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Author for correspondence: Nadya Golfenshtein, PhD, MHA, RN, University of Haifa, Department of Nursing, Haifa Israel, 199 Abba Hushi Ave. 3498838, Haifa, Israel.
Tel: +(972)46146207; Fax: +(972) 828801.
E-mail: ngolfinsh@univ.haifa.ac.il

Maternal parenting stress changes over the first year of life in infants with complex cardiac defects and in healthy infants

Nadya Golfenshtein[1,2], Alexandra L Hanlon[3], Janet A Deatrick[2] and Barbara Medoff-Cooper[2,4]

[1]University of Haifa, Department of Nursing, 199 Abba Hushi Ave. 3498838, Haifa, Israel; [2]University of Pennsylvania, School of Nursing, 418 Curie Blvd, Claire M. Fagin Hall, Philadelphia, PA 19104, USA; [3]Virginia Tech. Center for Biostatistics and Health Data Science, 4 Riverside Circle, Roanoke, VA 24016, USA and [4]Children's Hospital of Philadelphia. 3401 Civic Center Blvd, Philadelphia, PA 19104, USA

Abstract

Objectives: Parents of infants with CHDs experience increased parenting stress compared to the general population, potentially interfering with parenting practices and bear adverse family outcomes. The changes in stress over the critical period of infancy have yet to be studied. The current study aimed to compare parenting stress changes over time between parents of infants with CHDs and parents of healthy infants during the first year of infants' life. *Methods:* Data from a larger prospective cohort study were longitudinally analysed using mixed-effects multivariable regression modelling. Sample included mothers of 129 infants with complex cardiac defects and healthy infants, recruited from the cardiac ICU of a large cardiac centre and outpatient paediatric practices in Northeastern America. Outcome was measured over four visits via the Parenting Stress Index Long Form. *Results:* Stress in the cardiac group has significantly decreased over time on the Parent Domain ($p = 0.025$), and stress in the healthy group has significantly increased over time on the Child Domain ($p = 0.033$). Parenting stress trajectories demonstrated significant differences between groups on the Parent Domain ($p = 0.026$) and on the Total Stress ($p = 0.039$) subscales. *Conclusions:* Parenting stress in the paediatric cardiac population changes over time and differs from stress experienced by parents of healthy infants. Findings highlight stressful periods that may be potentially risky for parents of infants with CHDs and introduce additional illness-related and psychosocial/familial aspects to the parenting stress concept.

CHD is the most prevalent congenital defect diagnosed in 1:100 live births.[1] Complex CHD conditions that require surgical interventions early in life and prolonged hospitalisations can be life-threatening (e.g., Hypoplastic Left Heart Syndrome) and cause profound stress to families who face health and quality-of-life issues.[1,2] The first year after the baby is born (i.e., infancy; 0–12 months of age) is critical, as during this year most surgical interventions occur. The initial period of hospitalisation and early care of an infant with complex CHD at home requires parental adjustment to the environment of cardiac ICU and to the multiple post-surgical caretaking demands.[3] Parents who are required to adhere to the continuous and complicated post-operative medical needs, often experience excessive burden and may feel incompetent in providing the needed care for their child. Among the issues parents face are included, for example, feeding and growth failure problems, haemodynamic and respiratory instability, risk for infections, and developmental delays. The parenting stress levels in the paediatric CHD population are higher compared to other (healthy or sick) paediatric populations, and often resulting from the care burden and parental feelings of incompetence.[3-5] High parenting stress levels have been widely linked to adverse outcomes in individuals and families, such as parental anxiety and depression, disturbed parent–child relationship,[6,7] decreased familial wellbeing and quality of life,[8,9] maladaptive behaviours, and poor social competence among children.[9,10]

Richard Abidin has conceptualised the various stress-evoking factors with regard to the parenting role and the parent-child system, and categorised them in his Parenting Stress Model[11] into Parent and Child domains. The factors within the Child Domain include behavioral and temperamental characteristics of the child, and the perceptions and expectations of parents towards their child. Such factors include, for example, child's demandingness, mood, distractibility, parental acceptance of their child's characteristics, and parental feelings of reinforcement. The factors within the Parent Domain include parental personality and functional components (competence, attachment), spousal support, parental physical and mental health, social isolation, and role restriction. General life-situational circumstances are perceived as moderators of parenting stress in this model. Most of the stress sources reported by research align with Abidin's model. However, certain condition-unique characteristics arise within the child or the parenting role demands, such as the children's irritable temperaments.[5,12-14] Stressors reported in this population also include poor parental competence related to the medical fragility of the child at the critical care unit, and to the caretaking burden at home after discharge.[3,13,15,16]

Although parenting stress has gained research attention in recent years in the CHD paediatric populations, longitudinal stress trajectories over infancy have not been studied yet. The infancy period (0–12 months of age) is critical for establishing a healthy infant–parent relationship.[17] This is important for the family system readjustment to the new structure, roles, and routines and may directly impact infant development.[18] Whereas the general expectation from parenting stress is to diminish over time as part of the normal adjustment process to the parenting role,[11] critical paediatric cardiac condition introduces additional complexities to the process, which may alter the natural trajectory of the familial readjustment.[19] The aim of the current study was to examine changes in parenting stress over infancy in mothers of infants with CHD and compare them to those of mothers of healthy infants.

Materials and methods

The current study obtained data from a larger prospective cohort study. The parent study was conducted at the Children's Hospital of Philadelphia. Two hundred and one mother–infant dyads were recruited at initial hospital discharge and followed during four additional time points over their infancy – at three, six, nine, and twelve months of age, during their paediatric follow-up visits. Mothers of infants with complex CHD were recruited via convenience sampling from the hospitals' cardiac ICU; mothers of healthy infants were recruited via convenience sampling from regional primary care practices. Inclusion criteria for infants in the CHD group included 1) Diagnosis of a complex cardiac condition requiring a corrective or palliative surgery within the first six weeks of life, 2) birth at or above 35 gestational weeks, 3) birthweight of 2000 grams and above. Exclusion criteria included non-cardiac congenital anomalies or genetic syndromes other than DiGeorge syndrome and 22q deletion. Healthy infants included in the study were born above 35 gestational weeks, with no congenital anomalies, genetic syndromes, or health conditions after birth. Infants in both groups were age matched at the 3–12 follow-up visits. The sample size for the current study was 129 mothers, who had parenting stress data, and their infants.

The study gained institutional review board approval and mothers provided informed consent. The research team obtained data during five time points – at hospital discharge, and further at three, six, nine, and at twelve months of age during outpatient visits. Mothers completed self-report questionnaires of parenting stress, infant temperament, and demographic information. Clinical information was obtained from infants' medical records (For further information with regard to the parent study please see.[20]

Mothers completed the Parenting Stress Index-Long Form (PSI-LF) at three-, six-, nine-, and twelve-month follow-up physician visits. The PSI-LF consists of 120 self-report, 5-point Likert scale items, with subscales measuring stressors within the Child and Parent Domains as conceptualised in Abidin's Parenting Stress Model.[11] Forty-seven items measure the six Child Domain stressors (Distractibility, Adaptability, Reinforcement, Demandingness, Mood, and Acceptability). Item for example to assess the Demandingness factor: "My child seems to be much harder to care for than most". Item to assess the mood factor: "My child seems to cry or fuss more often than most children". Item to assess the Acceptability factor: "My child looks a little different than I expected, and it bothers me at times". Fifty-four items measure the seven stressors within the Parent Domain (Competence, Isolation, Attachment, Health, Role restriction, Depression, Spouse support). Item for example to assess parental Competence: "When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent". Item to assess the attachment factor: "I expected to have closer and warmer feelings for my child than I do, and this bothers me". Item to assess parental role restriction: "I feel trapped by my responsibilities as a parent". Domains' scores are summed to a Total Stress score, with higher score indicating higher parenting stress. The PSI demonstrates good validity and reliability psychometrics, and has been in use in the CHD population.[8,21,22] Covariates considered for analysis included Clinical and Demographic characteristics. Clinical parameters were obtained from infants' medical records and included post-operative heart physiology (single- versus bi-ventricular physiology for the CHD group),[21] and infant WHO growth z-scores[20] for both groups. Demographic characteristics were self-reported by mothers and included infant gender, maternal education, race, and ethnicity.

Analyses were performed in STATA 16 statistical package.[22] Descriptives included central tendency and variation measures (mean, median, standard deviation, and ranges). A linear mixed-effects model analysis was performed to examine changes in parenting stress over time.[23] The estimates produced are robust to missing data and dropout.[24] We examined patterns of missing data for bias and compared estimates from a complete data analysis to estimates generated from an imputed data set. No systematic bias in missingness patterns was evident.[25] Parenting stress outcomes (Child Domain, Parent Domain, and Total Stress) were separately regressed over the independent variable of time (continuous parameter represented by infants 3–12 month's follow-up visits). Covariates included in the analysis were identified in main effect bivariate models, and in two-way interaction (*Covariate x Visit*) bivariate models ($\alpha = 0.2$), and were further eliminated via the backwards deletion process. The covariates included in the final multivariable models were mothers' education, race, and infant length z-scores. Parenting stress changes over time group comparisons relied on *Group x Visit* interaction term estimates ($\alpha = 0.05$).

Results

Sample's demographic characteristics, baseline growth, and group stress comparisons are presented in Table 1. The 129 infants included in the final sample were predominantly non-Hispanic ($n = 110$; 86%), white ($n = 105$; 82%) males ($n = 84$; 66%). The CHD group constructed 58% of the sample, and almost half of this group (48%) had single-ventricle functioning heart (see defects distribution in Table 2). The median length of stay at the initial hospitalisation for infants in this group was 15 (2-159) days. Groups significantly differ by mothers' race and education level. Healthy infants had significantly higher growth parameters at baseline (3 months). Child Domain parenting stress was significantly higher for mother in the CHD group at baseline ($p = 0.040$). Table 3 presents the PSI scores for the two groups and the PSI measure's percentile ranking as were derived from age appropriate frequency distribution of a normative samples.[11] Finding indicate stress levels ranging from the 30–45th percentiles in the CHD group, and 25–35th percentiles in the Healthy group, across the various follow-up visits.

Tables 4 and 5 display results from Mixed Effects regression models. In these sets of multivariable models. PSI subscales were separately regressed over the independent variable of time

Table 1. Demographic characteristics, growth parameters, and baseline parenting stress comparisons of the study sample, N = 129

	CHD N = 66		Healthy N = 63		
	N (%)		N (%)		P[a]
Infant gender					0.716
Male	44 (67)		40 (63)		
Female	22 (33)		23 (37)		
Ethnicity					0.195
Hispanic	7 (11)		3 (5)		
Non-Hispanic	46 (70)		53 (84)		
Unreported	13 (20)		7 (11)		
Race					0.010
White	59 (89)		43 (68)		
Black	5 (8)		15 (24)		
Other	1 (2)		3 (5)		
Unreported	1 (2)		2 (3)		
Mother's education					0.034
High school	4 (6)		4 (6)		
College	28 (42)		22 (35)		
Post-graduate	8 (12)		22 (35)		
Unreported	26(39)		15(24)		
Clinical Parameters	Mean (SD[b])	Median (IQR[c])	Mean (SD)	Median (IQR)	P
Gestational age	39 (1.2)	39 (35–41)	39 (1.3)	39 (36–41)	0.094
Birthweight	3365 (49)	3320 (665)	3406 (51)	3420 (712)	0.274
Infant Growth[d]					
Weight	−1.26 (1.34)	−1.28 (−5.1, 0.84)	−0.24 (0.86)	−0.25 (−2.51, 1.61)	<0.001
Length	−0.91 (1.38)	−.75 (−5.45, 1.53)	0.12 (1.18)	0 (−2.07, 3.53)	<0.001
Head	−0.69 (1.32)	−0.57 (−3.99, 2.46)	0.45 (1.02)	0.51 (−1.6, 2.64)	0.0000
Parenting Stress at 3 mo					
Child Domain	95.52 (21.37)	94.5 (28–162)	88.51 (16.49)	90 (38–128)	0.040
Parent Domain	112.42 (20.76)	109.5 (66–178)	107.23 (21.57)	108.5 (67–161)	0.171
Total Stress	207.94 (38.04)	205 (133–340)	195.85 (34.17)	194.5 (129–280)	0.064

[a]Group comparisons via t-tests for continues parameters, and Fisher's Exact test for categorical parameters; [b]standard deviation; [c]interquartile range; [d]WHO growth z-score at 3 months

(represented by infant visits at three, six, nine, and twelve months). Models were adjusted for infant length z-scores, mothers' education, and ethnicity. Table 4 presents the main effects of *Visit* (the groups' individual stress change over time) for the various PSI outcomes. Findings demonstrate a general stress decrease in mothers of CHD infants and a general stress increase in mothers of healthy infants over time. Specifically, stress in the CHD group has significantly decreased over time on the Parent Domain ($p = 0.025$), whereas stress in the healthy group has significantly increased over time on the Child Domain ($p = 0.033$). No significant changes over time in the Total Stress scores were found in either group. Table 5 further presents group differences in PSI trajectories as represented by the *Visit x Group* interaction term. Parenting stress trajectories significantly differed between groups on the Parent Domain ($p = 0.026$) and on the Total Stress ($p = 0.039$) subscales. No significant differences were demonstrated on the Child Domain. Group comparisons for the Total Stress trajectories are graphically presented in Figure 1.

Discussion

Our study aimed to examine changes in parenting stress of mothers of infants with complex cardiac defects and compare them to those of healthy infants over infancy. Findings indicate higher initial child-locused stress levels in mothers of cardiac infants, compared to mothers of healthy infants. Findings also indicate a general decrease in stress over time in mothers of infants with CHD and a general increase in stress in mothers of healthy infants. The decreases in parenting stress in the CHD group appeared to be primarily in parent-locused stress, whereas the increases in parenting stress over time among mothers of healthy infants were primarily in the child-locused domain. The stress trajectories significantly differ between groups on both Parent Domain and Total Stress subscales. Surprisingly, the stress levels of our sample seem to be ranked mildly lower when compared to normative sample distributions. This trend of lower-than-expected scores across both groups is surprising, as healthy controls' mean should correspond

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Table 2. Distribution of cardiac defects in the study sample, N = 129

Cardiac physiology	Groups of defects	Defects within group	N (%)
Single Ventricle Physiology N = 32	Contruncal Defects	Dextro-Transposition of the Great Arteries (D-TGA); Levo-Transposition of the Great Arteries (L-TGA); Double Outlet Right Ventricle (DORV)	2 (1.6)
	Septal Defects	Atrioventricular Canal Defect (AVCD)	1 (0.8)
	Right-Sided Defects	Valvular Pulm, Atresia; Tricuspid Atresia	6 (4.7)
	Left-Sided Defects	Hypoplastic Left Heart Syndrome (HLHS); Valvar Aortic Stenosis; Aortic Valve Atresia	20 (15.5)
	Other Defects	Double Inlet Left Vent	3 (2.3)
Bi-Ventricle Physiology N = 34	Contruncal Defects	Tetralogy of Fallot (TOF); Interrupted Aortic Arch (IAA); Truncus Arteriosus; D-TGA; DORV	24 (18.6)
	Septal Defects	Aortopulmonary (AP) Window; Ventricular Septal Defect (VSD)	1 (0.8)
	Right-Sided Defects	Valvular Pulm, Atresia	1 (0.8)
	Left-Sided Defects	Valvar Aortic Stenosis; Coarc. Of Aorta	6 (4.7)
	Pulm Venous Anomalies	Total Anomalous Pulmonary Venous Return (TAPVR)	1 (0.8)
	Other Defects	Not Specified	1 (0.8)
Healthy Infants	Normal Physiology		63 (48.8)

Table 3. PSI scores and percent rankings by follow-up visits for mothers of infants with CHD and mothers of healthy infants

		CHD group			Healthy group	
PSI scores by visit	N	Mean (SD[a])	% Ranking[b]	N	Mean (SD)	% Ranking
3 months	66			63		
Child Domain		95.52 (21.37)	45		88.51 (16.49)	30
Parent Domain		112.42 (20.76)	40		107.23 (21.57)	25
Total Stress		207.94 (38.04)	45		195.85 (34.17)	25
6 months	54			46		
Child Domain		91.67 (16.24)	40		88.22 (16.73)	30
Parent Domain		109.87 (20.59)	35		108.80 (23.48)	30
Total Stress		201.54 (32.13)	35		197.02 (36.88)	30
9 months	56			39		
Child Domain		93.50 (16.47)	40		89.95 (16.08)	35
Parent Domain		109.23 (20.69)	35		110.08 (24.33)	35
Total Stress		202.73(34.44)	35		199.03(37.81)	30
12 months	64			56		
Child Domain		93.64 (15.67)	40		92.14 (16.17)	35
Parent Domain		106.55 (25.61)	25		107.75 (22.34)	30
Total Stress		200.19 (37.35)	30		200.11 (36.24)	30

[a]Standatd deviation; [b]PSI percentile ranking derived from the age appropriate frequency distribution of normative samples (Abidin, 1995)

to the 50th. According to Abidin,[11] this might result from several factors, such as defensive, or socially desirable responding to the questionnaire, or due to parental disengagement in the parental role. It is also possible that the sample we recruited was relatively homogenous in terms of higher SES levels, and therefore had lower stress levels. Findings suggest that the higher early stress, at three months of age, experienced by mothers of cardiac infants is related to child characteristics. Indeed, infants with CHD possess distinct characteristics and challenges unique to the early infancy period including difficult temperaments, irritability, and feeding issues, these are added to the general illness condition and in-hospital medical fragility and the cardiac ICU stay.[13,14,26] The post-operational period and the lengthy cardiac ICU stay have been described as peak stressful periods for parents.[27] The post-discharge period is critical as well, especially for infants with single-ventricle, who remain within the interstage mortality zone until the second surgery at four to six months of age.[28] The second surgery is probably an additional stressful period for these parents; however, this was not reflected in our findings, perhaps due to the spacing of the follow-up measurement that potentially could have missed the peak stressful period and reflect the stress when it has already decreased. With time, most infants become more medically stable and require

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Table 4. Mixed effects regression analysis results[a] for PSI subscales regressed on Visit[b]

	Healthy infants					CHD infants				
Parenting Stress[c]	β+	SE[d]	95% CI[e]	P	N	β+	SE	95% CI	P	N
Child domain	1.36	0.64	(0.11, 2.62)	0.033	53	−0.04	0.91	(−1.82, 1.74)	0.965	71
Parent domain	0.46	0.67	(−0.86, 1.77)	0.496	52	−1.90	0.85	(−3.57, −0.24)	0.025	71
Total stress	1.741	1.09	(−0.40, 3.88)	0.111	52	−1.84	1.41	(−4.61, 0.92)	0.192	71

[a]All models are adjusted for mothers' education, race, and infant length z-scores; [b]estimates in table correspond to main effect of "Visit"; Visit represents the independent variable of time (continuous); [c]Parenting Stress Index subscales scores as the outcome of interest, each represents a separate multivariable model within each group, CHD and healthy; [d]standard error; [e]95% confidence intervals

Table 5. Mixed-effects model results[a] for PSI subscales regressed on visit, CHD/healthy infant, and visit x CHD/healthy infant terms. N = 129

PSI subscale[d]	Parameter	β	SE[e]	95% CI[f]	P
Child domain					
	Visit[b]	1.33	0.81	(−0.25, 2.91)	0.099
	CHD infants	9.64	5.05	(−0.25, 19.53)	0.056
	Visit x CHD/healthy	−1.55	1.13	(−3.77, 0.67)	0.171
Parent Domain					
	Visit	0.46	0.76	(−1.04, 1.95)	0.551
	CHD infants	12.13	4.88	(2.57, 21.69)	0.013
	Visit x CHD/healthy	−2.41	1.08	(−4.53, −0.29)	0.026
Total stress					
	Visit	1.70	1.27	(−0.79, 4.18)	0.181
	CHD infants	20.52	8.31	(4.22, 36.82)	0.014
	Visit x CHD/healthy	−3.69	1.79	(−7.20, −0.18)	0.039

[a]Models are adjusted for mothers' education, race, and infant length z-scores; [b]Visit represents the independent variable of time (continuous); [c]CHD versus healthy infants; [d]Parenting Stress Index subscales scores as the outcome of interest, each represents a separate multivariable

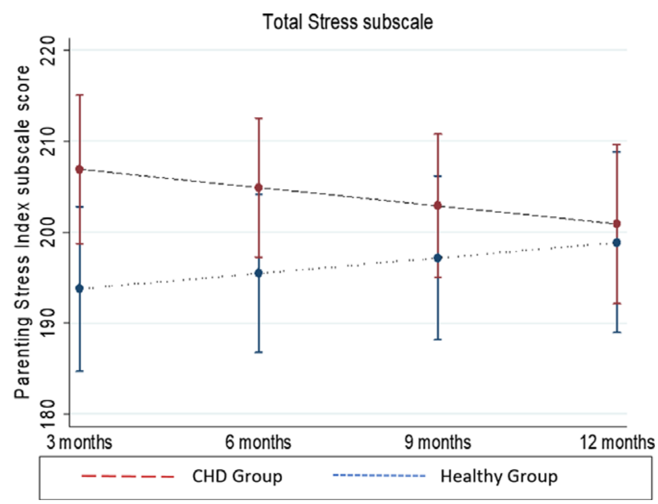

Figure 1. Parenting stress trajectories for the Total Stress subscale, in mothers of infants with CHD and mothers of healthy infants.

fewer treatments and physician visits and parents learn how to manage medications and the condition.[2,29]

Our findings indicated significant decrease in parent-locused stress over time. The stress on the Parent Domain may reflect, among others, the parental mental health associated with their infant condition. Studies have found that mothers experience mental health symptoms during their infants' hospitalisation, such as anxiety, depression, and post-traumatic stress[16,30,31] and that their mental health may be impacted long after hospital discharge.[32] These symptoms may have further implications on mothers' familial functioning and relationships with their infants.[33] Many studies have described mothers' feelings of incompetence in their maternal role when caring for their infant in this population. However, studies have also shown that parents grow into the parenting role as a result of their adjustment to the CHD condition and to the care burden over time.[34,35] Gaskin et al.[30] showed a decrease in post-traumatic stress symptoms in parents of infants who underwent cardiac surgery, as their parental confidence increased.

As our findings suggest, mothers' experiences and needs may change over time, and maternal mental resilience, as well as certain individual-familial factors, may play a role in their successful adjustment to the condition.[36,37] Intervention in this population should be implemented early, perhaps even targeted during the hospitalisation to support maternal mental health and reduce initial stress and anxiety.[38,39] Furthermore, interventions should be designed to empower mothers, while promoting constructive parenting practices and maternal adaptive coping strategies within the broader context of family and community. Research indicates that interventions aimed at changing parental illness perceptions and coping mechanisms were most effective in reducing parenting stress.[40,41]

In mothers of healthy infants, infant-locused stress appeared to increase over time. Abidin[11] mentioned that parenting stress should be expected to decrease between 1 and 3 years of age in the general population. Both Dyson[42] and Crnic et al.[43] found stable parenting stress levels in healthy preschool children over time. Nevertheless, we could not find any earlier evidence for parenting stress trajectories during infancy. The stress increase in the healthy group in our study may perhaps be explained by infants' temperamental and behavioural repertoire development over time.[44] Also the increase in stress may be attributed to the mothers' return to work after several months postpartum.[45,46]

Our study has several limitations arising from non-excluding infants with certain genetic syndromes (DiGeorge and 22q deletion), which were unapparent at the time of recruitment and may have biased results. Additional limitations arise from the secondary nature of analysis restricting sample size and availability of other family variables. The sample only included mothers. Studies examining fathers and mothers have demonstrated different patterns of parenting between parents.[3,12] It was hard to understand/interpret maternal education with the high rate of missing. Maternal

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education, SES, and other family variables may play a role in shaping the parenting stress trajectory and should be accounted for in future studies. Moreover, although validated in the paediatric cardiac population, illness-related factors are currently absent from the PSI,[47] preventing from identification of illness-specific stressors. It would be of interest to examine further moderators of stress change in parents of these infants. Although we accounted for dropout and missingness in our analysis with no evidence of bias,[24] this certainly limited the power of our study. A post hoc power analyses indicated that we had only 50% power to detect significant effect for the Child Domain (as compared to 76% power for the Parent Domain and Total Stress). This potentially prevented us from identifying a significant effect, if existed, within this domain. Furthermore, using a continuous measure of "time" provided linear results for the stress trajectories. Non-linear analysis may provide more detailed information of potential peak stressful periods in infancy. Previous research has identified the early post-surgical period as very stressful for mothers of cardiac infants.[29,36] This population might benefit from close screening of stress through and beyond infancy. Due to the lower-than-expected stress levels in our sample, we suspect that our findings may present a response bias (social desirability, or willingness to complete the screener due to lower stress). Future studies should recruit more heterogeneous populations, from various SES levels, and demographic backgrounds.

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Conflicts of interest. None.

Ethical standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (USA) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees (Children's Hospital of Philadelphia).

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