



HAL
open science

Sleep Patterns in Young Children with Congenital Heart Disease

Anjali Sadhwani, Samantha Butler, Valerie Rofeberg, Kristina Espinosa, Laura Wood, Adam Cassidy, Johanna Calderon, Caitlin Rollins, Jayne Singer, Brandi Henson, et al.

► **To cite this version:**

Anjali Sadhwani, Samantha Butler, Valerie Rofeberg, Kristina Espinosa, Laura Wood, et al.. Sleep Patterns in Young Children with Congenital Heart Disease. *The Journal of Pediatrics*, 2022, 10.1016/j.jpeds.2022.08.031 . hal-03762558

HAL Id: hal-03762558

<https://hal.science/hal-03762558>

Submitted on 10 Nov 2022

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Sleep patterns in young children with congenital heart disease

Anjali Sadhwani, PhD^{1,2}, Samantha Butler, PhD^{1,2}, Valerie Rofeberg, MS³, Kristina Espinosa, PsyD^{1,2,4}, Laura Wood, PhD^{1,2,5}, Adam R. Cassidy, PhD^{1,2}, Johanna Calderon, PhD^{1,2,6}, Caitlin K. Rollins, MD, SM^{7,8}, Jayne Singer, PhD^{2,9}, Brandi Henson, PsyD^{1,2}, Catherine Ullman-Shade, PhD³, Catherine Clark, PsyD^{1,2}, David Wypij, PhD^{3,10,11}, Jane W. Newburger, MD, MPH^{3,10}, David C. Bellinger, PhD, MSc^{2,7,8}, and Janice Ware, PhD^{2,9}

Sleep patterns of 419 toddlers with congenital heart disease were comparable with the normative population except for increased likelihood across the cohort of sleeping in parents' room and increased disrupted sleep in children aged 18-23 months. Disrupted sleep patterns were associated with lower maternal education and increased medical complexity.

Sleep is essential for normal growth, brain maturation, physical and emotional health, and immune function.¹⁻³ The establishment of organized patterns of sleep and waking in children is a significant milestone of early development.⁴ Sleep affects a child's development, learning, behavioral functioning, and overall quality of life.⁵ Recently, the National Sleep Foundation (2015)⁶ and the American Academy of Sleep Medicine (2016)⁷ each released consensus statements on recommended sleep. However, children vary widely in their sleep,⁸ with patterns influenced by genetic, behavioral, medical, cultural, familial, and environmental factors.⁵ Sleep problems are an area of concern for many families in early childhood. Approximately 20%-30% of typically developing children from infancy to preschool age demonstrate sleep problems.^{8,9}

Children with congenital heart disease (CHD) face multiple neurodevelopmental (ND) challenges,¹⁰⁻¹⁶ including difficulties in self-regulation, beginning in infancy¹⁷ and continuing through childhood and adolescence.¹⁸⁻²⁰ Challenges to self-regulation in infancy and toddlerhood often are expressed through sleeping disturbances, yet research characterizing the sleep patterns of children with CHD is limited and focused primarily on infants younger than the age of 12 months.²¹ Understanding the sleep patterns of young children with CHD is particularly important, given their high risk for developmental delay, medical comorbidity, and context of high family stress and parental anxiety.²²⁻²⁴ Of note, early dysregulated sleep patterns are linked to challenges in social-emotional and executive functioning both in infancy and later years.^{22,25-27} A comprehensive understanding of the patterns of early self-regulatory processes could identify children at increased risk for later executive and emotional challenges.

The goals of this study were (1) to characterize the sleep patterns of young children (12-36 months of age) with CHD as well as parental concerns about their child's sleep, and (2) to identify medical, developmental, and family factors associated with parent-reported sleep patterns and concerns about their child's sleep. We hypothesized that children with CHD would be at greater risk for disrupted sleep patterns compared with the normative sample (eg, shorter duration of sleep at night, increased night-time awakenings) and that increased medical complexity would be associated with disrupted sleep patterns.

Methods

This retrospective study compared the sleep patterns of a cohort of children with CHD with data from a large web-based normative sample of 5006 parents of children aged birth to 3 years who completed an online questionnaire about their child's sleep.²⁸ The CHD cohort was a convenience sample of toddlers with CHD who returned for clinical evaluation in the Cardiac Neurodevelopmental Program (CNP) at Boston Children's Hospital between September 2009 and October 2018. Inclusion criteria were history of CHD and heart surgery within the first 12 months of life, completion of a ND evaluation between 12 and 36 months of age, and parent/legal guardian informed consent for inclusion of their

Bayley-III	Bayley Scales of Infant and Toddler Development, Third Edition
CHD	Congenital heart disease
CNP	Cardiac Neurodevelopmental Program
ND	Neurodevelopmental

From the ¹Department of Psychiatry and Behavioral Sciences, Boston Children's Hospital; ²Department of Psychiatry, Harvard Medical School; ³Department of Cardiology, Boston Children's Hospital, Boston, MA; ⁴Department of Pediatrics, Children's National Hospital, Washington, DC; ⁵School of Public Health, Georgia State University, Atlanta, GA; ⁶Unit of Physiology and Experimental Medicine of Heart and Muscles, Phymedexp, Université de Montpellier, Inserm, Montpellier, France; ⁷Department of Neurology, Boston Children's Hospital; ⁸Department of Neurology, Harvard Medical School; ⁹Developmental Medicine Center, Boston Children's Hospital; ¹⁰Department of Pediatrics, Harvard Medical School; and the ¹¹Department of Biostatistics, Harvard T.H. Chan School of Public Health, Boston, MA

Supported by The Kenrose Kitchen Table Foundation. The authors declare no conflicts of interest.

Portions of this study were presented as a poster during the 8th Annual scientific sessions of the Cardiac Neurodevelopmental Outcome Collaborative, October 2019, Toronto, Canada.

child's ND and medical data in our institutional CNP research registry. Children were stratified into 3 age groups (12-17, 18-23, and 24-36 months) for comparison with the normative data.

ND evaluation included parent interview, parent questionnaires, and direct child assessment. Demographic and clinical information collected through an intake form included parental education, feeding method at time of assessment, medical history, and current medical status. Medical information also was extracted from the child's electronic medical record. Parents provided information about their child's sleep patterns, including total hours of sleep (day and night), number of night-time awakenings, and child sleep location (categorized as alone in own room, in separate bed in parents' room, in parents' bed, in room with sibling, or other), as well as responded to a closed-ended question (yes/no) of whether they had any concerns regarding their child's sleep. Development was assessed using the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III),²⁹ administered by a licensed clinical psychologist. The Bayley-III Motor composite score was selected as a proxy for overall development as sleep is particularly important for motor learning^{30,31} and acquisition of new motor skills often disrupts sleep.^{32,33} Motor skills are often an area of developmental concern for children with CHD.³⁴ For children who had more than one ND evaluation, data from all evaluations were included in the analyses.

Two-sample *t*-tests were used to compare children having CHD with the normative sample for each age group in terms of sleep characteristics (hours of daytime, night-time, or total sleep and number of night-time awakenings). Normative data for sleep location were combined across age groups using a weighted average based on sample size, and multinomial logistic regression using generalized estimating equations to account for participants with two evaluations was used to compare sleep location between children with CHD and normative data. Linear, ordinal, or multinomial regression with generalized estimating equations was used to compare sleep characteristics including sleep location between patients with vs without parent-reported concerns, adjusting for age group.

Linear and logistic regression with generalized estimating equations were used to identify demographic, medical, and developmental predictors of total hours of sleep, total hours of night-time sleep, any night-time awakening, and parent-reported concerns for sleep. Predictors associated with each of these variables univariably at a level of $P < .25$ were considered for stepwise regression, and significant improvement in the Quasi Information Criterion and $P < .05$ were required to remain in the final multivariable models. Candidate predictor variables included primary caregiver education, birth weight, gestational age, single-ventricle anatomy, number of operations, number of catheterizations, history of extracorporeal membranous oxygenation, history of stroke or seizure, use of a feeding tube, and presence of motor delay (defined as standard score ≤ 85 on the Bayley-III Motor domain). All models included adjustment for age group.

Association of select medical and demographic factors with specific sleep location was assessed via χ^2 tests. Analyses were conducted using R (version 3.6.0; R Foundation for Statistical Computing) with the significance threshold set at $P < .05$.

Results

Of 419 participants seen for an ND evaluation, 97 (23%) were born preterm (gestational age < 37 weeks), 48 (12%) had a genetic diagnosis, and 65 (16%) had single-ventricle anatomy. Approximately 41% (173 participants) came for their initial ND evaluation in our CNP clinic at ages 18-23 months and 129 (31%) returned to the clinic for 2 or more visits (**Table I**; available at www.jpeds.com). With respect to sleep patterns across all ages, 17% of parents reported concern for their child's sleep and 53% of children were reported to awaken at least once each night.

When compared with the recommended hours of sleep as proposed by the National Sleep Foundation⁶ and American Academy of Sleep Medicine,⁷ 79% of toddlers (12-35 months) fell within the recommended 11-14 hours of sleep, with 13% receiving less than 11 hours of sleep. For preschoolers (36 months of age), 77% fell within the recommended 10-13 hours of sleep, with 14% receiving more than 13 hours of sleep.

Compared with the normative population, toddlers with CHD were less likely to sleep in their own room (CHD 54% vs normative sample 69%; **Figure 1**; available at www.jpeds.com). Across all ages, children with CHD received an average of 12.4 hours of sleep (SD = 1.6 hours) with about 10.3 hours during the night (SD = 1.4 hours) and 2.1 hours during the day (SD = 0.9 hours). Children aged 24-36 months had fewer hours of total sleep compared with children 12-17 and 18-23 months, which is developmentally appropriate and consistent with the normative population (**Table II**). In addition, toddlers with CHD aged 18-23 months experienced more frequent night-time awakenings (CHD 1.1 ± 1.1 vs normative sample 0.8 ± 0.9 ; $P = .009$) and increased hours of daytime sleep (CHD 2.3 ± 0.8 vs normative sample 2.2 ± 0.7 ; $P = .02$) compared with the normative group. Among children with CHD aged 12-17 months and 24-36 months, all sleep variables were comparable with those in the normative data. After we adjusted for child age, parents who were concerned about their child's sleep were more likely than parents without concerns to report fewer hours of total sleep ($d = -1.1$, 95% CI -1.5 to -0.6 , $P < .001$), fewer hours of night-time sleep ($d = -0.9$, 95% CI -1.3 to -0.6 , $P < .001$), and increased night-time awakenings ($d = 1.4$, 95% CI $1.1-1.7$, $P < .001$).

Variations in sleep patterns were identified within the CHD sample based on demographic, medical, and developmental factors (**Table III**). The presence of a motor delay was associated with lower likelihood of night-time awakenings, and single-ventricle anatomy, greater number of cardiac operations, and presence of a known genetic

Table II. Sleep patterns in young children (12-36 months) with CHD compared with a normative sample (N = 548 assessments)

Variables	12-17 months		18-23 months		24-36 months		All ages All assessments
	CHD (n = 146)	Normative sample (n = 720)	CHD (n = 173)	Normative sample (n = 716)	CHD (n = 229)	Normative sample (n = 700)	CHD (N = 548)
Hours of daytime sleep, mean ± SD	2.4 ± 1.0	2.5 ± 0.8	2.3 ± 0.8*	2.2 ± 0.7	1.8 ± 0.8	1.9 ± 1.0	2.1 ± 0.9
Hours of night-time sleep	10.4 ± 1.4	10.3 ± 1.4	10.3 ± 1.4	10.3 ± 1.3	10.2 ± 1.3	10.0 ± 1.3	10.3 ± 1.4
Total hours of daytime or night-time sleep	12.7 ± 1.8	12.8 ± 1.6	12.7 ± 1.5	12.5 ± 1.5	12.0 ± 1.6	11.9 ± 1.5	12.4 ± 1.6
Number of night-time awakenings	0.9 ± 1.1	0.9 ± 1.2	1.1 ± 1.1*	0.8 ± 0.9	0.7 ± 1.0	0.8 ± 0.9	0.9 ± 1.1
One or more night-time awakenings, No. (%)	66 (50%)	–	106 (63%)	–	100 (46%)	–	272 (53%)
Parent current concern for child's sleep	26 (18%)	–	26 (15%)	–	39 (18%)	–	91 (17%)

*Results significantly different ($P < .05$) from normative sample (Sadeh et al²⁸) based on a 2-sample *t*-test for this age group.

diagnosis were associated with increased likelihood of night-time awakenings. In addition, greater primary caregiver education was associated with increased total hours of child sleep, increased hours of night-time sleep, lower likelihood of a night-time awakening, and lower likelihood of parental concerns about sleep.

Variations in sleep location within the CHD sample also were explored by examining univariable associations with maternal education, parent-reported concerns for sleep, and medical factors. Toddlers whose parents had a college education or greater were significantly more likely to sleep in their own room and less likely to sleep in the same room with their parent (own room 64%, parent's room 9%) compared with toddlers whose parents had less than a college education (own room 37%, parent's room 27%; $P < .001$; **Figure 2**; available at www.jpeds.com). In addition, parents who reported concerns were more likely than parents without concerns to have their child sleep in bed with them rather than in their own room (parents with sleep concerns: own room 35%, parent's bed 35% vs parents without sleep concerns: own room 59%, parent's bed 10%; $P < .001$; **Figure 3**; available at www.jpeds.com). Finally, toddlers with a genetic diagnosis were significantly less likely to sleep in their own room than those without a genetic diagnosis (39% vs 57%; $P = .004$; **Figure 4**; available at www.jpeds.com). Sleep location did not vary by cardiac anatomy ($P = .52$).

Discussion

Our study found that overall sleep patterns of children with CHD were largely comparable with those in a normative sample of children without CHD with some notable exceptions. There was a decreased likelihood of toddlers with CHD sleeping in their own room compared with the normative sample, and more frequent night-time awakenings and increased length of daytime sleep were reported in children aged 18-23 months with CHD compared with the normative group. In addition, disrupted sleep patterns in the children

with CHD were associated with lower maternal education and increased medical complexity.

In terms of sleep location, children with CHD, irrespective of severity of cardiac diagnosis, were twice as likely to sleep in their parents' room compared with the normative population. Although decisions about child sleeping location, particularly around co-sleeping, in the normative population may be based on family, cultural, and socioeconomic factors,³⁵ in our sample, the child's medical status and parental concern for a child's well-being in the context of a complex medical history may be important contributors. Literature has shown that parents of children with CHD experience increased stress and concern for their child's health compared with the normative population.³⁶ Parents of children with medical risk and perceived fragility may keep their children in their bedroom in order to monitor the child's medical status. Of note, the American Academy of Pediatrics recommends room-sharing for the first 12 months in order to reduce the risk of sudden infant death syndrome.³⁷ Although the children in this study were all older than 12 months, they often continued to sleep in their parent's room. Having a child sleep in the parents' room past 12 months may affect the child's ability to establish their own sleep patterns and self-regulation and should be further studied.

The biggest discrepancy in sleep patterns between children with CHD compared with the normative sample occurred in 18- to 23-month-old children who woke up more frequently during the night and slept more during the day. The cause for disrupted sleep patterns in children with CHD aged 18-23 months is unclear. Potential reasons include unmasking of reduced endurance with greater mobility and longer napping in daytime. It is also possible that parental anxiety around physical wellbeing of the child is greater because of upcoming interventions, such as the Fontan procedure for children with single ventricle anatomy.^{38,39} This may lead to an increased tendency of parents to check-in on their sleeping child immediately if restless, resulting in more interrupted sleep. Supporting this hypothesis, we also noted

Table III. Associations between demographic, medical, and developmental factors and sleep characteristics (N = 548 assessments)

Outcomes	Predictor	Beta (95% CI)	OR (95% CI)	P value
Total hours of sleep	Age 12-17 mo	Reference		—
	Age 18-23 mo	−0.06 (−0.45 to 0.32)		.75
	Age 24-36 mo	−0.72 (−1.08 to −0.35)		<.001
	Primary caregiver education: college or greater	0.92 (0.55-1.28)		<.001
Number of night-time hours of sleep	Age 12-17 mo	Reference		—
	Age 18-23 mo	−0.15 (−0.46 to 0.16)		.34
	Age 24-36 mo	−0.30 (−0.58 to −0.03)		.03
	Primary caregiver education: college or greater	0.77 (0.49-1.05)		<.001
Any night-time awakening	Age 12-17 mo		Reference	—
	Age 18-23 mo		1.72 (1.06-2.81)	.03
	Age 24-3 mo		0.78 (0.49-1.24)	.30
	Primary caregiver education: college or greater		0.59 (0.39-0.89)	.01
	Single-ventricle anatomy		2.00 (1.03-3.91)	.04
	Genetic diagnosis		2.09 (1.10-3.98)	.03
	More than 1 cardiac operation		1.83 (1.10-3.04)	.02
	Motor delay		0.58 (0.37-0.91)	.02
Parent report of sleep concerns	Age 12-17 mo		Reference	—
	Age 18-23 mo		0.83 (0.45-1.51)	.54
	Age 24-36 mo		0.92 (0.53-1.60)	.76
	Primary caregiver education: college or greater		0.52 (0.32-0.84)	.007
	More than 1 cardiac operation		2.20 (1.34-3.60)	.002

increased night-time awakenings in toddlers with more severe CHD including those with single-ventricle anatomy and greater number of cardiac operations.

Although the toddlers in our sample had sleep patterns comparable with the normative sample, between 9% and 13% of our cohort were getting less than the recommended hours of sleep^{6,7} compared with 34% of similarly aged children in a recent study.⁴⁰ In addition, fewer parents of children with CHD reported concern about for their child's sleep (17%) compared with parents in the general group (20%-30%)^{8,9} or parents of children born preterm (25%).⁴¹ This finding is contrary to the widely held belief among medical and developmental professionals that children with CHD have a greater prevalence of sleep challenges. It is possible that ongoing concerns around the child's medical condition lead parents of children with CHD to consider mild variations in sleep patterns as an expected area of behavior that does not raise concern. In addition, lower prevalence of parental sleep concern may be related to the greater prevalence of children with CHD sleeping in their parent's room. It is possible that parental presence in the room might mitigate any potential sleep difficulties that may be more apparent if the child were sleeping independently in a separate room.

Variations in sleep patterns within our CHD sample also were noted and associated with child, family, and environmental factors. Factors that reflect medical complexity of the child such as single-ventricle anatomy, number of cardiac operations, and presence of a genetic condition were associated with increased likelihood of night-time awakenings and reduced night-time sleep. Past research on children with chronic illness⁴² and genetic conditions such as 22q11^{43,44} also noted a connection with sleep-related problems. In addition, motor delay is well documented in children with

CHD.³⁴ It is possible that children with motor delays have reduced endurance and stamina and are less likely to have nightly awakenings.

Maternal education was consistently associated with sleep patterns. Children of parents who had a college degree had longer durations of uninterrupted sleep and were more likely to sleep in their own room compared with those who did not have a college degree. As one potential indicator of socioeconomic status, lower maternal education may be related to decreased sleep quality through a range of mechanisms, including reduced financial means leading to an uncondusive physical sleep environment with the lack of separate bedrooms and noise levels⁴⁵ or reduced awareness and knowledge⁴⁶ on implementing consistent sleep routines and schedules to promote better sleep.⁴⁷ Indeed, the American Academy of Pediatrics has recommended parental education about sleep health as a key factor in improving sleep,^{48,49} and making it a priority for discussion during visits to pediatric primary care. Sleep is critical for the developing brain's executive networks. Facilitating the development of healthy sleep habits promotes emergence of appropriate self-regulatory skills.⁵⁰

The current study has limitations. Because the cohort consisted of a convenience sample of children with CHD who returned for follow-up ND evaluation at a single cardiac center, there may be bias in those who return for ND follow-up and they may not be representative of all children with CHD, leading to an under- or overestimation of sleep disturbances that may limit the generalizability to all children with CHD. Data about night-time use of oxygen support or sleep-disordered breathing were not gathered, although these factors may impact sleep patterns and location. Future investigations should consider these factors to better account for the interaction between sleep and a child's medical complexity.

The interplay among family, socioeconomic and cultural factors, parental stress, and sleep patterns within the CHD population should be further examined using larger and more diverse cohorts representing data from multiple cardiac centers. Longitudinal follow-up may provide insight into how sleep patterns in children with CHD change over time. In addition, the relationship of sleep to other markers of self-regulation, such as executive functioning and behavioral functioning, should be examined in future studies. Standardized sleep questionnaires such as Brief Infant Sleep Questionnaires⁹ should be used to better capture parent report of their child's sleep. In addition, although parent-reported concerns are extremely important in understanding clinical implications for the family, given their child's medical complexity, it is possible that parents under- or over-reported sleep disruption in their children. Thus, objective measures such as a video-recorded observation or actigraphy along with sleep diaries could be used to assess the correlation between parent-report and objective measures of sleep hygiene. Screening high-risk groups for sleep concerns during ND follow-up and providing families with sleep education is crucial to provide support to optimize sleep. ■

References

- Davis KF, Parker KP, Montgomery GL. Sleep in infants and young children: part one: normal sleep. *J Pediatr Health Care* 2004;18:65-71.
- Knutson KL. Does inadequate sleep play a role in vulnerability to obesity? *Am J Human Biol* 2012;24:361-71.
- Leproult R, Van Cauter E. Role of sleep and sleep loss in hormonal release and metabolism. *Endocr Dev* 2010;17:11-21.
- Goodlin-Jones BL, Burnham MM, Gaylor EE, Anders TF. Night waking, sleep-wake organization, and self-soothing in the first year of life. *J Dev Behav Pediatr* 2001;22:226-33.
- Schlieber M, Han J. The role of sleep in young children's development: a review. *J Genet Psychol* 2021;182:205-17.
- Hirshkowitz M, Whiton K, Albert SM, Alessi C, Bruni O, DonCarlos L, et al. National Sleep Foundation's updated sleep duration recommendations: final report. *Sleep Health* 2015;1:233-43.
- Paruthi S, Brooks LJ, D'Ambrosio C, Hall WA, Kotagal S, Lloyd RM, et al. Recommended amount of sleep for pediatric populations: a consensus statement of the American Academy of Sleep Medicine. *J Clin Sleep Med* 2016;12:785-6.
- Covington LB, Armstrong B, Black MM. Perceived toddler sleep problems, co-sleeping, and maternal sleep and mental health. *J Dev Behav Pediatr* 2018;39:238-45.
- Sadeh A. A brief screening questionnaire for infant sleep problems: validation and findings for an Internet sample. *Pediatrics* 2004;113:e570-7.
- Brosig C, Butcher J, Butler S, Ilardi DL, Sananes R, Sanz JH, et al. Monitoring developmental risk and promoting success for children with congenital heart disease: recommendations for cardiac neurodevelopmental follow-up programs. *Clin Pract Pediatr Psychol* 2014;2:153-65.
- Brosig CL, Bear L, Allen S, Hoffmann RG, Pan A, Frommelt M, et al. Preschool Neurodevelopmental outcomes in children with congenital heart disease. *J Pediatr* 2017;183:80-6.e1.
- Brosig CL, Bear L, Allen S, Simpson P, Zhang L, Frommelt M, et al. Neurodevelopmental outcomes at 2 and 4 years in children with congenital heart disease. *Congenit Heart Dis* 2018;13:700-5.
- Mussatto KA, Hoffmann R, Hoffman G, Tweddell JS, Bear L, Cao Y, et al. Risk factors for abnormal developmental trajectories in young children with congenital heart disease. *Circulation* 2015;132:755-61.
- Mussatto KA, Hoffmann RG, Hoffman GM, Tweddell JS, Bear L, Cao Y, et al. Risk and prevalence of developmental delay in young children with congenital heart disease. *Pediatrics* 2014;133:e570-7.
- Gaynor JW, Stopp C, Wypij D, Andropoulos DB, Atallah J, Atz AM, et al. Neurodevelopmental outcomes after cardiac surgery in infancy. *Pediatrics* 2015;135:816-25.
- Marino Bradley S, Lipkin Paul H, Newburger Jane W, Peacock G, Gerdes M, Gaynor JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management. *Circulation* 2012;126:1143-72.
- Butler SC, Sathwani A, Stopp C, Singer J, Wypij D, Dunbar-Masterson C, et al. Neurodevelopmental assessment of infants with congenital heart disease in the early postoperative period. *Congenit Heart Dis* 2019;14:236-45.
- Hülser K, Dubowy K-O, Knobl H, Meyer H, Schölmerich A. Developmental outcome and psychosocial adjustment in children after surgery for congenital heart disease during infancy. *J Reprod Infant Psychol* 2007;25:139-51.
- Sanz JH, Wang J, Berl MM, Armour AC, Cheng YI, Donofrio MT. Executive function and psychosocial quality of life in school age children with congenital heart disease. *J Pediatr* 2018;202:63-9.
- Cassidy AR, White MT, DeMaso DR, Newburger JW, Bellinger DC. Executive function in children and adolescents with critical cyanotic congenital heart disease. *J Int Neuropsychol Soc* 2015;21:34-49.
- Ykeda DS, Lorenzi-Filho G, Lopes AA, Alves RS. Sleep in infants with congenital heart disease. *Clinics (Sao Paulo)* 2009;64:1205-10.
- Zaidman-Zait A, Hall WA. Children's night waking among toddlers: relationships with mothers' and fathers' parenting approaches and children's behavioural difficulties. *J Adv Nurs* 2015;71:1639-49.
- Sadeh A, Tikotzky L, Scher A. Parenting and infant sleep. *Sleep Med Rev* 2010;14:89-96.
- Golfenshtein N, Hanlon AL, Deatrick JA, Medoff-Cooper B. Parenting stress in parents of infants with congenital heart disease and parents of healthy infants: the first year of life. *Compr Child Adolesc Nurs* 2017;40:294-314.
- Mindell JA, Leichman ES, DuMond C, Sadeh A. Sleep and social-emotional development in infants and toddlers. *J Clin Child Adolesc Psychol* 2017;46:236-46.
- Bernier A, Beauchamp MH, Bouvette-Turcot AA, Carlson SM, Carrier J. Sleep and cognition in preschool years: specific links to executive functioning. *Child Dev* 2013;84:1542-53.
- Bernier A, Carlson SM, Bordeleau S, Carrier J. Relations between physiological and cognitive regulatory systems: infant sleep regulation and subsequent executive functioning. *Child Dev* 2010;81:1739-52.
- Sadeh A, Mindell JA, Luedtke K, Wiegand B. Sleep and sleep ecology in the first 3 years: a web-based study. *J Sleep Res* 2009;18:60-73.
- Bayley N. Bayley scales of infant and toddler development—third edition. San Antonio (TX):Pearson; 2006.
- Page J, Lustenberger C, Fröhlich F. Social, motor, and cognitive development through the lens of sleep network dynamics in infants and toddlers between 12 and 30 months of age. *Sleep* 2018;41:zsy024.
- Walker MP, Brakefield T, Seidman J, Morgan A, Hobson JA, Stickgold R. Sleep and the time course of motor skill learning. *Learn Mem* 2003;10:275-84.
- Atun-Einy O, Scher A. Sleep disruption and motor development: does pulling-to-stand impacts sleep-wake regulation? *Infant Behav Dev* 2016;42:36-44.
- Scher A, Cohen D. Locomotion and nightwaking. *Child Care Health Dev* 2005;31:685-91.
- Sprong MCA, Broeders W, van der Net J, Breur JMPJ, de Vries LS, Slieker MG, et al. Motor developmental delay after cardiac surgery in

- children with a critical congenital heart defect: a systematic literature review and meta-analysis. *Pediatr Phys Ther* 2021;33:186-97.
35. Owens JA. Sleep in children: cross-cultural perspectives. *Sleep Biological Rhythms* 2004;2:165-73.
 36. Soulvie MA, Desai PP, White CP, Sullivan BN. Psychological distress experienced by parents of young children with congenital heart defects: a comprehensive review of literature. *J Social Service Res* 2012;38:484-502.
 37. Byars KC, Simon SL. American Academy of Pediatrics 2016 safe sleep practices: implications for pediatric behavioral sleep medicine. *Behav Sleep Med* 2017;15:175-9.
 38. Wallace MC, Jagers J, Li JS, Jacobs ML, Jacobs JP, Benjamin DK, et al. Center variation in patient age and weight at Fontan operation and impact on postoperative outcomes. *Ann Thorac Surg* 2011;91:1445-52.
 39. Akintoye E, Veldtman GR, Miranda WR, Connolly HM, Egbe AC. Optimum age for performing Fontan operation in patients with univentricular heart. *Congenit Heart Dis* 2019;14:138-9.
 40. Wheaton AG, Claussen AH. Short sleep duration among infants, children, and adolescents aged 4 months-17 years—United States, 2016-2018. *MMWR Morb Mortal Wkly Rep* 2021;70:1315-21.
 41. Ungerer JA, Sigman M, Beckwith L, Cohen SE, Parmelee AH. Sleep behavior of preterm children at three years of age. *Dev Med Child Neurol* 1983;25:297-304.
 42. Hysing M, Sivertsen B, Stormark KM, Elgen I, Lundervold AJ. Sleep in children with chronic illness, and the relation to emotional and behavioral problems—a population-b: 665-70.
 43. Swillen A, Berghs I, Schoeters A, Frys JP, Hellinkcx W, Devriendt K. Parental perception of sleep behaviour and sleep disorders in children with VCFS and their siblings. *J Intellect Disabil Res* 2008;52:815.
 44. Arganbright JM, Tracy M, Hughes SS, Ingram DG. Sleep patterns and problems among children with 22q11 deletion syndrome. *Mol Genet Genomic Med* 2020;8:e1153.
 45. Doane LD, Breitenstein RS, Beekman C, Clifford S, Smith TJ, Lemery-Chalfant K. Early life socioeconomic disparities in children's sleep: the mediating role of the current home environment. *J Youth Adolesc* 2019;48:56-70.
 46. Bagley EJ, Kelly RJ, Buckhalt JA, El-Sheikh M. What keeps low-SES children from sleeping well: the role of presleep worries and sleep environment. *Sleep Med* 2015;16:496-502.
 47. Martins RM, Oliveira JR, Salgado CC, Marques BL, Oliveira LC, Oliveira GR, et al. Sleep habits in infants: the role of maternal education. *Sleep Med* 2018;52:138-44.
 48. Gruber R, Cassoff J, Knäuper B. Sleep health education in pediatric community settings: rationale and practical suggestions for incorporating healthy sleep education into pediatric practice. *Pediatr Clin* 2011;58:735-54.
 49. Bathory E, Tomopoulos S. Sleep regulation, physiology and development, sleep duration and patterns, and sleep hygiene in infants, toddlers, and preschool-age children. *Curr Prob Pediatr Adolesc Health Care* 2017;47:29-42.
 50. Turnbull K, Reid GJ, Morton JB. Behavioral sleep problems and their po: function in children. *Sleep*

Table I. Demographic, medical, and developmental characteristics of toddlers with CHD (N = 419 toddlers)

Characteristics	No. (%) or mean ± SD
Demographic characteristics	
Male	242 (58%)
White	354 (85%)
Hispanic	41 (10%)
Age at first neurodevelopmental assessment	
12-17 mo	146 (35%)
18-23 mo	173 (41%)
24-36 mo	100 (24%)
Number of neurodevelopmental assessments	
1	290 (69%)
2	129 (31%)
Primary caregiver education: college or greater	260 (64%)
Medical background	
Birth weight, kg	3.1 ± 0.7
Gestational age, wk	38.3 ± 2.3
Gestational age <37 wk	97 (23%)
Single-ventricle anatomy	62 (15%)
Prenatal diagnosis	221 (53%)
Genetic diagnosis	48 (12%)
Noncardiac congenital anomaly	77 (19%)
Events before first neurodevelopmental assessment	
Number of cardiac operations	
1	298 (71%)
2	86 (21%)
3 or more	35 (8%)
More than 1 cardiac operation	120 (29%)
More than 1 cardiac catheterization	103 (25%)
ECMO	21 (5%)
Stroke or seizure	17 (4%)
Use of a feeding tube	54 (13%)
Motor delay at first neurodevelopmental assessment	115 (28%)

ECMO, extracorporeal membrane oxygenation.

All variables <5% missing. Domain delays defined as standard score ≤85.

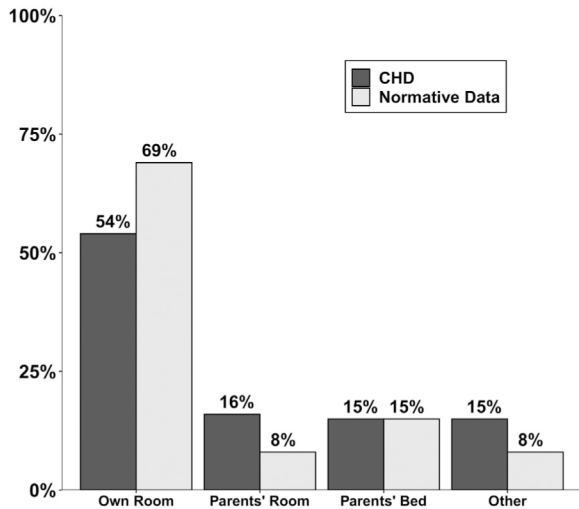


Figure 1. Child sleep location of young children (12-36 months) with CHD compared with a normative sample. *Own Room* indicates alone in own room; *Parents' Room* indicates in separate bed in parents' room; and *Other* indicates in room with siblings or other locations.

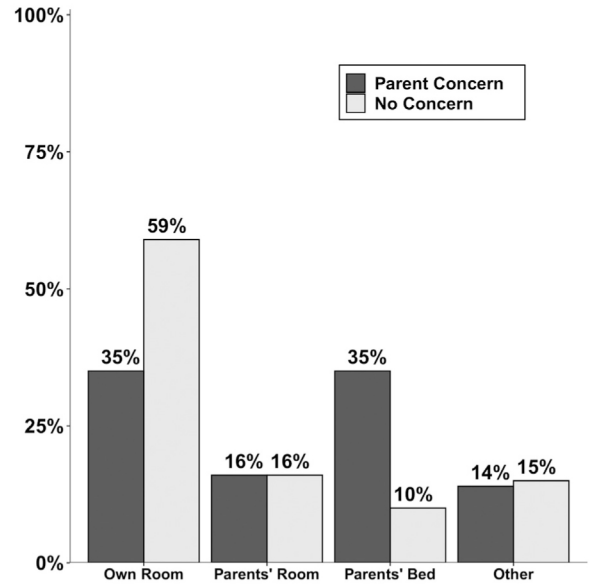


Figure 3. Distribution of child sleep location of young children (12-36 months) with CHD based on parent-reported sleep concerns. *Own Room* indicates alone in own room; *Parents' Room* indicates in separate bed in parents' room; and *Other* indicates in room with siblings or other locations.

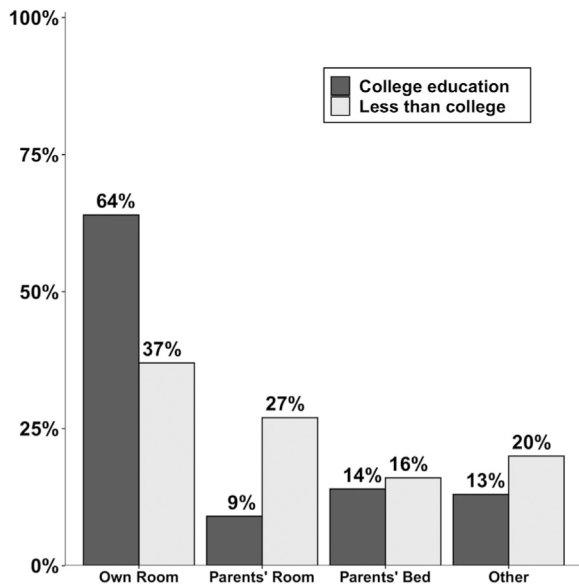


Figure 2. Distribution of child sleep location of young children (12-36 months) with CHD based on level of maternal education. *Own Room* indicates alone in own room; *Parents' Room* indicates in separate bed in parents' room; and *Other* indicates in room with siblings or other locations.

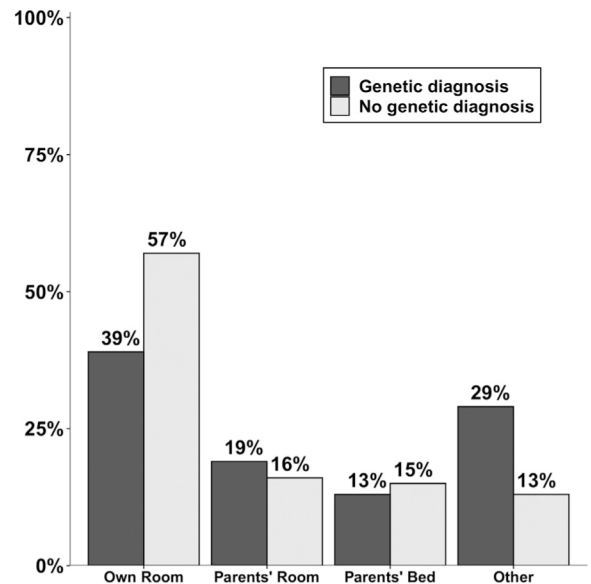


Figure 4. Distribution of child sleep location of young children (12-36 months) with CHD and presence of genetic diagnosis. *Own Room* indicates alone in own room; *Parents' Room* indicates in separate bed in parents' room; and *Other* indicates in room with siblings or other locations.