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Infant Temperament and Parent Stress in 3 month old Infants following Surgery for Complex Congenital Heart Disease

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Abstract

Objective—This study aimed to identify and compare differences in temperament and maternal stress between infants with complex congenital heart disease (CHD) and healthy controls at 3 months of age.

Methods—Study sample was drawn from an existing longitudinal study examining growth in infants with CHD as compared to healthy controls. Infant temperament and parental stress were measured in 129 mother-infant dyads. Inclusion criteria for infants with CHD were ≥ 36 weeks post-menstrual age, ≥ 2500 grams at birth, surgery in first 6 weeks of life, and no major congenital anomalies or genetic syndromes. The Early Infancy Temperament Questionnaire and Parent Stress Index were the assessment tools used.

Results—Infants with single ventricle (SV) physiology were more negative in mood (F=7.14, p<0.001) and less distractible (F=5.00, p<0.008) than the biventricular physiology (BV) or control (C) infant groups. The demands of care for infants with CHD was a source of stress as compared to control infants (p<.05). Five of six subscales of the Child Domain were significant sources of stress in the SV group compared to BV and Control groups. Negative mood and difficulty to soothe were predictors for Child Domain and Total Life Stress in SV infants.

Conclusion—The demands of parenting an irritable infant with SV physiology puts these mothers at risk for high levels of stress. Results suggest the need for pre-discharge anticipatory guidance for parents to better understand and respond to the behavioral style of their infants, in particular, infants with SV physiology.

Key Terms

infant temperament; parent stress; complex congenital heart disease; burden of care

OBJECTIVE

Approximately 32,000 babies are born with congenital heart disease (CHD) each year in the United States (1). Of those, 2.3 of every 1000 live births will require some form of intervention before the age of one or the infant will die (2). With advances in medical and surgical management increasing infant survival, CHD is becoming the most common chronic illness of childhood (3). Infants with complex CHD are often classified as having either having single

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ventricular physiology (SV), hearts that are functionally one ventricular as in hypo plastic left heart syndrome (HLHS) or biventricular physiology (BV), two functioning ventricles as in Tetralogy of Falot or Transposition of the Great Arteries. For the most part infants with SV physiology have a higher acuity level and longer hospital stay after surgery.

Infants with complex heart disease, particularly infants with SV physiology, are often described by caregivers as difficult to soothe, irritable, and more negative in mood. Irritable infants have been linked to maternal feelings of inadequacy, fatigue and resentment (4), and are described as more challenging to parent (5). The stress experienced by parents, mothers in particular, is well recognized (6,7). The burden of care that manifests in the early stages of initial diagnosis and treatment, medical and surgical intervention(s), prolonged and/or multiple hospitalizations, various diagnostic procedures, numerous medications, and the emotional rollercoaster experienced by parents all contribute to the degree of parent stress (3).

To address the paucity of data on the relationship between infant temperament and parental stress in mothers of infants with complex CHD this study addressed the following questions: 1) What is the temperament of critically ill cardiac infants at three months of age, 2) Is there a difference in temperament between infants classified as single ventricle (SV) physiology, biventricular (BV) physiology, and healthy controls (C), and 3) is there a relationship between infant temperament and parent stress?

METHODS

Subjects

The infants for this study were a subset of infants from a prospective, longitudinal, observational study of infants with complex (defined as requiring surgical intervention within the first six weeks of life) congenital heart disease. The study was approved by the institutional review board at The Children's Hospital of Philadelphia, Philadelphia, PA. Informed, written consent was obtained from parents of all enrolled participants. Participants were recruited and enrolled from the Cardiac Intensive Care Unit. Inclusion criteria required infants to be full term (>35 weeks post menstrual age), have a minimum birth weight of ≥2500 grams and have undergone palliative or corrective surgery in the first six weeks of life. Physiology group was defined in the larger study based on review of post-operative echocardiogram by a pediatric cardiologists, one of the Co-Investigators. Infants were excluded if they had known congenital disorders that could potentially affect nutrient intake and growth. Other exclusion criteria included infants with congenital or acquired anomalies inclusive of the trisomies, gastrointestinal disorders, orofacial clefts, and neurological impairment.

Procedures for Data Collection

Infants were seen post discharge in the Clinical and Translational Research Center (CTRC) at 3 months of age. The instruments were self-administered and were completed by a parent, most often the mother during the clinic visit.

Measures

Parental Stress Index (PSI) (long form)—The PSI consists of a 120-item test booklet with a 19-item Life Stress scale. It yields 17 scores, including seven Child Domain scores, eight Parent Domain scores, and a Total Stress score, plus the optional Life Stress score.(8). All items are ranked on a five point Likert scale (from 1 – 5, strongly agree to strongly disagree). The 47-item child domain measures six dimensions of stress: 1) distractibility/hyperactivity, 2) adaptability, 3) reinforces parent, 4) demandingness, 5) mood, and 6) acceptability. The 54-item parent domain measures seven dimensions of stress: 1) competence, 2) isolation, 3) attachment, 4) health, 5) role restriction, 6) depression, and 7) spouse. The child domain and parent domain are scored independently and are then summed to generate a Total Stress (TS) Score. Higher scores indicate more stress. The TS score is of primary importance as it is designed to provide an understanding of the overall level of parenting stress in a particular family. Reliability for the TS score is alpha 0.91 and ranges from 0.80 to 0.87 for each of the subscales

Early Infancy Temperament Questionnaire (EITQ) (1–4 months): The EITQ (9) is a self administered 76-item questionnaire for assessing the 9 New York Longitudinal Study temperament characteristics in 1 to 4 month old infants (10). The majority of the items were adapted from the Revised Infant Temperament Questionnaire (11) to be developmentally appropriate for the very young infant. The standardization population consisted of 404 infants from one pediatric practice. Means for the 9 categories were calculated separately for infants from 1–2 months and 3–4 months of age. Internal consistency for the nine categories ranged from 0.42 to 0.76. Test-retest scores, completed between 2 to 3 weeks after the initial rating, ranged from 0.43 to 0.87, with generally increasing retest levels in the older age group. None of the categories showed significant differences between male and female infants.

Statistical Analysis

Descriptive statistics are provided for all demographic measures, as well as by physiology group identified as SV, BV, and Control. Infant clinical characteristics are described by physiology group. Descriptive estimates for categorical, demographic and clinical characteristics include frequencies and percents; clinical variables were compared by physiology group using chi-square tests of association. Estimates for continuous EITQ and PSI subscale scores include measures of central tendency (means) and variation (standard deviations). An analysis of distributional properties was performed and demonstrated that variance stabilizing or normalizing transformations were not necessary. The outliers were assessed by visual inspection of distributions and checked for accuracy. Comparisons of mean EITQ and PSI subscale scores by physiology group were accomplished using one-way Analysis of Variance models; pair-wise comparisons were performed using post-hoc Tukey's tests with 0.05 overall level of significance. Among the CHD infants, Pearson correlation coefficients were used to estimate the bi-variate linear association between EITQ and PSI subscale scores, they demonstrate significance in the mean values of these subscales from the control group. Individual general linear models were used to regress PSI subscale scores, separately, on EITQ Mood and Distractibility measures. Adjustment was made for number of medications (measured on a continuum), "thriving" defined by World Health Organization (WHO) standardized weight score above −2.0, and an indicator variable for re-hospitalization if this occurred after the initial neonatal surgical period. Due to the high correlation between EITQ mood and distractibility subscale measures ($r=0.6$, $p<0.0001$) in the Child Domain, a separate set of models were generated for each of these EITQ subscale scores. Similarly, because of the demonstrated differences in PSI by physiology group, separate sets of general linear models were estimated within each of the physiologic groups.

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RESULTS

Table 1 provides male/female distribution and clinical characteristics for the 129 infants included in the study sample. Sixty-five percent of the infants were male, 72% Caucasian, with 67% being non-Hispanic and 94% of the mothers had at least a high school education. There were no significant differences in the gender distribution across the three groups. Among the infants with CHD, 58% and 67% of the SV and BV infants, respectively, did not experience repeat hospitalization prior to the follow-up clinic visit. Forty-five percent of SV infants demonstrated growth failure as defined by a WHO standardized weight score below −2.0, compared to less than a quarter of the BV infants ($p=0.04$). Similarly, a third of the SV infants

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were receiving more than five medications (per day), compared to 11% of the BV infants ($p=0.03$). Mean maternal age ranged from 20 to 44 years of age with a mean of 32.55 ± 4.8 years. There were no significant differences in maternal age between the three groups of mothers. Three quarters of the mothers completed either some college or had a college degree and again there were no significant differences across the three groups.

The mean EITQ and PSI subscale scores for each physiology group (SV, BV, and controls) are presented in Table 2. Mean values for infant mood and distractibility differed significantly between the SV and control groups ($p<0.05$ for both subscales). Infants with SV physiology had more negative mood and were more difficult to soothe. The mean subscale scores were significantly higher among the SV infants as compared to the control group in five of the six areas in the child domain, competence in the parent domain and overall total stress. Further, mean PSI subscale scores on the dimension of demandingness, within the child domain, differed significantly among the BV and control groups, with a linear trend in decreasing scores according to physiology

Table 3 demonstrates significant positive correlations between EITQ subscale measures of Mood and Distractibility and selected PSI subscale measures. The PSI and temperament subscales included in this table were chosen on the basis of significant results emerging from the post-hoc ANOVA analyses shown in Table 2.

Summary results from general linear modeling (GLM) of PSI subscale measures regressed on EITQ mood and distractibility are presented in Table 4. The regression analysis of selected PSI subscales using GLM, in association with EITQ mood and distractibility subscales, was based upon the significant findings presented in Table 2. With the exception of demandingness, in the PSI Child Domain dimension the percent variability in PSI subscale measure, (as measured by the model r^2,) explained by EITQ mood was similar to or higher in the SV group, as compared to the BV group. Within the SV group, EITQ mood was a statistically significant independent predictor of all but two (distractibility and demandingness) PSI subscale measures, with higher (more irritable) infant mood responses predicting higher parent stress subscale values. Among the BV infants, infant mood (EITQ) was a significant predictor of PSI subscales measures of mood, child domain, competence, and total stress. As before, with the exception of PSI demandingness, the percent variability in PSI subscale measure explained by EITQ distractibility was higher in the SV group than in the BV group. Within the SV group, EITQ distractibility was a significant predictor of all but one of the PSI subscales (competence) examined, with higher infant distractibility associated with higher parent stress. EITQ distractibility was marginally predictive of PSI competence after adjusting for medications, thriving status and hospitalizations. Among the BV infants, EITQ distractibility was a significant predictor of PSI subscales measures of distractibility and mood, with higher distractibility predictive of higher parent stress subscales for distractibility and mood.

DISCUSSION

These findings indicate SV physiology infants display a more negative mood and are more difficult to soothe as compared to infants with BV physiology or healthy control infants. Behavioral difficulties have been described in early toddlers and preschoolers with CHD (12) yet despite clinical reports of irritability and difficulty to soothe or comfort this is the first study to measure behavioral style or temperament in infants with complex CHD at 3 months of age. The finding of a pronounced negative behavioral style in SV infants at 3 months of age compared to infants with BV physiology was not unexpected. However, it was not expected to find that infants with BV physiology would be rated to be similar to healthy control infants. It may be that the BV infants, who had corrective rather than palliative surgery, are more stable physiologically by three months of age and mothers perceive them to be healthy and easy to parent. In contrast, the irritability, as measured by negative mood and difficulty to soothe, seen in the infants with SV physiology may be related to post-operative instability as well as the medically fragile status of these infants that is established during hospitalization and continued upon discharge to home. Both temperament characteristics of negative mood and difficulty to soothe contribute to a perception of negative emotionality which is considered to be the core of the difficult temperament paradigm (13).

Though the etiology of infant irritability is unclear, difficult infant temperament characteristics identified in the infant with SV physiology may be related to complex surgical intervention, repeated exposure to noxious stimuli during hospitalization, and a prolonged intensive care and/or overall hospital stay. The BV group is less likely to experience post-operative complications and in general have a shorter length of stay (14,15) than their SV counterparts. The negative stimuli of an intensive care milieu may create permanent alterations in neuronal and synaptic organization further contributing to a difficult infant behavioral style (14).

In addition, infants with SV physiology are more likely to demonstrate growth failure (16) which has been suggested to be related to more negative behaviors, such as frequent bouts of irritability (17). Furthermore, Licht (18) has shown in particular that infants with hypoplastic left heart syndrome have more immature brain development and low cerebral blood flow, both of which have been associated with more negative behavioral styles in preterm infants (5,19). While there is emerging data that 25% of infants who undergo surgery for CHD are at risk for some form of neurologic morbidity(20), and therefore poor developmental outcomes, no infants in this study had a documented neurologic insult either before or after surgery.

It is well established that mothers of infants with CHD have higher levels of distress and hopelessness when compared to mothers of healthy children or mothers of infants and children with other chronic illnesses such as cystic fibrosis (21). Goldberg and Uzark both report that the level of parenting stress did not appear to be related to the severity of the child’s heart disease, family socioeconomic status, or time since most recent surgery (22,23), which is in contrast to the findings presented here which suggest that mothers of infants with SV physiology are more stressed than mothers of infants with BV physiology. Parental stress was significantly higher on the majority of the Child Domain subscales, Child Domain summary scale and Life Stress subscale for those infants with SV physiology. Despite the differences in maternal stress, none of the mothers in either CHD group were found to have high levels of depression. Considering it is the infants with SV physiology who are more likely to be discharged and maintained on multiple medications per day (up to 15 in this sample), experience multiple re-hospitalizations, demonstrate feeding difficulties and are at risk for profound growth failure (24), these results demonstrate a “burden of care” for SV infants not previously delineated and validates the need for additional parenting and emotional support.

While the temperament literature is replete with examples of the relationship between difficult infant temperament and maternal stress, this is the first study to examine the relationship between infants with complex congenital heart disease, temperament and parental stress. Negative mood and high distractibility (difficult to soothe) mutually explain over 50% percent of the variance for the TS subscale in infants with SV physiology even when controlling for medications, growth status and repeat hospital admissions. In the Total Child Domain Scale, which represents a summary of infant characteristics related to parental stress, both mood and distractibility explained approximately 50% of the variance for mothers of SV infants

In assessment and management of infants with complex CHD, caregivers need to be educated to recognize the potential for a negative parent-infant relationship resulting from infant characteristics. Recognition of the burden of care for these medically fragile infants who face challenges related to recovery from surgery, necessary nutrient intake for growth, medication regimes and frequent assessments by health care professionals can directly influence parental stress (25). Findings from the neuro-psych-biological literature have demonstrated that early maternal infant interactions effect brain growth and neuronal organization with implications for long-term physiologic and psychological development (26,27). Creating and educating care providers on a "goodness of fit" model of infant care, allows mothers to have a realistic perception of their infant's behavioral style, and is paramount to providing the appropriate milieu for infant emotional development which may be influenced by their temperament early in infancy.

Study Limitations

Infants enrolled were part of a convenience sample from a single high volume cardiac center. This regional, national and international receiving center has a high proportion of infants with very complex congenital cardiac defects who may be at greater risk for more complicated and demanding home regimes; and may limit the generalizability of the study findings. Furthermore, approximately 90% of the infants treated in the Cardiac Center are diagnosed in the prenatal period. Prenatal screening and subsequent diagnosis has been found to be stressful for mothers of infants with CHD (28) Brosig and associates(29) found mothers had higher levels of stress six months after birth compared to mothers who had infants diagnosed in the post natal period, further limiting the study findings. Because a large proportion of infants with CHD are at risk for neurological abnormalities it is unclear what percentage of the subject infants with SV physiology had an unrecognized and undiagnosed neurological impairment that may contribute their generalized irritability. The impact of neurologic insults on infant temperament in infants with CHD is unknown.

Sheinkopt and colleagues(30)found maternal personality and psychosocial factors to influence maternal perception of infant temperament, however, these concepts were not measured in this study.. Psychosocial factors may indeed be a moderating factor in this population of mothers and suggests further investigation.

Conclusion

Overall results suggest the need for pre-discharge, anticipatory guidance for parents, mothers in particular, to better recognize, understand and respond to the behavioral style of their infants. This is particularly true for infants who have SV physiology. The demands of parenting a medically fragile who is irritable and difficult to soothe requires a complex home medical regime, demonstrates poor feeding skills coupled with poor growth, puts these families at risk for high levels of stress.

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Table 1

Infant Characteristics, N (%)

Demographics	SV (n=33)	BV (n=36)	Control (n=60)	All Infants (n=129)
Male	24 (73%)	22 (61%)	38 (63%)	84 (65%)
Female	9 (27%)	14 (39%)	22 (37%)	45 (35%)
Clinical				
				p-value‡
Not Hospitalized	19 (58%)	24 (67%)		
Re-Hospitalization	11 (33%)	8 (22%)		
Unreported	3 (9%)	4 (11%)		0.5198
Not Thriving†	15 (45%)	8 (22%)		
Thriving	18 (55%)	28 (78%)		0.0409
≤5 Medications	22 (67%)	32 (89%)		
>5 Medications	11 (33%)	4 (11%)		0.0254

† Defined by WHO standardized weight score below −2.0

‡ Chi-square p-value test of association between characteristic and SV/BV group

Table 2

ANOVA for PSI and EITQ

		Mean (Standard Deviation) (Range)		
	Parent Stress Index	**SV (n=33)**	**BV (n=36)**	**Control (n=60)**
Child Domain	**Child Domain**			
	Distractibility/Hyperactivity	24.77 (3.64) † (17–33)	22.56 (3.70) (14–31)	23.81 (3.62) (15–33)
	Adaptability	27.17 (5.84) † (15–45)	24.31 (4.45) (13–45)	24.39 (4.90) (13–41)
	Reinforces Parent	8.32 (3.30) (6–22)	7.91 (2.39) (6–16)	7.76 (2.14) (6–13)
	Demandingness	20.00 (5.33) † (11–32)	18.48 (4.73) † (9–28)	15.09 (3.50) ‡ (9–23)
	Mood	10.25 (3.48) † (5–20)	9.00 (2.52) (5–15)	8.51 (2.67) ((5–17)
	Acceptability	12.45 (4.37) † (7–24)	11.00 (3.13) (7–19)	10.49 (2.76) (7–16)
	Child Domain	103.03 (21.70) † (67–162)	93.28 (14.60) (60–136)	90.18 (14.85) (62–128)
Parent Domain	**Parent Domain**			
	Competence	25.74 (6.03) † (15–42)	22.91 (4.73) (14–34)	22.82 (5.05) (14–35)
	Isolation	12.75 (4.66) (7–27)	12.06 (3.23) (6–19)	11.74 (4.46) (1–22)
	Attachment	11.63 (3.30) (8–21)	10.91 (1.93) (8–14)	11.00 (3.05) (1–19)
	Role Restriction	17.47 (5.55) (9–35)	18.21 (4.65) (11–35)	16.86 (5.49) (1–27)
	Depression	17.78 (4.43) (9–28)	17.59 (3.84) (9–28)	16.59 (5.51) 1–30)
	Parent Domain	114.87 (24.17) (66–178)	110.53 (17.74) (78–173)	106.13 (24.63) (24–161)
	Spouse	17.66 (5.53) (7–29)	16.21 (4.63) (7–30)	15.38 (5.09) (1–25)
	Total Stress	218.07 (43.38) † (133–340)	203.21 (30.13) (145–309)	196.84 (34.93) (118–280)

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		Mean (Standard Deviation) (Range)		
	Parent Stress Index	**SV (n=33)**	**BV (n=36)**	**Control (n=60)**
	Life Stress	10.66 (8.01) (1–35)	8.24 (7.02) (1–24)	10.79 (9.05) (1–42)
EITQ Estimates	**Early Infancy Temperament Questionnaire**			
	Activity	3.86 (0.77) (2.5–5.8)	3.81 (0.91) (1.75–5.38)	3.85 (0.73) (2.25–5.61)
	Approach	2.91 (0.79) (1.60–4.82)	2.62 (0.70) (1.17–4.0)	2.64 (0.75) (1.33–6.0)
	Mood	3.11 (0.77) † (1.55–4.73)	2.77 (0.69) 91.73–4.3)	2.56 (0.59) (1.36–3.73)
	Intensity	3.80 (0.91) (1.33–5.17)	3.96 (0.57) (2.67–5.0)	3.69 (0.75) (2.0–5.3)
	Distractibility	2.39 (0.80) † (1.14–4.57)	2.11 (0.59) (1.14–3.0)	1.94 (0.60) (1.0–3.17_
	Persistence	2.17 (0.64) (1.12–3.5)	2.15 (0.54) (1.12–3.38)	2.15 (0.74) (1.0–3.38)
	Threshold	4.35 (0.66) (2.8–5.69)	4.37 (0.68) (2.8–5.59)	4.16 (0.80) (1.9–5.5)
	Rhythmicity	3.06 (0.69) (1.8–4.9)	3.01 (0.73) (1.50–4.86))	3.01 (0.69) (1.70–4.69)
	Adaptability	2.56 (0.75) (1.0–4.0)	2.42 (0.72) (1.30–3.85)	2.47 (0.66) (1.40–4.19)

† Differs from control, ANOVA post-hoc Tukey's test p<.05

‡ Differs from BV, ANOVA post-hoc Tukey's test p<.05

Table 3

Pearson Correlation Coefficients between EITQ (Mood and Distractibility) and Selected PSI Measures Among Infants with CHD (N=69)

	Mood		Distractibility	
PSI Measure	**r**	**P-value**	**r**	**P-value**
Distractibility/Hyperactivity	0.30	0.0165	0.51	<.0001
Adaptability	0.52	<.0001	0.57	<.0001
Demandingness	0.35	0.0054	0.33	0.0099
Mood	0.64	<.0001	0.54	<.0001
Acceptability	0.39	0.0014	0.32	0.0117
Child Domain	0.59	<.0001	0.60	<.0001
Competence	0.53	<.0001	0.39	0.0012
Total Stress	0.60	<.0001	0.54	<.0001

Table 4

GLM Results

Dependent PSI Variable	SV Group (n=33)			BV Group (n=36)		
	Model r^2	F-value	Prob >F	Model r^2	F-value	Prob >F
	PSI Measures Regressed on EITQ Mood†					
Distractibility/Hyperactivity	17%	1.98	0.1710	18%	2.73	0.1102
Adaptability	45%	8.10	0.0087	20%	3.17	0.0861
Demandingness	23%	2.37	0.1357	43%	1.54	0.2258
Mood	56%	12.89	0.0013	35%	13.70	0.0009
Acceptability	36%	4.12	0.0527	17%	0.95	0.3376
Child Domain	47%	10.70	0.0031	37%	7.98	0.0094
Competence	31%	4.83	0.0371	33%	8.94	0.0056
Total Stress	53%	7.08	0.0134	45%	11.42	0.0025
	PSI Measures Regressed on EITQ Distractibility†					
Distractibility/Hyperactivity	49%	19.38	0.0002	26%	5.88	0.0223
Adaptability	52%	12.91	0.0014	20%	3.27	0.0816
Demandingness	29%	4.99	0.0344	40%	0.12	0.7318
Mood	48%	6.95	0.0137	22%	6.67	0.0151
Acceptability	48%	10.66	0.0031	18%	1.45	0.2388
Child Domain	58%	20.37	0.0001	22%	1.63	0.2142
Competence	29%	3.88	0.0595	19%	2.30	0.1399
Total Stress	58%	11.24	0.0026	25%	2.14	0.1566

† Controlling for number of medications, thriving status, and hospitalization since discharge