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Stress and Quality of Life Among Parents of Children with Congenital Heart Disease Referred for Psychological Services

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Stress and Quality of Life Among Parents of Children with Congenital Heart Disease Referred for Psychological Services

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Abstract:

Objective: The study examined parent stress and health-related quality of life (HRQOL) among families of children with **congenital heart disease** (CHD) referred for psychological services.

Methods: Parents of 54 children (85% boys) aged 3 to 13 (<italic>M</italic>_{age} = 7.48, <italic>SD</italic> = 2.38) completed measures to assess parenting stress (Parenting Stress Index – Short Form; Pediatric Inventory for Parents) and the PedsQL Family Impact Module. Medical information was retrieved from

medical record review. Results: Half of parents of children with single ventricle anatomy had clinically significant levels of parenting stress. Parents of children with single ventricle anatomy reported more frequent illness-related stress and more difficulty dealing with illness-related stress than parents of children with two ventricle anatomy. Younger gestational age at birth and referral for attention or behavior problems were associated with greater likelihood of parent at-risk psychosocial functioning.

Conclusions: Among children referred for psychological services, many parents report significant stress and significant negative impact of the child's medical condition on the family. Results underscore the need to consider assessing parent psychosocial functioning and providing additional support for parents of children with CHD.

Keywords

children; congenital heart disease; health-related quality of life; parent stress; parents

INTRODUCTION

Congenital heart disease (CHD) is a leading cause of death in the United States and the most prevalent birth defect.[1] Survival rates of children with CHD have improved over the past two decades. Yet, children with CHD may experience cognitive, social, and behavioral sequelae that can impact daily and long-term functioning.[2] Parents of children with CHD must adapt to their children's medical and psychosocial needs not just in infancy, when medical intervention is typically necessary, but also throughout childhood as they address their children's ongoing medical concerns and/or neurodevelopmental, emotional, social, and educational functioning.

A growing body of literature is documenting that parents of children with CHD report greater stress, anxiety, and depression as compared to the general population,[3] which may relate to the life-threatening nature and unpredictability of the child's medical condition, as well as the caregiving needs that are required.[4] While studies vary in terms of what aspects of parents' psychological health are being measured as well as the assessment measures used,[3] emotional distress has been reported in parents of children spanning early infancy (i.e., one-day old) through young adulthood (i.e., 21 years of age) with a variety of CHD diagnoses. Although medical involvement may be less frequent as children grow older, new problems related to neurocognitive or emotional functioning may present themselves, causing additional stress for parents. Therefore, parents' responses and adjustments to their child's condition are important to examine over time.

Parenting stress

Of interest in the present study is parents' overall stress, which may include parenting challenges as well as general stress. Uzark and Jones[5] reported that five years after a child's open-heart surgery, 17.5% of participating parents of children ages 2 to 12 years reported clinically significant levels of stress on the Parenting Stress Index (PSI), while approximately a quarter of parents indicated a high level of parenting stress.[6] Percentage of participants who had high scores on the PSI defensive responding scale (suggesting that parents may have been underreporting stress symptoms to present themselves in a socially desirable manner) ranged from 19%[6] to 28%[7] in the few studies that reported this score.

Several studies have compared PSI scores across different cardiology patient populations, with different disease severity, with mixed results. While some studies have found that parental stress level was not related to child disease severity,[5] [8] [9] Brosig et al.[10] found that parental stress was related to the severity of the child's heart defect; parents of children with severe CHD reported higher stress levels. Timing of the child's last surgery was related to parenting stress levels in some studies (i.e., less parental stress the farther the child was out from surgery)[9] but not others.[5] Similarly, age of the child has been associated with parental stress levels in some studies (i.e., more parental stress in parents of older children)[5] but not others.[8] The presence of comorbid

medical, neurological, or developmental issues has also been associated with higher parental stress levels.[11] Prenatal diagnosis, gender, or family SES were not associated with differences in parenting stress.[5] [7] Parents who perceived having less social support reported higher parental stress.[12]

When parenting stress scores for parents of children with CHD have been compared with normative PSI scores, the results again have been inconsistent. Some studies found that parents of children with CHD had significantly higher total stress scores than the normative sample[5] other studies found parenting stress levels for parents of children with CHD that were comparable to the normative sample.[9] Still other studies found parenting stress levels for parents of children with CHD that were lower than the normative sample.[10] [12] When compared to healthy control samples, one study found no significant differences in PSI subscale scores for mothers of children with CHD and mothers of healthy children,[13] but another study found that mothers and fathers of children with CHD had significantly higher total stress scores than controls.[7] This variability of results across studies underscores the need for closer examination of study participants and whether child and/or family functioning characteristics may clarify understanding of parenting stress predictors.

Relatively fewer studies have examined disease-related parental stress, as assessed with measures such as the Pediatric Inventory for Parents, in cardiology populations. Parental stress due to a child's illness may impact parents' mental health and subsequently children's functioning.[14] Among families of children two to six years after major cardiac surgery, parents of children with more severe CHD reported higher disease-related stress than parents of children with less severe CHD.[9] A cross-sectional study of parents of children (age < 1 year to 10 years) with severe CHD (i.e., hypoplastic left heart syndrome) found higher disease-related stress and more difficulty coping with this stress compared to caregivers of children with other chronic illnesses, such as inflammatory bowel disease, cancer, diabetes, or sickle cell disease.[11] These results underscore the need for assessment of parenting stress and disease-related parental stress by pediatric psychologists in outpatient pediatric cardiology clinics.[15]

Family HRQOL

Assessing health-related quality of life (HRQOL) provides information about parents' perceptions of their own physical and psychosocial functioning. Three cross-sectional.[16] [17] [18] and one prospective study[19] have examined HRQOL among parents of children with CHD. All four included parents of children with various CHD diagnoses. Although there was some variability in the HRQOL assessment measures used, there was evidence of impaired parental HRQOL and family functioning across studies. Parents of children with CHD reported impairment in multiple domains of HRQOL when compared to parents of children with minor illness[16] and parents of healthy children.[17] Parents of children with hypoplasia of the left ventricle (HLV) reported experiencing significantly poorer parent health-related quality of life and poorer family functioning as compared to parents of children with tetralogy of Fallot (TOF).[18] Among parents whose children were discharged from the hospital after open heart surgery, both mothers and fathers reported poorer quality of life in several domains of functioning, yet six months later all mean scores were within or above population norms.[19] However, 24.1% of mothers and 12.5% of fathers had low mental health summary scores six months after discharge. Across the four studies, child illness and parent characteristics predicted poorer HRQOL.

In recent years, there has been recognition of the need to provide specialized psychological services to children with CHD and their families within cardiology clinics thereby providing more integrated care.[15] Specifically, parents of children with CHD and difficulties with social, emotional, or academic functioning may experience increased stress due to the child's health condition, the child's psychological concerns, or both factors. Notably, parents of children with mental health problems may have four times the odds of high stress as compared to parents of children without mental health problems.[20] A better understanding of the psychosocial concerns of children[21] and their parents is necessary to fully provide appropriate integrated care.

The purpose of the present study was to examine parent stress and HRQOL among families of children with CHD referred for psychological services. Preliminary analyses examined the frequency of and correlates of at-risk parental stress and the impact of CHD on parents' HRQOL and family functioning. It was hypothesized that (1) parents of children with more severe disease (i.e., defined as having single ventricle anatomy[22]) would report experiencing higher levels of parent stress than parents of children with less severe disease (i.e., defined as having two ventricle anatomy); and (2) parents of children with single ventricle anatomy would report experiencing a more negative impact of CHD on parents' HRQOL and family functioning than parents of children with two ventricle anatomy. Finally, analyses examined predictors of at-risk parenting stress and parent and family quality of life.

METHODS

Procedures

During outpatient cardiac follow-up clinic visits, pediatric cardiologists and/or nurses asked children with CHD and their parents about the child's emotional, social, and academic functioning. If concerns were identified, the child was referred for an evaluation to a pediatric psychologist located within the cardiology clinic. The family was contacted by the pediatric psychologist's administrative assistant to schedule an appointment with the psychologist. Prior to the psychology appointment, families received questionnaires by mail. Parents provided consent, and children seven years of age and older gave assent to have the results from the questionnaires used for research purposes. Data for the present study was drawn from eligible patients seen in the cardiology psychology clinic for a six-year period and was analyzed retrospectively. The study was approved by the hospital's institutional review board.

Participants

From 2007 through 2013, of the new patients with CHD seen by the psychologist in the outpatient cardiology clinic, 68 patients/families with children between the ages of 3 and 13 consented to participate and had completed forms for at least one of the measures of parent functioning. Fourteen of those caregivers (20.6%) had Parenting Stress Index – Short Form (PSI-SF) or Parenting Stress Index - 4th edition - Short Form (PSI-4-SF) Defensive Responding scale scores that were extremely low (suggesting that the scores were not valid), and thus they were removed from further analyses. The present analyses included data from 54 parents who completed the three measures of interest described below and had acceptable validity scores on the PSI-SF. Data on child behavior and parents' perception of the child's quality of life for a subsample of the participants included in the present analyses were described in a previous paper.[15]

Measures

Demographic and illness-related characteristics

Parents answered questions about child and family demographic characteristics including questions about the child's medical history; past and current intervention services; parental age, education, and occupation; and family constellation. Information on parent education, occupation, sex, and marital status was used to calculate the Four Factor Index of Social Status.[23] A review of medical records was conducted to obtain information about child's birth weight, age at first cardiac surgery (days), cardiopulmonary bypass time (lifetime minutes), deep hypothermic circulatory arrest time (lifetime minutes), cumulative length of hospital stays (days), days since last hospital discharge, cardiac diagnoses, and other medical conditions (categorized as respiratory, endocrine, immunological, multisystem, neurological, orthopedic, sensory, and urological concerns). Patients were categorized based on whether cardiac anatomy resulted in achievement of a two ventricle repair or a single functional ventricle; these categories have been previously established as representing increasing complexity[22] and have been used in previous studies on developmental outcomes in patients with CHD.[24]

[25] Birth weight data was available for 85% of participants, while the other medical record data was available for 94% of participants. Information on participant demographic and illness-related characteristics is in Table .

Participant demographic and illness characteristics

	Total sample n = 54	**Single ventricle n = 32**	**Two ventricle n = 22**
Child gender (male)	46 (85.19%)	26 (81.25%)	20 (90.90%)
Child age (years)	7.48 (2.38)	7.46 (2.52)	7.50 (2.22)
Child's residence			
Both parents	40 (74.07%)	23 (71.88%)	17 (77.27%)
Mother only	13 (24.07%)	9 (28.13%)	4 (18.18%)
Other adult caregiver	1 (1.85%)	0 (0.00%)	1 (4.54%)
Parental marital status (married)	33 (61.11%)	18 (56.25%)	15 (68.18%)
Reason for referral			
Attention problems	32 (59.26%)	20 (62.50%)	12 (54.55%)
Behavior problems	18 (33.33%)	14 (43.75%)	4 (18.18%)
Developmental delay	7 (12.96%)	4 (12.50%)	3 (13.64%)
Emotional problems	9 (16.67%)	4 (12.50%)	5 (22.73%)
Learning problems	13 (24.07%)	6 (18.75%)	7 (31.82%)
Birth weight (kg)	3.02 (0.68)	3.07 (0.54)	3.00 (0.90)
Age at first surgery (days)	133.39 (192.08)	121.10 (191.68)	152.45 (196.09)
Number of open heart surgeries	2.29 (0.99)	2.71 (0.82)	1.65 (0.88)
Cardiopulmonary bypass time (lifetime minutes)	277.59 (145.06)	305.84 (141.70)	233.80 (142.64)
Deep hypothermic circulatory arrest time (lifetime minutes)	9.04 (20.03)	14.84 (24.08)	0.05 (.22)
Cumulative length of stay (days)	50.41 (40.00)	54.90 (34.54)	43.45 (47.37)
Days since most recent hospital discharge	1540.08 (1070.48)	1337.42 (955.91)	1854.20 (1184.04)
Other medical condition	21 (38.89%)	13 (40.63%)	8 (36.36%)

1 *P < .05.
2 **P < .01.
3 ***P < .001.

PSI-SF and PSI-4-SF

The PSI-SF[26] and PSI-4-SF[27] assess parents' perceptions of parenting stress. The PSI-SF and PSI-4-SF have 36 items that yield a Total Stress score from three scales: Parent Distress, Parent Child Dysfunctional Interaction, and Difficult Child. The Total Stress score was available for 93% of participants. Total Stress raw scores at or above the 85th percentile on either the PSI-SF or PSI-4-SF are considered high[26] [27] and were considered at-risk.

Pediatric Inventory for Parents (PIP)

The PIP[14] assesses parental stress related to caring for a child with chronic illness. It includes 42 items that ask parents to answer questions in four domains (i.e., communication, emotional distress, medical care, and role function). For each of the 42 items, respondents indicate how frequently the event occurred and the level of difficulty associated with the event. Frequency and Difficulty scores are calculated separately for each domain scale; the scale scores are added together to obtain Total Frequency (PIP-F) and Total Difficulty (PIP-D) scores. The PIP-F and PIP-D scores were available for 70% of participants. Higher scores indicate greater frequency and difficulty. The PIP has adequate reliability and validity.[14]

PedsQL FIM

The PedsQL FIM[28] includes 36 items that assess the impact of pediatric chronic health conditions on parents' self-reported health-related quality of life and family functioning. Parents respond using a 5-point response scale. The measure includes eight subscale scores: Physical Functioning (6 items), Emotional Functioning (5 items), Social Functioning (4 items), Cognitive Functioning (5 items), Communication (3 items), Worry (5 items), Daily Activities (3 items), and Family Relationships (5 items) The Parent HRQOL Summary Score is calculated by averaging 20 items in Physical, Emotional, Social, and Cognitive Functioning subscales; the Family Functioning Summary Score is computed by averaging items in the Daily Activities and Family Relationships subscales. A Total Scale score is the sum of all 36 items divided by the number of items answered. Items on the PedsQL FIM are reverse-scored and linearly transformed to a 0–100 scale whereas higher scores indicate better functioning. The Total Score, the Parent HRQOL, and Family Functioning summary scores were used in the present analyses; The Total Score was available for 96% of respondents, while 94% respondents had complete Parent HRQOL and Family Functioning scores. Respondents whose scores were 1 SD below the means of a normative, community sample population of parents of children without a chronic medical condition[29] were identified as being at-risk for impaired family HRQOL.[30]

Statistical analysis

Bivariate correlations and independent samples t-tests were conducted to assess which demographic and medical characteristics differed by CHD diagnosis (i.e., single ventricle vs. two ventricle; see list in Table) and/or were related to the scores of interest. Independent samples t-tests were used to examine group differences for primary outcome variables comparing scores for the parents of children with single ventricle and two ventricle anatomy. Spearman's rho correlations examined associations among parent stress, parent and family HRQOL, and demographic and medical characteristics. To examine which variables contributed to the likelihood of a parent having at-risk scores on measures of parent psychosocial functioning, a logistic regression was performed that included demographic and medical characteristics that were statistically different between the at-risk group and the not at-risk group.

RESULTS

Parenting stress results

Sixteen (50%) parents of children with single ventricle anatomy and seven (32%) parents of children with two ventricle anatomy reported clinically significant levels of Total Stress on the PSI-SF. There were no statistically significant differences on the PSI-SF Total Stress scores for the parents of children with single ventricle and two ventricle anatomy (see Table).

Descriptive characteristics for parent-report measures

	Total sample n = 54	**Single ventricle n = 32**	**Two ventricle n = 22**
PSI-SF Total Stress Score	81.33 (18.61)	84.34 (19.32)	76.95 (17.01)
PIP Total Frequency Score	90.29 (27.84)	99.00 (28.54)	78.31 (22.51)
PIP Total Difficulty Score	83.89 (29.45)	95.36 (30.12)	68.13 (20.27)
PedsQL Family Impact Total Impact	70.97 (20.93)	68.13 (22.66)	75.51 (17.39)
PedsQL Family Impact Parent HRQOL	71.96 (22.54)	69.18 (24.65)	76.63 (18.12)
PedsQL Family Impact Family Functioning	71.75 (27.46)	70.80 (27.78)	73.36 (27.61)

4 *P < .05.

5 **P < .01.

6 ***P < .001.

On the PIP, parents of children with single ventricle anatomy had higher Total Frequency and Total Difficulty scores than parents of children with two ventricle anatomy, t (36) = 2.40 and t (36) = 3.13, P = .022 and P = .003, respectively (see Table). Parents of children with additional medical conditions (besides CHD) had higher Total Frequency and Total Difficulty scores than parents of children with only CHD, t (36) = −2.42 and t (36) = −2.85, P = .02 and P = .007, respectively.

PedsQL family impact results

Ten (32%) parents of children with single ventricle anatomy and 6 (30%) of parents of children with two ventricle anatomy had at least one of three scores (i.e., Total Impact, Parent HRQOL, and Family Functioning Summary) in the at-risk range for impaired quality of life. There were no statistically significant differences between single ventricle and two ventricle anatomy groups for the three scores (see Table).

There were consistently strong correlations among the measures assessing parent stress and parent and family quality of life (see Table). No significant associations were found among parent stress, parent and family quality of life, and objective medical information.

Spearman's rho correlations among stress and PedsQL FIM

	PSI-SF Total Stress	**PIP Total Frequency**	**PIP Total Difficulty**	**PedsQL Family Impact Total Impact**	**PedsQL Family Impact Parent HRQOL**
PIP Total Frequency Score	.63				
PIP Total Difficulty Score	.61	.93			
PedsQL Family Impact Total Impact	–.55	–.74	–.79		
PedsQL Family Impact Parent HRQOL	–.50	–.70	–.76*	.94	
PedsQL Family Impact Family Functioning	–.51	–.63	–.64	.81	.64

7 ***P < .001.

Predictors of at-risk scores

Exactly half (50%) of the parents had at-risk scores on either the FIM Total Impact, Parent HRQOL or Family Functioning scales and/or PSI Total Score. A logistic regression was performed to determine the effects of gestational age, total time in deep hypothermic circulatory arrest, presence of other medical condition, referral for attention problems, and referral for behavior problems on the likelihood that parents had at-risk scores on measures of parent psychosocial functioning (see Table). The logistic regression model was statistically significant, χ^2(5) = 28.99, P < .001. The model explained 59% (Nagelkerke R^2) of the variance in at-risk parent psychosocial functioning and correctly classified 82% of cases. Parents of children who had a younger gestational age at birth were 1.99 times more likely to have at-risk psychosocial functioning, and referrals for attention and behavior problems were associated with increased risk of parent at-risk psychosocial functioning.

Summary of logistic regression analysis for variables predicting parent at-risk psychosocial functioning

Predictor	B	SE B	eB

Other medical condition	−1.69	.94	0.18
Gestational age	.69	.29	1.99
Total DHCA time	.04	.03	1.04
Referral for attention problems	−3.28	1.21	.04
Referral for behavior problems	−2.26	1.10	.11
Constant		−23.37	
χ^2		28.99	
df		5	

8 EB = exponentiated B.

9 aP < .10, * P < .05, ** P < .01, ***P < .001.

DISCUSSION

Parents of children with CHD referred for psychological services are a subgroup that has not been previously identified and studied individually, yet results document the importance of not only intervening with the referred children, but also assessing and potentially intervening with these parents. Notably, 43% of participating parents had clinically significant levels of parenting stress. This is greater than the percentage reported in other studies (e.g., 17.5%)[5] and is consistent with previous studies documenting concerns regarding parenting stress.[7] Similarly, a third of participating parents reported one or more HRQOL scores in the at-risk range. Unfortunately, percentages of PedsQL FIM HRQOL scores are not available for other cardiology populations for comparison. It is possible that parental stress levels were higher in the present sample and there were more at-risk HRQOL scores because all the children with CHD were referred for psychological concerns, whereas previous studies utilized general cardiology clinic samples. It is important to better understand the concerns of this subgroup of patients referred to a pediatric psychologist as both children and parents may benefit from psychosocial interventions.[20] [31]

As hypothesized, parents of children with more severe disease (i.e., single ventricle anatomy) more often reported experiencing illness-related stress and greater difficulty dealing with illness-related stressors than parents of children with less severe disease (i.e., two ventricle anatomy). This is consistent with a previous study finding the same group differences using a Dutch short form of the PIP.[9] Results are also consistent with the study by Caris et al.[11] who found that parents of children with hypoplastic left heart syndrome had higher disease-related stress and more difficulty coping with this stress compared to caregivers of children with other chronic illnesses, such as inflammatory bowel disease, cancer, diabetes, or sickle cell disease. Notably, parents of children with medical conditions in addition to CHD (i.e., 38% of participants with respiratory, endocrine, immunological, multisystem, neurological, orthopedic, sensory, and/or urological concerns) also reported more frequent and greater difficulty with illness-related stress when compared with parents of children with only a CHD diagnosis, which is again consistent with Caris et al.[11] who found that the presence of comorbid medical, neurological, or developmental issues was associated with higher parental stress levels. Although the composition of this present study subsample included a diverse array of medical conditions, the additional care required for children with more than one chronic illness, in addition to psychological concerns, adds increased demands for caregivers.

Contrary to the second hypothesis, parents of children with single ventricle and two ventricle anatomy did not differ in their reports of parenting stress and the impact of CHD on parents' HRQOL and family functioning. This suggests that the two groups may have different experiences with illness-related events that are more successfully detected using illness-specific measures as opposed to general parenting stress and family impact instruments.

Scores across the various measures of parent stress and family impact are related, and half of the participating parents reported clinically at-risk scores on one or two scales. It was interesting to note that younger child gestational age at birth was a significant predictor of at-risk parental stress and family functioning. Children with CHD who are born premature have a higher rate of neurodevelopmental problems, which again, may increase the caregiving burden on parents. Referrals for attention and behavior problems were also significant predictors of at-risk parent stress and family functioning, which is not surprising as children with these issues present more parenting challenges.

Limitations and future directions

Study limitations to consider include the age range included (3 to 13 years), which given the overall relatively small sample size, precludes more detailed comparisons of parents of different child age groups. This could illuminate how parent and family functioning may be impacted at different developmental levels. Further the data included primarily parent self-report. While self-report of stress and quality of life are critical, the inclusion of data from a second caregiver could have provided additional information for consideration. As results were based on a retrospective analysis of patients seen by the cardiac psychologist in clinic, the cardiac diagnoses represented within the single and two ventricle groups were heterogeneous, which may have influenced results. Finally, as results were based on a sample of CHD patients/parents who were referred for psychological services, findings may not generalize to other CHD patients/parents who are seen in a general cardiology clinic but are not specifically referred for psychological evaluation.

Overall, study results highlight the fact that although children with CHD were the target for psychological referral, parents of these children are also in need of psychological services. Ongoing parenting stress may impact parenting styles that may sustain child adjustment difficulties.[31] Interventions that are designed to reduce parental stress and improve parental coping are likely to benefit parents, but may also have a positive impact on child outcomes. Preliminary work by McCusker et al.[32] showed that mothers who participated in a brief psychosocial intervention had less anxiety and worry than mothers in the control group; interestingly, infants of mothers who participated in the intervention group had higher scores on the Bayley-II mental scale when compared to infants of mothers in the control group when they were assessed at 6 months follow-up. In a subsequent study, McCusker et al.[33] designed an intervention to promote adjustment in children with CHD and their families as the children were entering school. Mothers who participated in the intervention reported improved mental health and family functioning, and their children missed fewer days of school when compared to families in the control group at 10-month follow up. Further examination of ways to effectively assess parent psychological functioning and potentially intervene will be important while continuing to support parents as they adjust to children's conditions and needs over time.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare and did not receive any financial support for the study.

AUTHOR CONTRIBUTIONS

All authors contributed revisions and approved the submission.

Study Design: Brosig

Acquisition of data: Brosig

Conducted the data analysis: Brosig, Kaugars, Shields

Interpreted the results: Brosig, Kaugars, Shields

Wrote the first draft: Kaugars

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