent-Child Sleep Interaction Scale (PSIS; Alfano et al., 2013). The PSIS is a 12-item parent report questionnaire which aims to assess bedtimes behaviours and parent-child interactions related to problematic and dysfunctional sleep-wake patterns. Parents are asked to indicate how frequently each behaviour or interaction occurred during the past month on a 5-point Likert scale.

The PSIS consists in three subscales: Sleep Reinforcement (SR; parental reassurance/reinforcement of child sleep behaviors), Sleep Conflict (SC; conflict and child noncompliance surrounding sleep) and Sleep Dependence (SD; problems with independent sleep); A "Total Score" index shows parental perception of hyper-involvement in children's sleep routines, presence of non-independent sleep patterns and need to be reassured and praised at bedtime. All subscales and PSIS total score demonstrated good internal consistency: Sleep Reinforcement (α= .78), Sleep Conflict (α= .74), Sleep Dependence (α= .72), PSIS total (α= .82) (Smith, Leppert, Alfano, & Dougherty, 2014).

The Emotion Regulation Checklist. The Emotion Regulation Checklist (ERC; Shields & Cicchetti, 1997) is a 24-item parent-report measure of children's self-regulation. Items are rated on a 4-point Likert scale and it is composed by two subscales: the Lability/Negativity subscale is comprised of items representing a lack of flexibility, mood lability, and dysregulated negative affect, instead the Emotion Regulation subscale includes items describing situationally appropriate affective displays, empathy, and emotional self-awareness. Internal consistencies, assessed through Cronbach's alpha, were .96 for Lability/Negativity and .83 for Emotion Regulation (Shields & Cicchetti, 1997). The composite ERC score indicated the total emotion regulation level including both regulation and dysregulation. The internal consistency of this composite ERC score was .89 (Shields & Cicchetti, 1997).

The Parenting Stress Index (PSI–Short Form; Abidin, 1990). The PSI assesses parental perception of stress, perceiving in relation to child and parenting role. Its 36 items are rated on a 6-point Likert scale and three subscales can be distinguished, each consisting of 12 items: Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child. Higher scores on the subscales and higher PSI-SF total score indicate higher levels of stress perceived. The PSI shows excellent internal consistency and convergent validity with respect to prenatal stress, to other indices of postnatal stress, and to the quality of parent–infant interactions (Abidin, 1990). Cronbach's alpha is .75.

Father's involvement. By an ad-hoc questionnaire, paternal perceptions of personal involvement in bed-time children's caring was evaluated. The questionnaire was created on the basis of the items focused on bedtime routine of Parental Involvement Questionnaire (Tikotzky et al., 2011) given that—to the best of our knowledge—there were no existing Italian-language scales for measuring paternal involvement. It was composed by 4 items rated on a 5-point Likert scale. The items assessed both night time involvement and overall (daytime) involvement. The composite score is computed by averaging all the items.

Sleep Quality Indicators. Sleep onset difficulties and nocturnal awakenings were evaluated with an ad-hoc questionnaire filled by mothers. They indicated how many times children wake during the night and how many minutes needed to settle down the child. Considering the *Diagnostic Classification of Mental Health and Development Disorders of Infancy and Early Childhood* (DC: 0-3R; Revised Edition; ZERO TO THREE, 2005) criteria to define Sleep Problems (Sleep Onset Disorder and Night Waking Disorder), we used sleep difficulties at bedtime (minutes take the child to fall asleep) and the number of night wakings as children's sleep quality indicators

2.3 Data Analyses

Data were analysed using PASW Statistic version 24.0 (SPSS, Chicago, IL). Descriptive statistics (including maternal and paternal socio-demographic factors) comparing children with congenital heart diseases at birth and healthy children groups are reported with categorical variables, such as number and percentage, and continuous variables such as mean (M) and standard deviation (SD). An independent-sample t-test was conducted to determine group differences in paternal and maternal ERC scores scales, PSIS total scores, PSI-SF total scores, number of nocturnal awakenings, minutes to settle down children at bedtime and paternal involvement at night. Pearson correlations were conducted to examine associations between children's age, children's emotion regulation (ERC subscales scores), parenting stress (PSI-SF total score), problematic bedtime routines (PSIS total score and subscales scores), number of nocturnal awakenings, minutes to settle down children at bedtime and paternal involvement at night, in the two groups.

3. Results

As described in Table 1, CHD patients' group included 20 intact two-parent families of children aging from 11 to 36 months (M= 22.55 SD=7.66); 40% of them were boys (n=8) and 55% first-born (n=11). Maternal mean age was 35 years (SD= 4,44), and paternal one was 39 (SD= 5,78). 55 % of CHD children's mothers and 60% of fathers had a high-school diploma; 45% of mothers and 20% of fathers a university degree. The control group was composed by 30 intact two-parent families of children aging from 16 to 36 months (M= 24.3 SD= 6.54); 50% of them were boys (n=15) and 50% first-born (n=15). Maternal mean age was 37 years (SD= 5,35), and paternal one was 44 (SD= 8,11). 50% of mothers and 67% of fathers had a high-school diploma; 50% of mothers and 17l% of fathers a university degree.

Table 1. Descriptive statistics. Socio-demographic characteristics of the two groups

Participants characteristics	Infants with cong. Heart disease N= 20			Healthy infants N= 30		
	Mean	SD	Range	Mean	SD	Range
Children age (months)	22.55	7.66	11-36	24.3	6.54	16-36
Maternal age	35.4	4.44	29-50	37.1	5.35	29-48
Paternal age	39.05	5.78	34-56	43.95	8.11	34-60
	n	%		n	%	
Male	8	40		15	50	
First son	11	55		15	50	
Maternal education:						
High school diploma	11	55		15	50	
Bachelor or master degree	9	45		15	50	
Paternal education:						
Middle school	1	5		5	17	
High school diploma	12	60		20	67	
Bachelor or master degree	4	20		5	17	

3.1 Correlations

Table 2 displayed bivariate correlations between study variables. Results for healthy children at birth showed a positive relationship between maternal perceived children's emotional lability and paternal subscale PSIS "Sleep Dependence" score (r= .59, p < .05), and also positive relationships between paternal perceived children's emotional lability and maternal subscale PSIS "Sleep Conflict" score (r= .52, p < .05), paternal and maternal subscale PSIS "Sleep Dependence" scores (MD: r= .52, p < .05; PD: r= .54, p < .05) and minutes took to settle down the child (r= .58, p < .05). Furthermore, positive relationships emerged between maternal perceived children's emotion regulation and paternal involvement at bedtime (r=.64, p <.05). An higher number of night awakenings were positive related to maternal parenting stress total score (r=.52, p < .05), negative related to paternal bedtime involvement (r=-.61, p<.05). Paternal involvement at bedtime resulted also related to lesser scores on parental parenting stress total score both for mothers (r=-.68, p < .01) and fathers (r= -.65, p <.05). Finally, emerged a negative relationship between children's age and maternal perceived emotional lability (r= -.47, p<.05) and between children's age and maternal parenting stress total score (r=-.51, p<.05). For *CHD children* results showed positive relationships between paternal perceived children's emotional lability and both paternal and maternal subscale PSIS "Sleep Conflict" scores (PD: r=.49, p < .05; MD: r= .58, p <.05) and also between maternal perceived children's emotional lability and both paternal and maternal subscale PSIS "Sleep Conflict" scores (PD: r=.73, p < .05; MD: r= .57, p <.05). Furthermore, parenting stress total scores were positive related to parental subscale

PSIS "Sleep conflict" score both for mothers (r=.58, p < .01) and fathers (r= .70, p < .01). Minutes took to settle down CHD children were positive related to maternal PSIS "Sleep conflict" score (r=.71, p < .05) and, an higher number of CHD child nocturnal awakenings were positive related to maternal perceived emotional lability (r=.71, p < .01), maternal parenting stress total score (r=.73, p < .01) and to paternal PSIS "Sleep Conflict" score (r= .64, p < .01). Finally, in contrast to the healthy group, emerged a positive relationship between children's age, maternal perceived emotional lability (r= .51, p<.05) and paternal PSIS "Sleep conflict" score (r=.57, p<.05).

Table 2. Bivariate correlations between ERC, PSI, PSIS scores and children's sleep quality for the CHD children group and healthy children group

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Children age	1	.08	.51*	.09	.11	.21	.19	.37	.01	.57*	.39	-.12	.05	.45	.21	.29	.46	.23
2. Paternal Emotional Lability	-.12	1	.64**	-.35	.17	.74**	.65**	.23	.07	.49*	.58*	.11	-.11	.41	.27	.61	.24	-.12
3. Maternal Emotional Lability	-.47*	.79**	1	-.29	-.18	.55*	.79**	.25	-.10	.73**	.57*	.13	.10	.51*	.23	.32	.71**	.00
4. Paternal Emotion Regulation	.28	-.41	-.49*	1	.33	-.51*	-.60*	.00	.20	-.31	-.40	-.32	.16	-.26	.01	-.25	-.51	.06
5. Maternal Emotion Regulation	.11	-.74**	-.53*	.70**	1	.01	-.28	-.09	.41	-.07	.07	-.12	.09	-.13	.35	.18	-.30	.44
6. Paternal PSI_TOT	-.30	.42	.18	-.53*	-.69**	1	.71**	-.05	-.09	.70**	.34	.22	.11	.37	.14	.53	.34	-.25
7. Maternal PSI_TOT	-.51*	.49*	.48*	-.50*	-.68**	.86**	1	.05	-.08	.77**	.58**	.06	-.03	.39	.20	.48	.73**	-.05
8. Paternal PSIS_SR	-.22	.10	-.05	.25	.15	.11	.04	1	.36	.27	.35	.15	.03	.81**	.41	.42	.39	.24
9. Maternal PSIS_SR	-.08	.11	.08	.17	.10	.02	.11	.75**	1	.17	.39	.25	.02	.37	.88**	.50	-.01	-.15
10. Paternal PSIS_SC	.10	.37	-.02	.07	-.18	.32	.05	.30	.24	1	.56*	.07	-.08	.65**	.34	.54	.64*	.01
11. Maternal PSIS_SC	-.10	.52*	.33	-.03	-.32	.46	.40	.08	.21	.76**	1	-.02	-.27	.44	.62**	.71*	.52	.03
12. Paternal PSIS_SD	-.39	.54*	.59*	-.11	-.30	.27	.45	.42	.50*	.10	.35	1	.45	.50*	.33	-.18	-.01	-.26
13 Maternal PSIS_SD	-.01	.52*	.27	-.15	-.22	.30	.12	.31	.40	.11	.20	.96**	1	.16	.27	-.03	.10	-.08
14. Paternal PSIS_TOT	-.28	.46	.28	.09	-.15	.31	.28	.81**	.72**	.55*	.48*	.76**	.69**	1	.50*	.44	.52	.03
15. Maternal PSIS_TOT	-.08	.49*	.30	.00	-.19	.32	.26	.53*	.76**	.43	.57**	.82**	.79**	.84**	1	.62*	.26	-.11
16. Minutes to settle down	.15	.58*	.38	-.07	-.48	.33	.31	.22	.18	.48	.42	.30	.20	.43	.33	1	.50	.00
17. N. nocturnal awakenings	-.44	.07	.40	-.14	-.10	.14	.52*	.09	.21	-.56*	-.07	.47	.33	.11	.24	-.01	1	.24
18. Paternal bedtime involvement	-.09	-.47	-.28	.29	.64*	-.65*	-.68**	.02	.06	-.08	-.24	-.40	-.48	-.23	-.29	-.33	-.61*	1

* p < .05; ** p < .01

Note. Correlations for the children with CHD group are displayed in the upper right part whereas correlations for the healthy children group are displayed in the lower left part.

Abbreviations. PSI_TOT= Parenting Stress Index Total score; PSIS_SR= Sleep Reinforcement; PSIS_SC= Sleep Conflict; PSIS_SD= Sleep Dependence; PSIS_TOT=Parent-Child Sleep Interactions Scale Total score.

Results of the independent-samples t-test showed a significant difference between the scores of two groups. The results evidenced that parents of healthy children reported significantly higher scores on children's emotion regulation compared with the other group. Specifically CHD children and healthy children's emotion regulation reported both by mothers (respectively CHD children's mothers: M= 26.11, SD= 2.9; healthy children's mothers: M= 28.85, SD= 2.71; t(37) = 3.10, p= .004) and fathers (respectively CHD children's fathers: M=25.76, SD= 2.79; healthy children's fathers: M= 27.37, SD= 2.02; t(31)= 2.71, p= .010).

Table 3. Independent-samples t-test. Mean scores on ERC, PSI, PSIS scales and children's sleep quality by Group membership

	Infants with Cong. Heart Disease N= 20 M (SD)	Healthy Infants N= 30 M (SD)	t	df	p
Paternal Emotional Lability	29.17 (5.11)	28.06 (3.22)	-1.311	30.309	.200
Maternal Emotional Lability	28.63 (5.57)	26.08 (4.03)	-1.651	32.612	.118
Paternal Emotion Regulation	25.76 (2.79)	27.37 (2.02)	2.713	30.954	.010
Maternal Emotion Regulation	26.11 (2.90)	28.85 (2.71)	3.102	36.75	.004
Paternal PSI_TOT	61.17 (15.61)	72.35 (19.63)	1.624	28.511	.115
Maternal PSI_TOT	66.68 (19.87)	66.2 (25)	-.206	35.913	.838
Paternal PSIS_TOT	18.82 (8.25)	15.31 (8.9)	-1.173	30.421	.25
Maternal PSIS_TOT	21.1 (8.18)	17.05 (9.09)	-1.465	36.899	.151
Minutes to settle down	29.58 (18.27)	21 (14.29)	-1.333	20.537	.197
N. nocturnal awakenings	.92 (.86)	.85 (.77)	-.209	24.139	.831
Paternal bedtime involvement	3.16 (.71)	3.33 (1.12)	.703	22.035	.444

Abbreviations. PSI_TOT= Parenting Stress Index Total score; PSIS_TOT=Parent-Child Sleep Interactions Scale Total score.

4. Discussion

In this study, we investigated bedtime routines and sleep quality, following hospital discharge, in a group of children affected by congenital heart disease and aged between 12 and 36 months.

Given that few studies in the literature have examined this topic, it seemed of great interest to analyse the sleep patterns and bedtime routines of this specific clinical population and their potential associations with salient dimensions of the proximal context (specifically, parental stress, parents' perceptions of infant emotion regulation, parental involvement in caregiving).

Taking into account the correlational nature of the current study, the main results evidenced that parents often believe the sleep patterns of their infants with congenital heart diseases to be related to conflictual interaction at bedtime. The data from our sample suggested that hostile interaction is associated with variables from the proximal context, such as parents' levels of stress and infant emotional dysregulation, perceived as particularly challenging. In turn, quality of sleep, as reflected in frequency of night awakenings and length of time required to fall asleep, is associated with parental stress, infant emotional dysregulation, and conflictual interaction at bedtime. The older the children, the more their parents perceive them as emotionally dysregulated and the more frequently the parents report bedtime conflict.

4.1 Healthy children at birth: sleep quality and parenting

Our findings suggest that healthy children perceived by their parents to have emotion regulation issues also display more problem behaviours at bedtime: they take longer to go to sleep and their bedtime routines are more likely to be a source of struggle.

It is well-established that the development of emotion regulation is a composite process that involves cognitive, social, behavioural and physiological variables; it enables individuals to maintain or increase emotional arousal, moderating experience and expression of emotions, in order to facilitate engagement with the context (Cole, Michel, & Teti, 1994; Molina 2014, Sroufe, 1996).

Emotional lability, or difficulty regulating emotions, involves irregular, unpredictable, and intense manifestations of negative affect, excessive emotional reactions, and frequent mood changes unrelated to external stimuli (Molina et al., 2014; Shields & Cicchetti, 1997). A study conducted by Troxel and colleagues (2013) identified strong associations between attachment and sleep problems, as well as between disrupted sleep and emotional and behavioural issues, but mainly in children who displayed higher levels of negative emotionality in infancy. This finding suggests that sleep problems in toddlerhood may be viewed as a potential marker of regulatory problems in children with strong negative emotionality. Infants that display negative

emotionality at lower thresholds may be induced to rely more strongly on their caregivers to be soothed and to obtain support and comfort, and so may also be more sensitive to sleep disturbances and adjustment difficulties (Troxel et al., 2013). Furthermore, according to Morrell and Steele (2003), fussy-difficult infant temperament can influence the parental strategies deployed to settle infants, eliciting less than optimal caregiving behaviours, and potentially leading to adverse developmental outcomes and behavioural problems (Spruyt et al., 2008).

Consistently with this, in our own subsample of healthy children, maternal parenting stress and children's quality of sleep were significantly related: higher levels of maternal stress were associated with more frequent night waking on the part of the child. These results confirm previous findings on maternal functioning, operationalized as stress, as a correlate or predictor of infant sleep and bedtime difficulties (De Stasio, Ragni, Boldrini, Bevilacqua, & Gentile, 2018; Goldberg et al., 2013; Meltzer & Mindell, 2007; Sinai & Tikotzky, 2012; Smith et al., 2014; Sorondo & Reeb-Sutherland, 2015). For example, Sinai and Tikotzky (2012) found that mothers and fathers who viewed their infant's sleep patterns as challenging, usually reported increased levels of stress. In a study by Hughes and colleagues (2015), mothers of 9-month old infants with shorter sleep duration and more sleep problems displayed higher levels of parental stress, depressive symptoms, and poorer self-reported health. Finally, in another study by Zaidman-Zait and Hall (2015), parents with lower levels of self-efficacy and higher overprotectiveness at 5, 17, and 29 months, reported more frequent infant night wakings at 29 months. Our own findings for healthy children also point up the protective role of paternal bedtime involvement, which was associated with fewer nocturnal awakenings and lower levels of maternal parenting stress. These outcomes are in line with recent studies showing a relationship between greater paternal involvement in infant and toddler caregiving and better infant sleep (Bernier, Tétreault, Bélanger, & Carrier, 2017; Millikovsky-Ayalon, Atzaba-Poria, & Meiri, 2015; Teti, Crosby, Mcdaniel, Shimizu, & Whitesell, 2015; Tikotzky et al., 2015). For example, Millikovsky-Ayalon and colleagues (2015) found that fathers of children with sleep disturbances were less involved in caregiving, while mothers of children with sleep disturbances reported higher levels of parenting stress but only when paternal involvement in child caregiving was lower. Paternal involvement appears to wield a moderating effect, providing a source of emotional and instrumental support for mothers and reducing their stress levels (Millikovsky-Ayalon et al., 2015). Bernier and colleagues (2017) and Tikotzky and colleagues (2015) also found that paternal involvement and reliable paternal emotional support to the child were associated with greater consolidation of sleep in both children and mothers.

4.2 Children with CHD: sleep quality and parenting

In this study, we found that perceived parenting stress in both mothers and fathers was positively associated with parent–child conflict and infant noncompliance at bedtime. Parenting infants affected by CHD at home appears to be a challenging task (Hartman & Medoff-Cooper, 2012). Specifically, the period immediately following infant cardiac surgery demands a considerable level of commitment from parents throughout the day and night, and leads to increased levels of parental emotional involvement (Mindell, Kuhn, Lewin, Meltzer, & Sadeh, 2006); nonetheless, the levels of parental stress experienced in this group are not necessarily of clinical significance (Caris et al., 2016). The daily care burden is usually correlated with the severity of the child's health condition (Torowicz et al., 2010) and may lead to a decrease in self-perceived parental competence (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007). In addition, in our own clinical sample, parental perceptions of poor regulation of affect on the part of the child, or "lability", were associated with more frequent conflictual interactions at bedtime. As far as we know, no studies in the literature have previously investigated the relationship between infant temperament and sleep architecture in clinical samples of children with CHD.

According to Torowicz and colleagues (2010), infants affected by congenital heart diseases are often described by parents as challenging and irritable during early infancy, especially when they undergo longer hospitalizations after surgery due to more complex health conditions.

Both negative infant mood and difficulty soothing the infant may contribute to parental perceptions of infant negative emotionality (Torowicz et al., 2010), when providing both specific care for the child's clinical condition and ordinary care, such as feeding and supervision of sleep routines.

In our sample, CHD infants' quality of sleep, measured in terms of the number of minutes it took them to fall asleep and their number of awakenings per night, was related to the other variables under study. More specifically, the length of time required to settle infants was positively associated with maternal perceptions of conflictual parent-infant interaction at bedtime.

We found that interrupted night-time sleep, due to CHD infants' frequent nocturnal awakenings, was associated with maternal perceived stress and infant emotional lability; number of nocturnal awakenings was also positively associated with conflict at bedtime as reported by fathers. Problematic interaction at bedtime seemed to be a characteristic feature of sleep behaviours in the clinical group, given that it was frequently reported both by mothers and fathers.

Furthermore, fathers' perceptions of conflict during bedtime routines and mothers' perceptions of infant emotional lability both increased as a function of the child's age. Indeed, the literature suggests that congenital heart disease can have long-lasting effects, which often become more marked over time: although surgical interventions are usually carried out during infancy, additional impairment due to the cardiac condition may become more pronounced as the child grows older (Werner, Latal, Valsangiacomo Buechel, Beck, & Landolt, 2014).

Overall, no significant differences were found between the clinical CHD group and the healthy controls in terms of their bed-time routines and sleep habits; this result is broadly confirmed by the current literature, although some contrasting findings have been reported.

According to Spence and colleagues (2011), sleep patterns are not of concern to mothers of children who underwent cardiac surgery in the early stages of life; the authors hypothesized that time spent in the neonatal intensive care unit may help mothers get to know their babies and learn how to manage their sleep behaviours, for example by teaching them to differentiate between normal cues and those related to the infant's cardiac condition. Furthermore, the sleep architecture of CHD infants gradually comes in line with that of healthy peers in the months following hospital discharge (Spence et al., 2011).

Several factors may underpin the absence of differences between our two subsamples. Limited sample size is one possible explanation. Larger numbers of participants would be required to build up a more detailed understanding of sleep patterns among children with CHD. The use of quantitative self-report questionnaires must also be taken into account: the selected research instruments may not be not sensitive enough to fully detect parental perceptions, or may elicit socially desirable responses, preventing us from accessing the true perceptions of parents caring for infants with CHD. Finally, as suggested by McCusker and colleagues (2012), providing these families with structured psychological follow-up from very early in the infant's life, may help parents to cope better with their child's diagnosis with a congenital health condition, and enhance their parenting skills.

Limitations and future directions

As mentioned above, the limitations of the study include the sample size and its correlational nature. The clinical participants were randomly selected from the sample for a broader research project, which consisted of all eligible parents of infants with congenital heart disease born during the recruitment period at the Bambino Gesù Hospital in Rome. The restricted number of participants of clinical sample couldn't allowed more sophisticated analyses, such as analyses of covariance. This meant that we could not control for the effects of potential confounding variables for parenting stress (e.g., education or income). The basic nature of the comparisons

and lack of control for potential confounders might be viewed as limitations in their own right. More sophisticated analyses in future research may bring to light a far more complex picture of the relationship between bedtime routines and parents' psychosocial functioning.

The results of this research will nonetheless make it clearer to clinicians what aspects of parental stress need to be addressed with the parents of children born with a risk condition. Clinicians' operative strategies will be more effective when informed by a more advanced understanding of the particular difficulties and needs of these parents. One possible strategy for enhancing parental self-competence could involve encouraging health professionals to provide more detailed explanations of the treatment administered to the infant.

In sum, it would be of great interest to offer specifically designed psychological support for parents whose children are affected by severe clinical conditions, with a view to protecting and enhancing their immediate and future well-being.

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