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Exploring relationships between parental stress, coping, and psychological outcomes for parents of infants with CHD

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Original Article

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Abstract

Objective: This study aimed to explore relationships between parental stress, coping, and outcomes for parents of infants with CHD, via observational approach reflecting domains of the Parental Stress and Resilience in CHD (PSRCHD) model. *Methods:* Fifty-five parents of 45 infants with CHD completed questionnaires with measures of parental stress, Problem-Focused Coping (PFC), Emotion-Focused Coping (EFC), Avoidant Coping (AC), mental health (symptoms of anxiety and symptoms of depression), post-traumatic growth (PTG) and quality of life (QoL). Demographic and infant clinical data were obtained. *Results:* Parental stress showed significant small to medium positive correlations with MH and PTG, but no significant correlations with QoL. EFC and AC showed significant small to medium positive correlations with MH, and medium negative correlations with parental QoL. EFC and PFC had significant small to medium correlations with PTG. PFC and AC had significant small to medium correlations with infant QoL. Hierarchical multiple regression analyses indicated that parental symptoms of anxiety, PTG, parental QoL, infant QoL were significantly predicted by models comprising of parental stress, coping styles, and clinical controls (adjusted $R^2 = 13.0–47.9\%$, p range $< 0.001–.048$), with results for parental symptoms of depression falling marginally above significance (adjusted $R^2 = 12.3\%$, $p = .056$). *Conclusions:* Parental stress, coping styles, and length of hospital stay are related to psychological outcomes in parents of infants with CHD. Future research may use the PSRCHD framework to assess mechanisms underlying CHD parents' stress and coping experiences and investigate longitudinal relationships between parental factors and parent and child outcomes.

Introduction

CHD is reported to be the most common birth defect, affecting approximately 1% of births each year, and linked to higher mortality rates, longer hospital stays, and poorer neurodevelopmental outcomes.[1,2] Recent empirical research and reviews have highlighted interplays between parental functioning and long-term outcomes for children with CHD, with increasing attention paid to roles of parental stress[2–6] and parental coping.[7,8] Parental stress refers to stress experienced by parents where demands outweigh resources available, and how intense parents find these acute and chronic stressors. Parental stress within the CHD context may increase due to unpredictability of cardiac conditions, including unexpected hospitalisations and parental separation from their baby.[9] Parental coping refers to parents' ability to adjust to their baby's CHD, and to manage parental stress that emerges in medical and child-related scenarios, whilst fulfilling their parental responsibilities.[10] Coping styles refer to parents' dispositional and situational coping tendencies when adjusting to stressful scenarios.[11] Specifically, Problem-Focused Coping (PFC) refers to cognitive and behavioural attempts to identify and resolve challenging situations, Emotion-Focused Coping (EFC) seeks to regulate emotional responses to a scenario instead of directly changing it, and Avoidant Coping (AC) involves avoiding stressful situations intentionally or involuntarily.[12] All three coping styles can be influenced by parents' use of specific coping strategies when addressing scenarios related to child's CHD (e.g. PFC strategy: seeking informational support, EFC strategy: seeking emotional support, and AC strategy: using distraction).

Conceptualising parental stress and coping as modifiable factors may help to understand and improve parental outcomes.[7] Approximately 80% parents of children with CHD report clinically significant symptoms of post-traumatic stress, and 25–50% report clinically significant symptoms of depression or anxiety.[13] There remains a lack of proactive clinical support around parental coping and adaptation, as evident by unmet long-term psychological needs reported by "CHD parents".[14,15]

Recent reviews have called for theory-driven methodologies guided by a conceptual model for parents of children with CHD.[15,16] Lisanti's Parent Stress and Resilience in CHD (PSRCHD) model[17] was developed from literature review and indicates acute and chronic stressors arising from child, parent, and environment domains, which impact parents' allostatic load. This model has been highlighted as a framework for CHD empirical research[15] and has been applied to families post-discharge from hospital[18] and within neonatal/paediatric ICU environments.[19,20] Importantly, PSRCHD is the only CHD-specific theoretical model offering a conceptual foundation for influences of parental, environmental, and child clinical factors on parental and child outcomes, thus allowing assessment of key risk factors including length of hospital stay[2,9] and CHD complexity.[8,21] However, the PSRCHD model has not yet been applied across hospital and home environments for parents of infants with CHD, and the roles of parental coping, post-traumatic growth (PTG), or quality of life (QoL) have yet to be explored empirically.

This observational cross-sectional study aimed to collect quantitative data to broadly fit the PSRCHD framework in order to assess relationships between parental stress, coping, and psychological outcomes for parents of infants with CHD. Study comprised of four objectives: (1) describe profile of recruited sample via demographic and clinical details; (2) outline psychometric details of scales measuring predictor variables (parental stress and coping styles), and outcome variables (symptoms of anxiety, symptoms of depression, PTG, parental QoL, and infant QoL); (3) investigate relationships between predictor and outcome variables via correlational analyses; and (4) assess whether predictor variables would significantly predict outcome variables in hierarchical multiple regression analyses. It was hypothesised that parental stress would be significantly correlated with all five outcomes, with medium positive correlations expected with MH outcomes, and medium negative correlations expected with PGT and QoL. It was hypothesised that parental coping would be significantly correlated with all five outcomes, with medium negative correlations expected with MH outcomes, and medium positive correlations expected with PGT and QoL. Finally, it was hypothesised that parental stress, coping, and clinical variables would together account for significant variance within each parental outcome.

Materials and methods

Design

An observational cross-sectional design was employed. Data were collected from parents via questionnaire at one timepoint, with child clinical data verified via clinical records. Study complied with good clinical practice and had approval from CHI and TCD ethics committees.

Participants

Parents were recruited at the Department of Cardiology and Cardiac Surgery at Children's Health Ireland (CHI) at Crumlin, Ireland, between July 2022 and March 2023. Recruitment was completed through recruitment flyers displayed in hospital or given to parents by clinicians. Letters were sent to eligible families identified by clinical members of study team. Study information was shared by a charity group (Heart Children Ireland) and three private social media groups for parents of infants with CHD. Study inclusion criteria referred to: (i) parent or legal guardian of infant with confirmed CHD or congenital heart condition, (ii) child receiving clinical care from Department of Cardiology and Cardiac Surgery at CHI Crumlin, and (iii) child under 12 months old at time of study. Exclusion criteria referred to (i) parent of child with CHD with adverse clinical outcomes (e.g. receiving palliative care) and (ii) child over 12 months of age.

Procedure

Parents who contacted study team were sent additional study information. Lead researcher contacted parents to explain study, confirm eligibility, and answer questions, before completing Informed Consent Form. Participants completed measures via online form or paper questionnaire, as per preference. Questionnaire data were inputted onto secure electronic database, with pseudonymity maintained for study duration. Data were processed and stored in line with data protection policies and legislation. All participant questionnaires were reviewed within 7 days to monitor clinical risk. Any participant scoring above clinical cut-off was contacted by study PI. Psychological support was available on request if any distress arose for participants during study.

Instruments

Questionnaire consisted of psychometric scales selected to fit domains of PSRCHD model. The present study is underpinned by the PSRCHD model, with a subset of constructs from each domain targeted. A substruction of PSRCHD model with study predictor and outcome measures is illustrated in Figure 1. Table of abbreviations for all measure names and subscales is provided in Supplementary Table S1.

Demographic and clinical data were collected via parental questionnaire. Cardiac-related clinical data were further verified through clinical records. Two clinical factors were included in studys substruction of PSRCHD model to reflect "Illness-Related Factors" construct under the Child (Infant) domain. The two illness-related factors were CHD complexity and length of hospital stay (both highlighted earlier as important risk factors). CHD complexity was verified by Clinical Nurse Specialist (CNS) on the study team at the paediatric hospital, based on patient's CHD diagnoses. It was agreed to use a dichotomous variable: Simple CHD or Complex CHD. Length of hospital stay referred to the total days spent as part of a hospital stay under the care of cardiology at paediatric hospital. This included both cardiac ward stays and ICU stays as part of cardiology care. ICU stays at maternity or general hospitals were not counted. The aim was to provide an understanding of the total number of days families spent in the cardiology hospital environment with their baby, including pre-/post-surgery care and for cardiac procedures. This figure (total number of days) was calculated by psychologists and CNS on study team at the paediatric hospital. Both illness-related factors were later used as controls in statistical analyses.

Parental stress was measured via Parental Stressor Scale: Infant Hospitalisation (PSS:IH). This 22-item measure assesses parental perception of stressors, while their infant is being cared for in hospital.[22] The current study is believed to be the first study using PSS:IH with parents of infants with CHD who are still in hospital and those already discharged home (but remaining as cardiology outpatients), and it is yet to be validated for retrospective use. This provided the current study with an opportunity to compare parental stress reported by parents of both inpatient and outpatient infants, with results from studies underpinned by PSRCHD model

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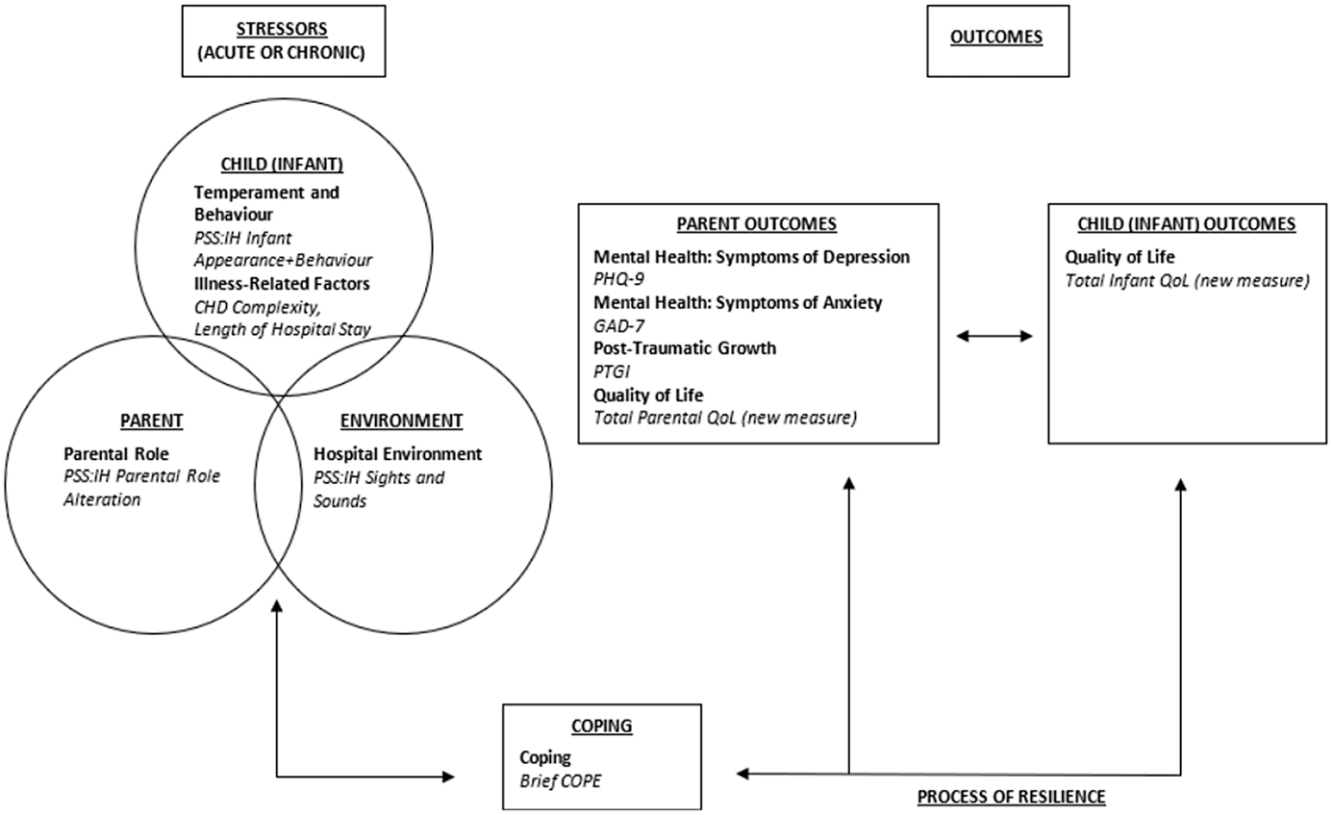

Figure 1. Study substruction of PSRCHD model with psychometric measures.

which only included parents of infants who were inpatients at time of study.[23,24] Alongside existing evidence for this measure's research suitability within this theoretical framework, it was deemed suitable to use PSS:IH for current sample given the frequency of hospital visits (outpatient and inpatient) typically required by cardiac patients in the early months of life.[2,25] PSS:IH subscales relate to infant (Infant Appearance and Behaviour, IAB), parental (Parental Role Alteration, PRA), and environmental stressors (Sights and Sounds, SAS). These subscales reflect respective constructs in PSRCHD model: child/infant (Temperament and Behaviour: PSS:IH IAB), parent (Parental Role: PSS:IH PRA) and environment (Hospital Environment: PSS: IH SAS). No clinical cut-off was developed for tool. Study used PSS: IH Total and three subscales above.

Parental coping styles were measured via Brief COPE. This 28-item measure assesses a broad range of coping responses, based in theory.[26] No clinical cut-off was designed for Brief COPE.[26] Recent studies have recommended to avoid Brief COPE's original 14 subscales, as each subscale is formed by only two items.[27] Further studies highlight three distinct "coping styles" underlying Brief COPE: PFC, EFC, and AC.[12,28] This study used these three composite coping styles, with the following Brief COPE subscales used, respectively, to calculate PFC (i.e. active coping, use of informational support, positive reframing, and planning), EFC (i.e. emotional support, venting, humour, acceptance, religion, and self-blame), and AC (i.e. self-distraction, denial, substance use, and behavioural disengagement). Parents reported on the coping strategies they used in the time they became aware (antenatally or postnatally) or their child's CHD, as confirmed through the following instruction regarding time frame: "*These questions ask about how you've been coping with the stress in your life since your child received a diagnosis of their heart condition.*"

Regarding outcomes, parental MH referred to symptoms of anxiety and depression. Symptoms of anxiety were assessed by Generalised Anxiety Disorder Assessment (GAD-7).[29] This seven-item self-report measure assesses symptoms of anxiety that align with DSM-V diagnostic criteria for Generalised Anxiety Disorder (GAD).[30] Study used Total GAD-7 score, with scores of 5, 10, and 15 representing cut-off points for mild, moderate, and severe anxiety, respectively, in line with standardised clinical cut-off points.[29] Symptoms of depression were assessed by Patient Health Questionnaire (PHQ-9),[31] which is a nine-item self-report measure of major depressive symptoms aligning with DSM-V diagnostic criteria.[30] Total PHQ-9 score was used, with scores of 5, 10, 15, and 20 representing cut-off points for mild, moderate, moderately severe, and severe depression, respectively, as per standardised clinical cut-offs.[31] GAD-7 and PHQ-9 have each been used to assess symptoms of anxiety and depression with parents of infants with CHD and other chronic illnesses.[32–34] Participants with GAD-7 or PHQ-9 responses above clinical cut-off (total score ≥10, or endorsement of risk to self on PHQ-9 final item) were contacted as per clinical risk protocol.

Parental PTG was assessed by Post-Traumatic Growth Inventory (PTGI).[35] This 21-item self-report measure assesses psychological growth after a traumatic event (i.e. parents' experience following child's CHD diagnosis), with higher scores indicating greater PTG levels. Previous research used PTGI to capture growth in parents following child's CHD diagnosis.[36] PTGI represents a five-factor structure with respective subscales: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life. No clinical cut-off was designed

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for tool, given that PTG construct reflects level of psychological growth and cannot infer clinical risk.[37] Study used PTGI Total in correlational and regression analyses, with summary psychometric details of PTGI Total and five subscales also provided.

Quality of life was measured for parents and infants. The WHOQOL-BREF quality of life assessment measure[38] was initially considered for study use, but it became clear from study questionnaire piloting that there were more aspects to parents QoL than that captured in a generic QoL measure that were key to QoL perception of parents of infants with CHD. There was also no clear QoL measure that had been used with the PSRCHD model, as many studies would instead focus on a specific aspect that may contribute to QoL, such as quality of relationship with partner, or financial satisfaction/strain.[18,39] A new measure was developed, following review of existing literature reflecting quantitative and qualitative accounts of parents' experienced quality of life as parents of children with CHD [7,8,40,41] and other congenital conditions.[42–46] This included additional factors that may influence parents' QoL, including their understanding of their child's medical condition and their satisfaction with paediatric clinical care.[8,40] A copy of our new QoL study measure is provided in Supplementary Figure S1 ("Quality of Life for Parents and their Children with CHD"). Nine QoL items were developed, employing a scale of 0–100 for each item, with higher scores indicating better QoL. Seven questions targeted parent QoL (self-report) and two questions targeted child QoL (parent report). Parent QoL questions referred to overall QoL, health-related QoL, perception of personal resilience (defined as "ability to cope"), level of understanding of child's CHD, satisfaction with cardiology care, financial satisfaction, and satisfaction with social support. For infants, parents reported on their perception of their child's overall QoL, and child's health-related QoL Total scores were computed for parents with complete data, where total parental QoL was based on the sum of seven parent-related items with total infant QoL derived from the sum of both infant-related items. Mean scores were calculated for both total scores, with the 0–100 score range maintained for the purpose of consistency across QoL measures. Psychometrics of QoL measures were tested for internal consistency, with minimum level set as Cronbach's alpha level of 0.50 or above, based on psychometric research guidance.[47,48] For parental QoL, Cronbach's alpha was 0.71 for all seven parental items, indicating a high level of internal consistency for the parental QoL measure. Corrected item-total statistics indicating that removal of one item would show marginal improvement: satisfaction with cardiology care (α after item deletion = .73); however, this still indicated high internal reliability of measure. Moreover, for the purposes of maintaining existing study design, alongside review of relevant CHD and paediatric literature, discussions with clinical staff and piloting with patients, it was agreed to retain all items and maintain high level of internal reliability. For infant QoL, Cronbach's alpha was 0.83, again indicating a high level of internal consistency (no corrected item-total statistics completed, given the two-factor structure). Results indicated the suitability of using the two total QoL variables as outcomes within study analyses: Total Parental QoL and Total Infant QoL

Open-ended questions were also completed by parents to reflect wider aspects of PSRCHD model; however, these qualitative data are not addressed in the current paper.

Statistical analyses

Analyses were completed with SPSS (v.27). Missing and extreme values were verified via original records and clarification from parents. Relationships between parental stress, coping, and parental outcomes were explored via Pearson's correlation analyses, with two-tailed α <0.05 considered statistically significant. Magnitude of effect sizes were calculated using Cohen's criteria for small (r = .10), medium (r = .30), and large (r = .50) effect sizes, respectively.[49] Hierarchical multiple regression analyses were conducted to examine predictive relationships between six predictor variables below and five outcomes (GAD-7, PHQ-9, PTGI, parent QoL, and infant QoL). Final predictive models comprised of one parental stress variable (PSS:IH total), three Brief COPE composites (PFC, EFC, and AC), and two clinical control variables (CHD complexity and length of hospital stay under cardiology care). Control variables were selected based on their previous recognition within research literature[2,8,21] and verified by preliminary analyses. Study aimed to recruit 150 families to allow for inclusion of all relevant variables in regression model; thus, the final sample size of 55 indicated that models were statistically underpowered, as per G*Power v3.1.9.7.[50] However, minimum of 50 participants required for regression analyses and number of cases per predictor variable was achieved.[51,52] A Bonferroni correction was used to adjust for multiple testing of variables within regression analyses. Based on six predictor variables, results of $p < 0.008$ were considered statistically significant for individual contribution of each predictor to final model. Significance level of predictive value of overall regression model for each outcome remained at α =.05.

Results

Participant characteristics

Final sample included 55 parents (42 mothers and 13 fathers) of 46 infants (9 infants had both parents participating). Following recruitment drive (including 167 letters sent), 60 parents responded (35.9%) of whom 55 completed study, showing a conversion rate of 92.7%. 96.4% of questionnaires were completed online, with 3.6% completed on paper. Mean age of parents was 36.77 years, and mean age of infants was 244.60 days, equivalent to approximately 8 months of age. Most parents identified as White Irish (87.7%), with 95.7% of families reporting English as primary language at home. Sample showed relatively high levels of education, with 85.4% of parents holding a university degree (Level 7 or higher). Fifty per cent families lived in areas of above average or below average SES, respectively. Full demographic profile is provided in Table 1.

Regarding clinical profile, infants spent an average of 21.26 days in hospital under cardiology care, with 82.6% infants requiring an ICU stay (maternity/paediatric hospital) and 78.3% infants requiring a stay on cardiac ward. Fifty per cent families received their child's CHD diagnosis antenatally, with 50% receiving postnatal diagnoses. A vast range of cardiac conditions were reported, with many infants having multiple diagnoses, as illustrated in Figure 2. 47.8% infants were reported to have simple CHD and 52.2% with complex CHD. Most children required one or more cardiac surgeries (80.4%), and 43.5% had additional medical conditions. Regarding parental clinical involvement, 23.6% parents reported to be accessing clinical support for their MH. Clinical profile of sample is outlined in Supplementary Table S2.

Psychometric descriptive data

Descriptive statistics are provided for parent' scores on all psychometric scales in Supplementary Table S3. For parental

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Table 1. *Demographic details for parents (n = 55), infants (n = 46), and families (n = 46)*

Demographic variables	*n*	%	Mean (SD)
Parent demographics (*n* = 55)			
Parent age (years)[a]			
Total sample	55	100%	36.77 (4.56)
Parent gender			
Mothers	42	76.4%	36.82 (4.37)
Fathers	13	23.6%	36.61 (5.32)
Relationship status			
Single	1	1.8%	
In a relationship (not married)	16	29.1%	
In a relationship (married)	38	69.1%	
Employment			
Yes, full-time	14	25.5%	
Yes, currently on leave (maternity/paternity/parental/other)	37	67.3%	
No	4	7.3%	
Education level			
Leaving certificate (Level 4/5)	3	5.5%	
Third-level certificate (Level 6)	5	9.1%	
Ordinary bachelor degree (Level 7)	8	14.5%	
Honours bachelor degree/higher diploma (Level 8)	18	32.7%	
Master's degree/postgraduate diploma (Level 9)	20	36.4%	
Doctoral degree/PhD (Level 10)	1	1.8%	
Country of origin[b]			
Republic of Ireland	47	85.4%	
Northern Ireland	3	5.5%	
Other	5	9.1%	
Ethnicity			
White Irish	48	87.3%	
Any other White background	4	7.3%	
Asian or Asian Irish	2	3.6%	
Other – including mixed race background	1	1.8%	
Mode of questionnaire completion			
Online	53	96.4%	
Paper	2	3.6%	
Infant demographics (*n* = 46)			
Number of parents responding for infant			
One parent	37	80.4%	
Both parents	9	19.6%	
Infant gender			
Female	18	39.1%	
Male	28	60.9%	
Infant age (days)[a]			
Total sample	46	100%	244.60 (93.45)

(*Continued*)

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Table 1. (*Continued*)

Demographic variables	*n*	%	Mean (SD)
Gestational age (at time of birth, in days)			
Total sample	46	100%	269.26 (14.18)
Preterm birth[c]			
Yes	6	13.0%	
No	40	87.0%	
Birth delivery mode			
Vaginal	17	37.0%	
Caesarean – planned	14	30.4%	
Caesarean – emergency	8	17.4%	
Instrumental – vacuum	6	13.0%	
Instrumental – forceps	1	2.2%	
Family demographics ($n = 46$)			
Infant with siblings			
Yes	15	32.6%	
No (only child)	31	67.4%	
Total number of children in family[d]			
One (infant with CHD)	15	32.6%	
Two	13	28.3%	
Three	13	28.3%	
Four to six	5	10.8%	
English spoken as main language at home[e]			
Yes	44	95.7%	
No	2	4.3%	
Socio-economic status (SES) proxy indicator[f]			
Low	8	17.4%	
Low average	15	32.6%	
High average	14	30.4%	
High	9	19.6%	

[a]Parent and infant age at time of parental questionnaire completion.
[b]Parents were asked "What country are you from?" with the options of Republic of Ireland, Northern Ireland, or Other (open-ended text provided). Five parents reported their country of origin as "Other." To protect identifiability, names of countries were excluded from final dataset and categorised by continent instead: Europe ($n = 2$) and Asia ($n = 3$). All participating parents/infants were living on the island of Ireland at time of participation.
[c]Premature birth is defined as infants born alive before 37 weeks of pregnancy (i.e. < 37 weeks gestational age).
[d]Number of children in family includes twins, half-siblings, and step-siblings. In all cases, the infant with CHD was the youngest member of the family.
[e]Two families reported to use another main language at home: Hindi and Arabic/Urdu.
[f]Socio-economic status was represented as a proxy indicator, by referencing official census based records for the small area data corresponding to families' address on the island of Ireland, via the Pobal index from 2016 Irish Census data (Pobal, 2017), or 2017 Northern Ireland Multiple Deprivation Measures (Northern Ireland Statistics and Research Agency, 2017). Indexes were merged and ranked on a scale of 1–8 (1=Extremely low SES, 2=Very low SES, 3=Low SES, 4=Marginally below average SES, 5=Marginally above average SES, 6=High SES, 7=Very high SES, 8=Extremely high SES). Given that most scores lay in the middle four categories (one family in "very low" range), these were recategorised into four categories: low, low average, high average, and high. This method has been recommended for estimating socio-economic data based on demographic data per living areas in Ireland [64].

stress (PSS:IH total, *mean* = 2.97), parents reported highest stress from IAB subscale (*mean* = 3.35), followed by PRA (*mean* = 2.97) and SAS (*mean* = 2.42). Highest endorsed Brief COPE coping style was PFC (*mean* = 2.50), followed by EFC (*mean* = 2.25) and AC (*mean* = 1.47). Parents had a mean score of 6.36 on GAD-7 and mean score of 6.05 on PHQ-9, with 25.5% and 21.8% parents falling in clinical ranges for symptoms of anxiety and depression, respectively. For PTG subscales (PTGI total *mean* = 53.71), highest scores were found for Appreciation of Life (*mean* = 3.32) with lowest scores reported on Spiritual Change (*mean* = 1.30). Total Infant QoL (*mean* = 83.15) was higher than Total Parental QoL (*mean* = 80.95). Highest rated QoL item was Satisfaction with Cardiology Care (*mean* = 91.87), with lowest scores for Financial Satisfaction (*mean* = 68.46).

Correlational analyses

Full correlational matrices are provided in Supplementary Tables S4–S6. For MH outcomes, a medium positive correlation was found between GAD-7 Total and PSS:IH SAS ($r = 0.308$, $p = .024$).

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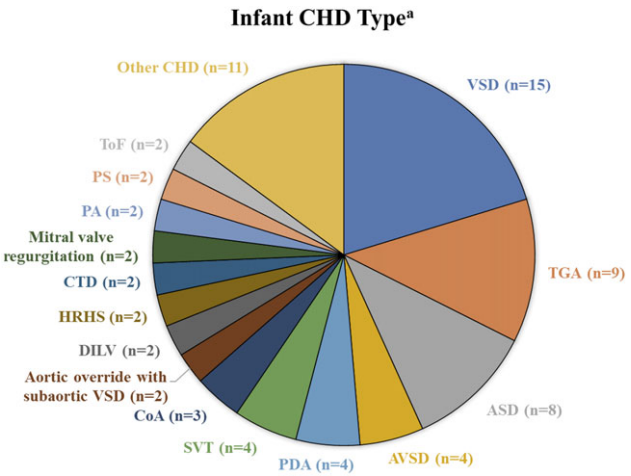

Figure 2. Infant diagnoses of CHD and cardiac condition. [a]At least one CHD diagnosis per infant, with some infants having received diagnoses of multiple CHDs or cardiac conditions. Cardiac conditions included ventricular septal defect (VSD, $n = 15$), transposition of the great arteries (TGA, $n = 9$), atrial septal defect (ASD, $n = 8$), atrioventricular septal defect (AVSD, $n = 4$), patent ductus arteriosus (PDA, $n = 4$), supraventricular tachycardia (SVT, $n = 4$), coarctation of the aorta (CoA, $n = 3$), aortic override with subaortic VSD (n = 2), double-inlet left ventricle (DILV, $n = 2$), hypoplastic right heart syndrome (HRHS, $n = 2$), cor triatriatum dexter (CTD, $n = 2$), mitral valve regurgitation (n = 2), pulmonary atresia (PA, $n = 2$), pulmonary stenosis (PS, $n = 2$), and tetralogy of fallot (ToF, $n = 2$). [b]Other CHD: anomalous left coronary artery from pulmonary artery (ALCAPA), aortic stenosis (AS), complete heart block, dilated aortic root, double-outlet right ventricle (DORV), dysplastic pulmonary valve, single mitral valve, aortic valve regurgitation, patent foramen ovale left-to-right shunt, Shone's complex, Taussig–Bing syndrome (each $n = 1$).

Regarding parental coping, AC showed a medium positive correlation with GAD-7 Total ($r = 0.377$, $p = .005$) and PHQ-9 Total ($r = 0.380$, $p = .004$). EFC showed a medium positive correlation with GAD-7 total ($r = 0.367$, $p = .006$) and a small positive correlation with PHQ-9 total ($r = 0.279$, $p = .039$). No other significant correlations were found for parental stress or coping scores with MH outcomes.

PTGI Total had a medium positive correlation with PSS:IH Total ($r = 0.406$, $p = .002$), PRA ($r = 0.381$, $p = 0.004$). IAB ($r = 0.362$, $p = .007$), and SAS ($r = 0.355$, $p = .008$). For parental coping, PFC showed a small positive correlation with PTGI total ($r = 0.283$, $p = .036$). EFC held a medium positive correlation with PTGI total ($r = 0.353$, $p = .008$). No significant correlation was found for AC and PTGI total.

Three parental stress scores showed medium negative correlations with Total Parental QoL; PSS:IH total ($r = -0.342$, $p = .020$), PRA subscale ($r = -0.338$, $p = .021$), and SAS subscale ($r = -0.377$, $p = .010$). No parental stress score was related to Total Infant QoL. For parental coping, PFC showed a small negative correlation with Total Infant QoL ($r = -0.293$, $p = .030$). EFC had a medium negative correlation with Total Parental QoL ($r = -0.403$, $p = .005$). AC had a had a medium negative correlation with both Total Parental QoL ($r = -0.420$, $p = .003$) and Total Infant QoL ($r = -0.395$, $p = .003$).

Regression analyses

Hierarchical multiple regression analyses were conducted for all five outcome variables (GAD-7 Total, PHQ-9 Total, PTGI Total, Total Parental QoL, and Total Infant QoL). In each hierarchical model, two clinical variables were entered first as controls (length of hospital stay and CHD complexity), as selected following preliminary analyses outlined in Supplementary Table S7. This was followed by PSS:IH and finally three coping styles (PFC, EFC, and AC). Final regression models are outlined in Table 2.

For GAD-7 Total, final model explained 22.9% of variance in scores which was statistically significant ($R^2 = 0.229$, Adjusted $R^2 = 0.130$, $F(6, 47) = 2.321$, $p = .048$). Using adjusted alpha value from Bonferroni correction ($\alpha = .008$), no predictor variable made a significant unique contribution to final model. For PHQ-9 Total, final model explained 22.2% of variance but fell marginally above significance level for predicting scores ($R^2 = 0.222$, Adjusted $R^2 = 0.123$, $F(6, 47) = 2.239$, $p = .056$). No variable made a significant individual contribution in final model. For PTGI Total, final model accounted for 30.4% variance in scores which was significant ($R^2 = 0.304$, Adjusted $R^2 = 0.215$, $F(6, 47) = 3.423$, $p = .007$), but no variable made significant unique contributions. For Total Parental QoL, final model explained 38.1% which was significant ($R^2 = 0.381$, Adjusted $R^2 = 0.285$, $F(6, 39) = 3.995$, $p = .003$), but no variable held significant individual contributions in final model. For Total Infant QoL, the statistically significant final model explained 53.8% variance in scores ($R^2 = 0.538$, Adjusted $R^2 = 0.479$, $F(6, 47) = 9.134$, $p < .001$). One variable made a significant unique contribution to final model, length of hospital stay (standardised beta = -0.687, $p < .001$).

Discussion

This observational cross-sectional study aimed to explore relationships between parental stress, coping, and psychological outcomes in parents of infants with CHD. Final sample of 55 parents (46 infants) was smaller than initial aim of 150 participants. However, the estimated 36% participation rate from eligible parents is comparable to another CHD parent study with an enrolment rate of 20%.[24] While the final sample showed evenness across socio-economic status backgrounds, many ethnic groups and education levels were not represented. Clinical data provided relative consistency across antenatal/postnatal diagnoses and CHD complexity; however, considerable heterogeneity was found across cardiac conditions and surgeries; thus, caution should be taken in interpretation.

The use of PSS:IH in current study reflects parental reports of their parental stress when their child was in hospital, which included children who had been discharged home (but remained outpatients) and children still in hospital as inpatients. Whilst there are no known comparable studies of parents retrospectively reporting on parental stress from their child's hospitalisation, the current results of PSS:IH were comparable to that from other studies with parents of babies with CHD who were still hospitalised at time of study. Specifically, while overall results were lower than studies conducted with inpatients only, current results showed that parental stress was again highest for IAB subscale, followed by PRA and SAS.[24,53] The comparable lower results may reflect a confounding influence of parental memory recall, given that parents' reports on parental stress covered a range of 0–12 months post-discharge for their child. Nevertheless, these findings build understanding of parental stress for CHD population across inpatient and outpatient settings; in that, parental stress may be particularly heightened when parents see their baby in distress and are unable to comfort them.

The highest scoring Brief COPE subscale was PFC, followed by EFC and finally AC. While there are no comparable results in CHD population, other adult studies showed same sequence, with PFC as highest rated coping style.[28] This provides preliminary evidence

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Table 2. Final hierarchical multiple regression models with predictors of parental outcomes

Parental outcome	Predictor variables	Standardised beta	*p*-Value
GAD-7 Total			
	Clinical Factors (Controls)		
	CHD Complexity	0.017	0.918
	Length of Hospital Stay under Cardiology	−0.022	0.887
	Parental Stress (PSS:IH)		
	PSS:IH Total	0.059	0.696
	Coping Styles (Brief COPE)		
	Problem-Focused Coping	−0.183	0.229
	Emotion-Focused Coping	0.348	0.042*
	Avoidant Coping	0.281	0.058
PHQ-9 Total			
	Clinical Factors (Controls)		
	CHD Complexity	−0.071	0.663
	Length of Hospital Stay under Cardiology	−0.038	0.806
	Parental Stress (PSS:IH)		
	PSS:IH Total	0.039	0.795
	Coping Styles (Brief COPE)		
	Problem-Focused Coping	−0.245	0.110
	Emotion-Focused Coping	0.248	0.144
	Avoidant Coping	0.343	0.022*
PTGI Total			
	Clinical Factors (Controls)		
	CHD Complexity	0.128	0.409
	Length of Hospital Stay under Cardiology	−0.016	0.912
	Parental Stress (PSS:IH)		
	PSS:IH Total	0.350	0.017*
	Coping Styles (Brief COPE)		
	Problem-Focused Coping	0.132	0.361
	Emotion-Focused Coping	0.335	0.039*
	Avoidant Coping	−0.177	0.203
Total Parental QoL			
	Clinical Factors (Controls)		
	CHD Complexity	0.201	0.215
	Length of Hospital Stay under Cardiology	−0.340	0.032*
	Parental Stress (PSS:IH)		
	PSS:IH Total	−0.191	0.201
	Coping Styles (Brief COPE)		
	Problem-Focused Coping	0.045	0.763
	Emotion-Focused Coping	−0.258	0.122
	Avoidant Coping	−0.204	0.159
Total Infant QoL			
	Clinical Factors (Controls)		
	CHD Complexity	0.217	0.090

(*Continued*)

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Table 2. (*Continued*)

Parental outcome	Predictor variables	Standardised beta	*p*-Value
	Length of Hospital Stay under Cardiology	−0.687	< 0.001***
	Parental Stress (PSS:IH)		
	PSS:IH Total	0.234	0.048*
	Coping Styles (Brief COPE)		
	Problem-Focused Coping	−0.249	0.038*
	Emotion-Focused Coping	0.125	0.335
	Avoidant Coping	−0.284	0.015*

*Significant correlation found (*p*-value < .05).
**Significant correlation found (*p*-value < .01).
***Significant correlation found (*p*-value < .001).

for coping styles employed by parents of infants with CHD, where all three styles seem to play a role in coping with CHD-related scenarios. Twenty-six per cent parents scored in clinical range for symptoms of anxiety (GAD-7 total), with 22% scoring in clinical range for symptoms of depression (PHQ-9 total). Results are in line with research with parents of babies with CHD, where 25–51% reported clinically significant anxiety symptoms[54,55] and 20–48% reported clinically significant depression symptoms.[24,54,56] However, current scores were at lower end of these ranges, and almost in line with general Irish population (20% adults in GAD-7 clinical range, 23% in PHQ-9 clinical range),[57] which may reflect a degree of under-reporting difficulties. Moreover, while 24% parents reported accessing personal MH support, this figure did not account for parents who reported an intention to access support but were unable to do so, thus minimising true figure of parents seeking MH support. PTGI results reflects recent research with CHD parents,[36] with variation across subscales supporting PTG outcome theory;[37] in that, CHD parental coping may be both restorative and transformative, whether negatively (increased MH symptoms) or positively (increased PTG). Finally, newly created measures for Total Parental QoL and Total Infant QoL showed good internal consistency, with higher perceptions of QoL held for child (*mean* = 83.15%) than for parents themselves (*mean* = 80.95%). Results may reflect an adaptive coping style for parents, consciously or unconsciously, to perceive their baby as doing well relative to themselves, as a means of developing hope in baby's favourable health prospects. Alternatively, results may indicate how parents' exposure to considerable acute and chronic stress during these months may impact negatively on their overall QoL and may intensify with increased prioritisation of baby's needs over their own.[41]

For correlational analyses, only one parental stress variable was linked to MH, with a medium positive correlation found between GAD-7 and PSS:IH SAS. While this evidenced the link between environmental factors and parental anxiety, the lack of other significant correlations provides insufficient support for hypothesis. For parental coping, EFC showed small and medium positive correlations with GAD-7 and PHQ-9 totals, respectively, with AC holding medium positive correlations with both MH outcomes and PFC not correlated to either MH outcome. Conflicting evidence was thus provided for hypothesis, with indications that mechanisms involved in AC and EFC may be more critical than PFC in understanding parents' MH outcomes. It is possible that parents of infants with CHD may depend on AC or EFC styles to manage increased anxiety and depressive symptoms, or that parents are more primed to identify or develop MH symptoms following prolonged use of avoidance or emotion-focused styles in CHD-related scenarios. The conflicting results could also suggest that coping may act as a moderator between other factors (e.g. parental stress and parental mental health), but it was not possible to confirm this within current exploratory analyses. Overall, results highlight the relative importance of coping styles over parental stress in understanding parents' MH outcomes, with potential to modify and encourage adaptive coping styles to better support management of anxiety and depression symptoms.[15]

For PTG outcomes, PSS:IH Total and all subscales were related to various PTG subscales, with small to medium positive correlations falling in line with hypothesis, thus highlighting potential for CHD parents' transformative growth whilst managing parental stress. PFC and EFC showed small-medium positive correlations with several types of PTG; however, no significant correlation was found between AC and any PTGI score. This conflicting evidence for hypothesis suggests that AC-related disengagement from scenarios may not allow for personal growth, whilst more interactive PFC and EFC styles may target stress management whilst also creating opportunities for personal growth.

A new QoL measure was used for this study ("Quality of Life for Parents and their Children with CHD"), to best reflect the breadth of diverse factors that can influence QoL for parents and their infants with CHD. While our newly constructed measure of parental QoL (7 items) and infant QoL (two items) each had high internal consistency, it is acknowledged that the construct may reflect more than QoL in itself and would benefit from further qualitative and qualitative review. Regarding current study results with QoL measures, all parental stress scores (apart from IAB) showed medium negative correlations with Total Parental QoL; however, no parental stress score was related to Total Infant QoL. In contrast, EFC and AC had medium negative correlations with Total Parental QoL, while AC and PFC had medium and small negative correlations with Total Infant QoL, respectively. Results suggest that coping styles are more central in accounting for parental perceptions of infants' QoL, despite these negative correlations being counter to positive direction hypothesised. Nevertheless, these results may build understanding of parents' experiences; where for infant QoL, prolonged PFC may lead to parental frustration given that their infant's well-being may not be directly under their active control, leading them to feel disempowered. Furthermore, parents may use EFC to manage their personal distress when unable to actively support their own

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parental QoL whilst caring for their baby. Finally, increased AC may reflect parents' capacity to evade distress arising from their altered life and their child's early-life experiences.

Hierarchical multiple regression analyses indicated that four outcomes (GAD-7, PTGI total, Total Parental QoL, and Total Infant QoL) were successfully predicted by final models, as hypothesised. Final models comprising of total parental stress, coping styles, and clinical control variables, accounted for 22.2–53.8% variance across all five outcome scores (adjusted variance 12.3–47.9%). Final model was marginally above significance for predicting PHQ-9 scores, which may reflect underpowered analyses due to sample size. Based on conservative alpha value from Bonferroni correction, the four target predictor variables (PSS:IH, PFC, EFC, and AC) did not have significant individual contributions for any outcome. However, if the standard 0.05 α value was retained, each target predictor would have at least one significant individual contribution to parental outcomes, thereby suggesting the benefit of revisiting these analyses in future high-powered studies. For clinical controls, results indicate significance of length of cardiac-related hospital stay in predicting Total Infant QoL, whereas CHD complexity did not offer significant individual contributions to any final model. This encourages consideration of chronicity over acuteness for length of hospital stays, and echoes literature suggesting lesser importance of cardiac-related factors in predicting outcomes.[4]

Theoretical, empirical, and clinical relevance

This study represented the first opportunity to apply a conceptual model of parental stress and coping to understand psychological outcomes of parents of infants with CHD across their first 12 months of life. From a theoretical perspective, results indicated how endorsement of each coping style does not necessarily indicate whether a parent is "coping well" or not, but instead reflected their quasi-dispositional styles and preferences towards specific strategies to manage stressful situations.[11] Study added evidence in support of PTG's place within PSRCHD model, adding a more dimensional view of parental outcomes and challenging traditional deficit-focused conceptualisations of post-traumatic impacts on parental resilience.[58] Regarding empirical implications, results support relevance of PSRCHD model in contextualising parental, child, and environmental domains that apply for CHD parents in this time frame, where parental stress, coping styles, and clinical variables together account for variance in outcomes across anxiety, PTG, parental QoL, and infant QoL. The study provided a baseline of parental outcomes that may be used for longitudinal follow-up over childhood, with an opportunity to introduce self-report outcome assessments for older children with CHD. From a clinical perspective, results highlight a significant need for cardiology staff to assess parental MH during first year of their baby's life and provide appropriate clinical support within this window. Our substruction of PSRCHD model highlights the utility of this model, with current results demonstrating how PSRCHD may be used as a framework for clinical psychologists to formulate with parents around what impacts their psychological well-being, based on parental stress domains and coping styles. Future research offers the opportunity to validate the whole PSRCHD model with this population. Given significant variance in parental and infant QoL outcomes accounted for by parental stress and coping styles, it would be valuable to include similar measures as part of parental screening in paediatric cardiology services, to help tailor parent interventions,[2,59] and to potentially form part of infant neurodevelopmental follow-up programmes.[6,8,60–62]

Limitations

The retrospective exploratory design acts as a key limitation of this study. First, the impact of parental memory bias was not controlled across participants whose children were still in hospital and those who had not had a hospital stay for up to 12 months before data collection. Furthermore, the use of retrospective design with regression analyses implied that results around variable relationships within PSRCHD model remained exploratory and observational, with no further conclusions to be drawn regarding potential causal relationships or their direction. There was limited opportunity to explore the reasons for the conflicting findings between the correlations and final models, or indeed whether some predictor variables may play a different role (e.g. coping as a moderator between parental stress and parental mental health). Moreover, we did not have baseline data for parents' mental health symptoms or pre-diagnosis coping styles; therefore, the influence of coping on mental health symptoms over time could not be determined. Nevertheless, current correlational results would indicate value in designing future prospective longitudinal research studies that could determine change over time. It is clear that that more sophisticated analyses are needed to understand the complex relationships between stress, coping, mental health, PTG, and QoL. Further refinement of PSRCHD model may involve investigating moderator and uni/bidirectional causal relationships between variables. Structural equation modelling with future datasets could provide an opportunity to identify model pathways, in line with recommended statistical approaches for theoretically informed CHD datasets,[16] which may in turn help explain the current results.

There were several limitations relating to data collected for each variable. It was not possible to gain clinical data relating to total number of cardiology patients eligible for this study; therefore it was not possible to ascertain whether the parents who responded, and were recruited, were a representative sample of total population eligible for this study. Given sample size and insufficient statistical power, it was not possible to stratify results based on demographic or clinical variables, despite growing evidence for impacts of social determinants on outcomes for families of children with chronic illness.[6] Similarly, the sample size and statistical power were insufficient to allow for control of potential association of parental scores for the nine infants with both parents responding. Heterogeneous CHD diagnoses were accounted for by avoiding constraint upon individual diagnostic categories and categorising via complexity, cyanotic status, and ventricular status; however, the idiosyncrasies of individual diagnoses were lost, thereby indicating limited generalisation of results to specific CHD diagnoses. QoL results should be considered with caution, given that this is the first use of this parent and infant measure in an empirical research study. Whilst both measures have high internal consistency, it is acknowledged that construct validity of parental QoL may need further review and that certain items in QoL measure may be more suited as part of another construct of PSRCHD model or used solely within qualitative research (e.g. satisfaction with cardiology care). We did not wish to redesign the study measures post hoc, as it would invalidate our planned study design. It is anticipated that future research may use our new measure to build understanding of how to fully capture parents' realm of experiences, including areas

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already highlighted empirically as central to the overall QoL of these parents and their infants with CHD.

Finally, we recommend caution around the generalisability of these results to all caregivers of infants with CHD. Results build existing understandings of maternal and paternal CHD parenting experiences but cannot be generalised to extended family members or other caregivers. Future research may benefit from person-centred methods to capture the range of CHD parenting and caregiver experiences, as modelled by recent research using multi-sensory methods to explore adjustment in mothers of premature babies.[63]

Conclusion

This observational study outlined how parental coping styles and parental stress play important roles in understanding psychological outcomes in parents of infants with CHD, including MH, PTG, and QoL. Clinical factors play a role, with poorer parental outcomes positively related to infants' longer hospital stays, but not to CHD complexity. There is clear empirical and clinical value in employing psychometric assessments with parents within this initial 12-month time frame. It is evident that the PSRCHD model remains highly relevant as a theoretical framework for conceptualising study design with parents and their children with CHD, thus providing an important opportunity to continue building our understanding of this population. Continued parent engagement would help refine theoretical knowledge and encourage meaningful translation to service provision, thereby improving parental support during early stages of their baby's cardiac journey.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S104795112402568X.

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Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by Research Ethics Committee of Children's Health Ireland (08/03/2022) and by the School of Psychology Research Ethics Committee at Trinity College Dublin (03/05/2022). Informed consent was obtained from all patients in accordance with the university hospital policies.

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