




Traumatic stress in parents of children with congenital heart disease: a scoping review

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Review

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Abstract

Congenital heart disease is the most common birth defect in the United States, with many of the affected infants requiring surgical and/or interventional procedures within their first year of life. The parental impacts of a child's diagnosis, subsequent hospitalization, and transition to home after discharge are numerous and burdensome, and many experience symptoms of traumatic stress along this trajectory. The purpose of this scoping review was to summarize current available literature related to the traumatic stress experienced by parents of children with heart disease to better understand the prevalence, related factors, and consequences. The Joanna Briggs Institute Scoping Review Framework was implemented to identify 31 relevant peer-reviewed articles published between 2000 and early 2024, including 25 quantitative studies, 3 qualitative studies, and 3 systematic reviews or meta-analyses. This scoping review provides an overview of parent traumatic stress for clinicians caring for children with heart disease at every stage of their clinical course.

Congenital heart disease (CHD) is the most common birth defect in the United States, affecting approximately 40,000 (1%) live births each year, and 25% of these infants are born with critical heart disease requiring surgical and/or interventional procedures during their first year of life.¹ While advances in medical and surgical care have dramatically improved survival rates for infants and children with critical CHD, the psychological impact on parents managing long hospitalizations, uncertain outcomes, multiple procedures and appointments, and high medication burdens is concerning. Parents of children with CHD are at risk for mental health disorders, including depression, anxiety, and traumatic stress.²

Traumatic stress is the most prevalent form of psychological distress experienced by parents of children with heart disease.^{2–4} Symptoms of traumatic stress have been reported at the time of diagnosis, during the hospitalization, and after discharge.^{2,3} Thus, it is important for clinicians who interact with parents during all phases of care to understand the prevalence of and factors associated with traumatic stress. Early recognition of traumatic stress is essential to trigger additional support. This scoping review summarizes the current literature related to prevalence, related factors, and consequences of traumatic stress in parents of children with CHD. Gaps in knowledge and opportunities for future research are discussed.

Definition of traumatic stress

Trauma can be defined as “sets of circumstances that represent significant challenges to the adaptive resources of the individual and that represent significant challenges to the individual's way of understanding the world and their place in it.”⁵ Traumatic medical events involving a child may trigger post-traumatic stress symptoms (PTSS) in parents, including re-experiencing, avoidance, and hyperarousal. Re-experiencing or thinking about the traumatic event can help with processing; however, flashbacks or nightmares may be intrusive or distressing and feel like one is reliving the trauma. Avoidance may be characterized as trying to stop thoughts or conversations about the trauma and may manifest new worries and fears. Additionally, while a new sense of caution may be appropriate after a traumatic event, these new fears and anxieties can be problematic if they interfere with daily life. Hyperarousal refers to an altered stress response, such that the response to a stimulus may be exaggerated and lead to physical symptoms of stress.^{6–7} Symptoms of traumatic stress may meet diagnostic criteria for acute stress disorder (ASD) or post-traumatic stress disorder (PTSD).⁸ ASD describes traumatic stress symptoms lasting up to 1 month after the traumatic event, whereas PTSD describes symptoms that last more than 1 month after the traumatic event.⁹

Materials and methods

Framework

The Joanna Briggs Institute Scoping Review Framework was selected because of its detailed guidance, inclusiveness of qualitative research, and alignment with the Preferred Reporting

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Items for Systematic Reviews and Meta-Analyses—Extension for Scoping Reviews (PRISMA-ScR).¹⁰ Accordingly, the following steps were taken: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting results.

Identifying the research question

The research team and a clinical librarian developed a protocol and research purpose to explore, “what is known about the prevalence, related factors, and consequences of traumatic stress in parents of children with heart disease?”

Identifying relevant studies

PubMed, PsycInfo, and Scopus databases were searched for relevant publications between 2000 and early 2024. Search terms used in PubMed were parent (mesh) and heart defects, congenital (mesh) and traumatic stress (tiab) or stress disorders, traumatic, and acute (mesh). PsychInfo search terms were parents or caregivers or mother or father or parent and CHD or cardiac defect or heart defect or CHD and traumatic stress or PTSD or ASD. Scopus search terms were congenital and heart and disease and parent and traumatic and stress or acute and stress and disorder.

This review included clinical trials, qualitative studies, and systematic reviews with samples that included parents of children with heart disease and measures or descriptions of traumatic stress. Exclusion criteria included studies of parents of children with exclusively non-cardiac illnesses or injuries, children with heart disease, adult patients with heart disease, and those that did not specifically examine traumatic stress. Bibliographies were also reviewed to find other relevant references. All publications were managed in Covidence.

Study selection and data abstraction

This search yielded 1492 studies. After 218 duplicates were removed, the title and abstract were screened on 1274 articles. Of the 1274 studies screened, 54 were included in the full-text review, and 11 were excluded for the wrong outcomes and 12 for the wrong patient population. Thirty-one articles were included in the final review. See Figure 1 for the PRISMA diagram of this process. One reviewer conducted the study selection and abstraction.

Results

The articles ($n = 31$) were published between 2000 and early 2024, with 14 published since 2020. Twenty-five were clinical trials, three were qualitative studies, and three were review studies (see Table 1–3). Of the three review papers included, one published by Woolf-King and colleagues in 2017 focused specifically and exclusively on the mental health outcomes of parents of children with heart disease.² This review cited five studies that focused specifically on traumatic stress and those were also included in this review. Two other review papers were included because their samples included parents of children with heart disease, one focused on parents of children with chronic physical illness and the other on parents of children following paediatric surgery.^{11,12}

Prevalence

Traumatic stress symptoms have been identified in 25–88% of parents at the time of diagnosis of CHD.^{13,14} Rychik and colleagues

found that 39% of pregnant mothers had PTSS after fetal diagnosis of CHD. Another study found that 85% of parents had PTSS 4 weeks after the diagnosis and 27.3% continued to have PTSS 4 months after diagnosis.⁴ In a mixed methods study of 29 parents, 88% of mothers and 66% of fathers developed PTSD after prenatal diagnosis of hypoplastic left heart syndrome (HLHS), and 100% of mothers and 75% of fathers experience PTSD after postnatal diagnosis of HLHS.¹⁵

After their child's cardiac surgery, 83% of parents endorsed at least one symptom of traumatic stress, with mothers reporting higher levels of traumatic stress symptoms than fathers.³ After the Norwood operation, 50% of mothers and 39% of fathers experienced PTSD.¹⁶ In other reports, ASD was reported in 25% of parents 3–4 weeks after their child's cardiac surgery.^{17,18}

Two studies found that 25% of parents met the criteria for PTSD at the time of hospital discharge.^{18,19} Other studies report 16–17% of mothers and 6–13% of fathers meet the criteria for PTSD at the time of hospital discharge.^{20–22} In one report, all parents of infants with single ventricle anatomy between Stage 1 and Stage 2 operations were noted to have PTSS at the time of discharge.¹⁹ One month after discharge, 33% of mothers and 18% of fathers had ASD.³ Three months after surgery, 19% of parents reported PTSS.²³ Bainton and colleagues found that the prevalence of PTSD in parents of infants with single ventricle heart disease decreases in mothers (50–27%) and fathers (39–24%) between the Norwood operation and 16 months of age. PTSD lasting greater than 4 months was found in 9–25% of all parents of children with heart disease (see Table 1).^{24–27}

Stressors and symptoms

Lisanti *et al.* found that 3 months after discharge, postnatal diagnosis and parental role alteration predicted PTSS, as well as anxiety and depressive symptoms.²³ In their qualitative descriptive study, Harvey *et al.* described six themes extrapolated from mother's journal entries related to stress, including feeling intense fluctuating emotions, navigating the medical world, dealing with the unknown, facing the possibility of a child dying, finding meaning and spiritual connection, and mothering through it all.²⁸ These themes overlap with some of the themes described by Kosta *et al.* in their qualitative study exploring parental experiences after their infant's cardiac surgery. These themes include uncertainty, structural and systemic issues related to the microenvironment within the unit and macro-environment within the hospital, relationships with staff, social networks, communication of important information, and individual coping strategies.²⁹ Consistent with Harvey *et al.*, Cantwell-Bartl *et al.* found that the main stressor for parents was fear of their child dying.¹⁵ Other stressors described by Cantwell-Bartl and colleagues were the appearance of their child, ICU environment, hearing about their child's poor prognosis and/or complications, and witnessing another child's death (see Table 3).

Few studies reported on the prevalence of specific symptoms of traumatic stress; however, Bainton *et al.* found that intrusive thoughts and hyperarousal symptoms were the most commonly reported symptoms among parents.¹⁶ Another study found that receiving a prenatal diagnosis compared to a postnatal diagnosis increased the likelihood of avoidance symptoms of mothers and fathers and hyperarousal symptoms in fathers.³

Demographic factors associated with traumatic stress

Both mothers and fathers experience high levels of stress related to their child's diagnosis, surgery, and recovery; however, more mothers experience PTSS than fathers.^{2,16,20–22,15,30,31} (see Table 1) Mothers also experienced higher levels of PTSS.^{3,30,31} Golfenshtein

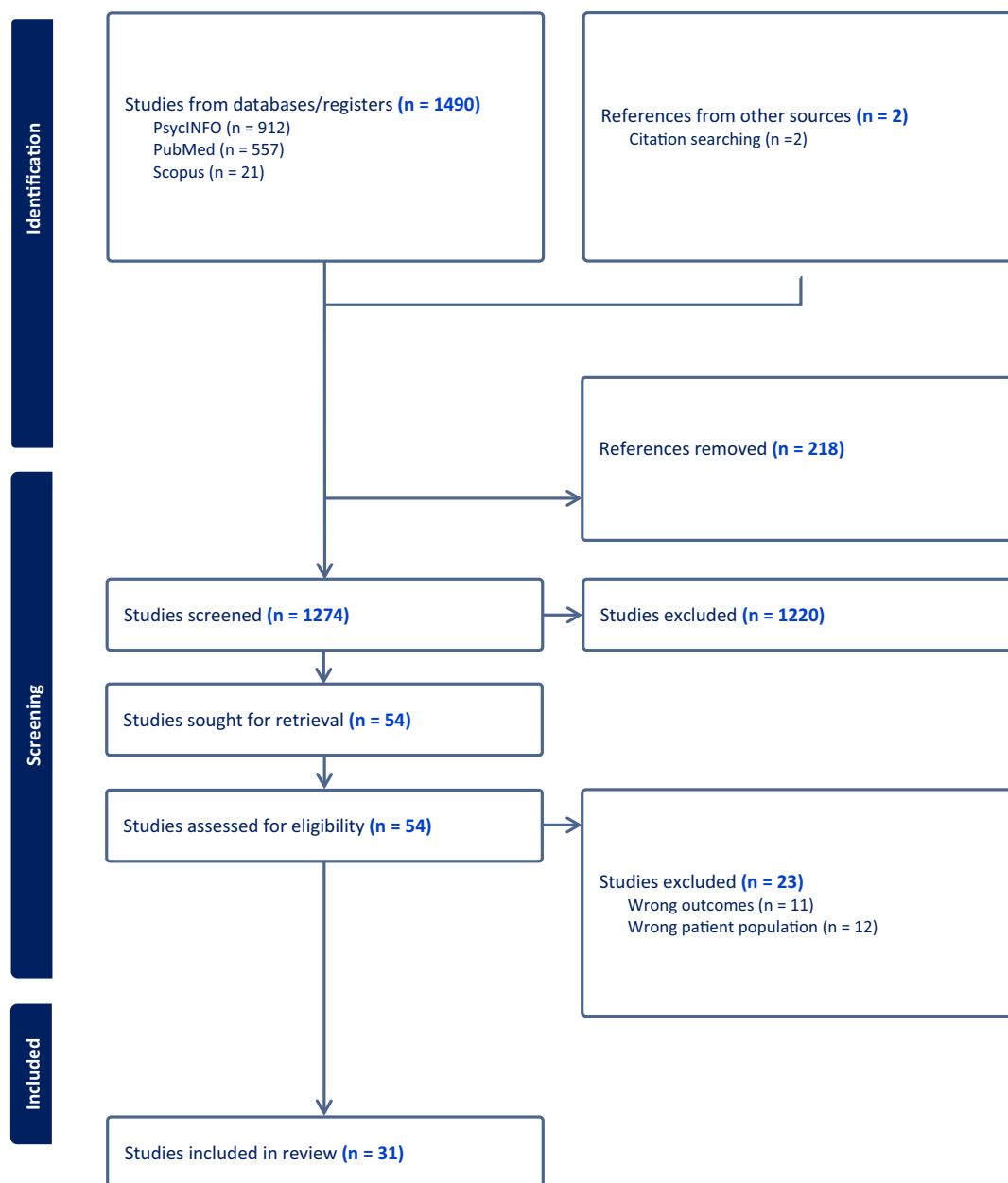


Figure 1. Flowchart of PRISMA diagram depicting the literature review and inclusion process.

and colleagues reported that at the time of hospital discharge, the number of PTSS was associated with parent education and insurance, and 4 months later, the severity of PTSS and PTSD was predicted by ethnicity and number of children in the household, respectively.⁶ Mothers of very young children were also found to have higher levels of stress (see Table 1).²⁰

Psychosocial factors associated with traumatic stress

Muscara et al. reported that psychosocial factors explained 36% of the variance in parents with ASD, compared to demographic factors that explained only 4.5% of the variance.³² Currie found that higher psychosocial risks, mediated by the stress response, were predictive of PTSS 4 months after diagnosis.¹⁴ After fetal diagnosis, those who experienced denial or were unresolved to the diagnosis had higher rates of PTSD.^{13,14}

Stokes et al. reported that parents' acute stress responses to unexpected complications during the hospitalization, including prolonged mechanical ventilation, were significantly associated with post-traumatic stress scores 2 years after the hospitalization.³³ Acute stress reactions explained 44% of the variance of parents' long-term PTSS.³³ Unexpected complications causing an acute stress response in parents had a greater impact on long-term mental health outcomes, including PTSD, than the patients' diagnosis, perioperative factors, or demographics.³³ Several studies found that high levels of anxiety, reduced coping, perceived lack of social support, and low parenting satisfaction were associated with PTSD (see Table 1).^{11,12,16,17,22} Helfricht et al. report that traumatic stress severity at the time of discharge was associated with PTSD after 6 months after discharge.¹⁷ Additionally, parenting stress at discharge was associated with both the number and severity of PTSS.⁶ Four months after discharge, parenting stress predicted PTSD.⁶

Table 1. Key findings of included quantitative studies (n = 25)

Authors	Title	Population	Question/aim	Design	Relevant findings
Bainton et al., 2022 ¹⁶	Prevalence and associated risk factors of PTSD in parents whose infants have single ventricle heart disease	143 mothers, 72 fathers	Determine prevalence factors associated with PTSD in parents whose infant underwent stated palliation for single ventricle heart disease	Multicentre longitudinal study	<ul style="list-style-type: none"> • Probable PTSD in 50% of mothers and 39% of fathers after the Norwood operation • Prevalence decreased to 27% of mothers and 24% of fathers when the child was 16 months • Intrusive and hyperarousal symptoms were the most common • High anxiety, reduced coping, and low parenting satisfaction significantly associated with PTSD
Currie et al., 2020 ⁴	Parental distress in response to childhood medical trauma: A mediation model	132 parents, 99 mothers, 33 fathers (children with from cardiology, oncology, or PICU)	Explore the relationship between psychosocial risk as a predictor of long-term stress	Single-centre longitudinal study	<ul style="list-style-type: none"> • 84.8% with symptoms of acute stress response 4 weeks after diagnosis • 27.3% with PTSS 4 months after diagnosis • Higher psychosocial risk mediated by acute stress response predicted PTSS 4 months after diagnosis
Davey et al., 2023 ¹⁴	Maternal Reaction and Psychological Coping After Diagnosis of Congenital Heart Disease	36 mothers	<ul style="list-style-type: none"> • Assess maternal resolution and adaptation to a new diagnosis of CHD • Explore how maternal resolution and adaptation relate to psychological well-being • Evaluate whether specific illness parameters impact resolution status 	Single-centre cross-sectional study	<ul style="list-style-type: none"> • 25.7% of mothers with PTSD • Higher PTSS in mothers unresolved to the diagnosis
Farley et al., 2006 ²⁷	Parenting Stress and Parental Post-traumatic Stress Disorder in Families After Pediatric Heart Transplantation	46 mothers, 6 fathers	Quantify paediatric medical traumatic stress in parents of paediatric heart transplant recipients and compare them to parents of other medically ill children	Single-centre cross-sectional study	<ul style="list-style-type: none"> • 56% of parents with moderate PTSD • 39% with moderate to severe PTSD • 19% met clinical criteria for PTSD (2.5x prevalence in general population) • Rates are consistent with parents of children with other medical conditions

Table 1. (Continued)

Franck et al., 2010 ³⁰	Parent Stress Levels During Children's Hospital Recovery After Congenital Heart Surgery	211 parents	Investigate parent stress pre- and post-operatively and examine influencing factors	Single-centre two-phase prospective repeated measures descriptive study	<ul style="list-style-type: none"> • Parents' stress remained moderate to high throughout admission regardless of the severity of illness • Mothers with higher levels of stress than fathers • Parents with accurate perceptions of their child's condition
Franich-Ray et al., 2013 ³	Trauma Reactions in Mothers and Fathers After Their Infants Cardiac Surgery	77 mothers, 55 fathers	Investigate the prevalence and nature of trauma symptoms in mothers and fathers of infants who had cardiac surgery	Single-centre cross-sectional study	<ul style="list-style-type: none"> • One month after discharge, 33.8% of mothers with ASD and 18.2% of fathers with ASD • Mothers with significantly higher levels of symptoms (except in dissociation) than fathers • 83% of parents endorsed at least 1 trauma symptom, and only 11.4% endorsed one symptom • Dissociation was the most commonly endorsed cluster with 26% of parents endorsing all symptoms of dissociation
Gaskin et al., 2021 ¹⁹	Parents' Experiences of Transition from Hospital to Home After Their Infant's First-Stage Cardiac Surgery: Psychological, Physical, Physiological, and Financial Survival	16 parents of 12 interstage infants, 12 mothers, 4 fathers	Explore the parents' experience of the transition from hospital to home with their infant after stage 1 cardiac surgery for complex CHD	Single-centre longitudinal, mixed method feasibility study	<ul style="list-style-type: none"> • All parents with symptoms of ASD • Four parents (25%) with PTSD before discharge and sustained at 4 months
Golfenshtein et al., 2021 ³⁸	Parental Post-traumatic Stress and Healthcare Use in Infants with Complex Cardiac Defects	153 parents	Examine the association between PTSD in parents of infants with CHD and healthcare usage during infancy	Secondary data analysis of multicentre randomized control trial; correlational study	<ul style="list-style-type: none"> • Parents with PTSD are more likely to have unscheduled ED and cardiology visits • Increased symptom clusters associated with more ED visits and unplanned cardiology and paediatrician visits

(Continued)

Table 1. (Continued)

Authors	Title	Population	Question/aim	Design	Relevant findings
Golfenshtein et al., 2022 ⁶	Predictors of Post-traumatic Stress Symptomology in Parents of Infants with Congenital Heart Disease post-surgery and after four months	158 parent-infant dyads	Identify predictors of PTSS at discharge and after 4 months	Secondary data analysis of multicentre randomized control trial; correlational study	<ul style="list-style-type: none"> At discharge: <ul style="list-style-type: none"> Severity of PTSS associated with parenting stress, education, and number of infant medications Number of PTSS associated with parenting stress, education, insurance, and number of infant medications Tube-assisted feeding predicted PTSD At 4 months <ul style="list-style-type: none"> Severity of PTSS associated with parenting Stress, ethnicity, and number of ED visits PTSD predicted by parenting stress, single ventricle physiology, and number of children
Helfricht et al., 2008 ²¹	Surgery-related posttraumatic stress disorder in parents of children undergoing cardiopulmonary bypass surgery: A prospective cohort study	122 mothers, 92 fathers	Examine surgery-related PTSD in parents of children undergoing cardiopulmonary bypass surgery	Single-centre longitudinal study	<ul style="list-style-type: none"> 16.4% of mothers and 13.3 % of fathers with PTSD after discharge Another 15.7% of mothers and 13.3% of fathers with PTSS Six months after surgery, PTSD rates are lower in mothers (14.9%) and fathers (9.5%) Acute PTSS severity at discharge only predictor of chronic PTSD severity at 6 months Pre-, peri-, and postoperative factors did not predict PTSD
Helfricht et al., 2009 ¹⁷	Psychometric evaluation and validation of the German version of the Acute Stress Disorder Scale across two distinct trauma populations	61 parents, 35 mothers, 26 fathers, 22 couples	Validate a German version of the Acute Stress Disorder Scale	Single-centre longitudinal study	<ul style="list-style-type: none"> 25% of parents with ASD 3 weeks after surgery ASD scale significantly correlated with anxiety and depression and predicted PTSD 6 months after admission
Landolt et al., 2011 ¹⁸	Predictors of Parental Quality of Life after Child Open Heart Surgery: A 6-Month Prospective Study	135 mothers, 97 fathers	Assess parental health-related quality of life and its predictors after child open heart surgery	Single-centre longitudinal study	<ul style="list-style-type: none"> 25% of parents met the criteria for PTSD at discharge 34% had partial PTSD Those with full or partial PTSD were significantly more likely to report lower mental health-related quality of life

Table 1. (Continued)

Lisanti et al., 2022 ³⁷	Quality of Life of Mothers of Infants Subjected to Neonatal Cardiac Surgery: The Importance of Psychosocial Factors	148 mothers	Examine the association of infant, environmental, and parental factors with the QOL of mothers of infants at 4 months post-hospital discharge from cardiac surgery	Secondary data analysis of multicentre randomized control trial	<ul style="list-style-type: none"> Multivariable model found combination of dyadic adjustment, social support, parenting stress, and PTSS explained approximately three-quarters of the variance in QOL scores
Lisanti et al., 2023 ³⁵	Early Growth Trajectory is Associated with Psychological Stress in Parents of Infants with CHD, but Moderated by Quality of Partner Relationship	148 mothers	Explore the relationships between growth trajectory, parenting stress, and parent post-traumatic stress	Secondary data analysis of multicentre randomized control trial; Correlational study	<ul style="list-style-type: none"> Infant growth trajectory over the first 4 months is associated with parenting stress and PTSS
Lisanti et al., 2024 ²³	Mental Health Symptoms in Parents of Infants 3 Months After Discharge Following Neonatal Cardiac Surgery	56 parents (28 mother-father dyads)	Describe mental health symptoms of parents 3 months post-discharge from PCICU and identify predictors of such symptoms	Single-centre longitudinal study	<ul style="list-style-type: none"> 19% of parents with PTSS Parental role alteration was predictive of anxiety, depression, and PTSS Postnatal diagnosis predictive of PTSS
Lisanti et al., 2024 ³⁶	Salivary Diurnal Cortisol Predicts Post-Traumatic Stress Symptoms in Parents of Infants With Congenital Heart Disease	40 parents	Explore whether measures of biomarker cortisol in parents during their postoperative period were associated with subsequent psychological distress symptoms	Single-centre longitudinal study	<ul style="list-style-type: none"> Cortisol area under the curve with respect to ground predicted PTSS at 3 months post-discharge
McWhorter et al., 2021 ²⁴	Parental post-traumatic stress, overprotective parenting, and emotional and behavioural problems for children with critical congenital heart disease	45 mothers, 15 fathers	Examine the relationship between PTSS, post-traumatic growth, overparenting, and child emotional and behavioural problems	Multicentre cross-sectional study	<ul style="list-style-type: none"> 18% with PTSD PTSS associated with overprotective parenting and child emotional/behavioral problems Overprotective parenting was positively associated with child emotional/behavioral problems
Medoff Cooper et al., 2020 ²⁵	Telehealth Home Monitoring and Postcardiac Surgery for Congenital Heart Disease	219 infant-parent dyads	To test the effect of telehealth home monitoring (REACH) on parenting stress, PTSD, and parent quality of life	Multicentre randomized control trial	<ul style="list-style-type: none"> No difference in intervention and control group 18% PTSD in both groups

(Continued)

Table 1. (Continued)

Authors	Title	Population	Question/aim	Design	Relevant findings
Mortensen et al., 2015 ²⁰	Family-centered care and traumatic stress symptoms in parents of children admitted to the PICU	90 parents	Evaluate the association between parent's experience with nursing care and the degree of traumatization. Identify factors contributing to ASD	Single-centre cross-sectional study	<ul style="list-style-type: none"> • 33% of parents with ASD or subclinical ASD • 17% of mothers with ASD and 7% of fathers with ASD • Mothers with very young children had higher levels of acute stress • Fathers with higher acuity children with higher acute stress
Muscara et al., 2017 ³⁴	Psychosocial, Demographic, and Illness-Related Factors Associated With Acute Traumatic Stress Responses in Parents of Children With a Serious Illness or Injury	115 mothers, 56 fathers (children from cardiology, ICU, and oncology)	Investigate factors associated with ASD in parents	Single-centre cross-sectional study	<ul style="list-style-type: none"> • Psychosocial factors explained 36.8% variance in parent ASD, and demographic variables explained an additional 4.5% • Clinical variables not significantly associated with ASD
Muscara et al., 2018 ³²	Featured Article: Trajectories of Posttraumatic Stress Symptoms in Parents of Children With a Serious Childhood Illness or Injury	159 parents, 115 mothers, 44 fathers (children from cardiology, oncology, and PICU)	Document PTSS in parents of children with serious illness or injury, identify the trajectory patterns of PTSS over 18 months, and determine factors associated with each group	Single-centre longitudinal study	<ul style="list-style-type: none"> • Identified three distinct parent profiles: <ul style="list-style-type: none"> ◦ Resilient (33%), low distress across time point ◦ Recovery (52%): high distress at diagnosis, decreases over subsequent months ◦ Chronic (13%): consistently high distress across all time points • Psychosocial factors predicted group membership; severity of illness and demographic factors did not
Rychik et al., 2013 ¹³	Maternal Psychological Stress after Prenatal Diagnosis of Congenital Heart Disease	59 pregnant women with a fetal diagnosis of CHD	Determine if prenatal diagnosis of CHD increases maternal stress	Single-centre cross-sectional study	<ul style="list-style-type: none"> • 39% with PTSS • After controlling for partner satisfaction and income, "denial" was most associated with traumatic stress

Table 1. (Continued)

Scrimin et al., 2009 ²²	Anxiety and stress in mothers and fathers in the 24 h after their child's surgery	154 parents, 91 mothers, 63 fathers (children had undergone major, minor, or day surgery)	Investigate the impact of three levels of severity of paediatric surgery on mothers' and fathers' anxiety and stress and identify factors that contribute to parental anxiety and acute stress symptoms in the first 24 h after child surgery	Single-centre cross-sectional study	<ul style="list-style-type: none"> • 16% with ASD • Acute stress symptoms increase with complexity of surgery • More acute stress symptoms predicted by parental trait anxiety, health external locus of control, lower level of education, and number of social contacts • Mothers and fathers with high levels of stress during major surgery
Stokes et al., 2020 ³³	Surgical and Psychosocial Predictors of Mental Health in Parents of Children with Cardiac Admissions	31 parents of children with cardiac disease	To investigate factors associated with long-term mental health outcomes in parents of children with cardiac disease	Single-centre longitudinal study	<ul style="list-style-type: none"> • Acute stress reactions contributed significantly to parent mental health, explaining 44% variance in parents with PTSS • Acute mental health status more strongly related to long-term mental health outcomes than patient morphology, demographics, or perioperative variables
Wray et al., 2018 ³¹	Psychosocial functioning of parents of children with heart disease—describing the landscape	1197 mothers, 1053 fathers	To describe the psychosocial functioning of parents of school-age children with heart disease	Multicentre cross-sectional study	<ul style="list-style-type: none"> • Parents of children with mild heart disease with lower PTSS than parents of children with SV or cardiomyopathy • Mothers with significantly more PTSS than fathers

ASD = acute stress disorder; CHD = congenital heart disease; ED = emergency department; ICU = intensive care unit; PCICU = paediatric cardiac intensive care unit; PICU = paediatric intensive care unit; PTSD = post-traumatic stress disorder; PTSS = post-traumatic stress symptoms; QOL = quality of life; SV = single ventricle.

Table 2. Key findings of included qualitative studies (n = 3)

Authors	Title	Population	Question/aim	Design	Relevant findings
Cantwell-Bartl et al., 2013 ¹⁵	Psychosocial experiences of parents of infants with hypoplastic left heart syndrome in the PICU	29 parents, 16 mothers, 13 fathers	Evaluate the psychosocial status of mothers and fathers of infants with hypoplastic left heart syndrome while in the ICU	Single-centre mixed methods study	<ul style="list-style-type: none"> • 83% of parents with ASD or PTSD • 88% of mothers and 66% of fathers developed PTSD in response to prenatal diagnosis of CHD • 100% of mothers and 75% of fathers with ASD in response to postnatal diagnosis of CHD • The main traumatic stressor was the fear child could die • Additional stressors identified: appearance of their child, infant's open chest after surgery, ICU environment, hearing their child's poor prognosis, hearing about complications, witnessing another child's death
Harvey et al., 2013 ²⁸	Experiences of mothers of infants with congenital heart disease before, during, and after cardiac surgery	8 mothers	Explore the experience of mothers of infants undergoing cardiac surgery, before, during, and after the surgery through evaluation of journal entries	Qualitative descriptive study	<ul style="list-style-type: none"> • Six themes were identified: <ul style="list-style-type: none"> ◦ Feeling intense fluctuating emotion ◦ Navigating the medical world ◦ Dealing with the unknown ◦ Facing the possibility of my baby dying ◦ Finding meaning and spiritual connection ◦ Mothering through it all
Kosta 2015 ²⁹	Parental experiences of their infant's hospitalization for cardiac surgery	154 parents, 91 mothers, 63 fathers	Explored parents' perception of what they found difficult, what they would like to be different, and what they found to be helpful during their infant's hospitalization for heart surgery	Structured interviews with thematic and frequency analysis	<ul style="list-style-type: none"> • Themes included: <ul style="list-style-type: none"> ◦ Uncertain or unfolding nature of diagnosis and surgery ◦ Structural and systemic issues: microenvironment (physical space, visiting hours) and macro-environment (parking, access to food, accommodations) ◦ Relationships with staff and interface with hospital systems can have positive and negative effects ◦ Social network helpful ◦ The amount, timing, availability, and source of information was an identified theme ◦ Individual coping strategies varied

ASD = acute stress disorder; CHD = congenital heart disease; ICU = intensive care unit; PICU = paediatric intensive care unit; PTSD = post-traumatic stress disorder.

Table 3. Key findings of included review studies (*N* = 3)

Authors	Title	Population	Question/aim	Design	Relevant findings
Pinquart et al., 2019 ¹¹	Posttraumatic Stress Symptoms and Disorders in Parents of Children and Adolescents with Chronic Physical Illnesses: A Meta-Analysis	184 studies including 30,068 parents (1490 parents of children with heart disease)	To analyse rates of PTSD and PTSS in parents of children with chronic physical illness	Meta-analysis	<ul style="list-style-type: none"> • 19% of parents in analysis with PTSD • Significant elevations of PTSS were observed in parents of children with heart disease among other conditions • Higher illness severity, treatment intensity, or duration associated with higher PTSS • Longer time since treatment and diagnosis associated with lower PTSS • Moderate correlation between parent and child PTSS • Perceived social support, marriage with lower PTSS • Mothers with higher levels of PTSS than fathers
Turgoose et al., 2021 ¹²	Prevalence of Traumatic Psychological Stress Reactions in Children and Parents Following Paediatric Surgery: A Systematic Review and Meta-analysis	16 studies	To understand the prevalence of post-traumatic stress reactions in children undergoing surgery and their parents	Systematic review and meta-analysis	<ul style="list-style-type: none"> • Eleven studies reported traumatic stress in parents of children who had surgery • Four studies with parents of children after cardiac surgery (see Franich-Ray et al., Helfricht et al., Landolt et al., and Stokes et al.) • Longer admissions, the complexity of surgery, and less social support more likely to experience PTSD
Woolf-King et al., 2017 ²	Mental Health Among Parents of Children with Critical Congenital Heart Defects: A Systematic Review	30 studies on mental health of parents of children with CHD	Systematic review of literature to inform further research and improve care of families affected with CHD	Systematic review	<ul style="list-style-type: none"> • Five studies focused on trauma • Rates of PTSD and ASD in parents of children with CHD exceed national rates • Rates of PTSD and ASD are consistent with other populations of parents with children in the ICU

ASD = acute stress disorder; CHD = congenital heart disease; ICU = intensive care unit; PTSD = post-traumatic stress disorder; PTSS = post-traumatic stress symptoms.

Clinical factors associated with traumatic stress

Wray and colleagues examined over 2000 parents and described 2 pathways of psychological well-being of parents defined by the complexity of heart disease, specifically that parents of children with mild heart disease report fewer PTSS than parents of children with cardiomyopathy or single ventricle heart disease.³¹ This finding was consistent with another study of parents 4 months after discharge that found that having a child with single ventricle physiology was predictive of PTSD.⁶ Complexity of surgery was associated with more acute stress symptoms in two studies^{11,22} and another found that specifically, fathers of children with high clinical acuity had higher levels of acute stress.²⁰ However, other studies found little to no relationship between clinical variables and PTSS or PTSD (Table 1).^{21,33,34} The number of infant medications at the time of discharge was associated with the severity of PTSS, and the need for tube-assisted feedings at discharge predicted PTSD.⁶ Infant growth trajectory over the first 4 months was associated with PTSS and parenting stress.³⁵ Four months after discharge, the number of emergency visits was associated with the severity of PTSS.⁶ In a recent study examining parent biomarkers of stress, Lisanti *et al.* found that parents' salivary cortisol area under the curve with respect to the ground measured at discharge predicted PTSS 3 months later.³⁶

Consequences of parental post-traumatic stress

Parents with full or partial PTSD were more likely to experience lower mental health-related quality of life.^{18,37} In a multivariable model, Lisanti *et al.* found that the combination of the relationship quality between partners, social support, parenting stress, and PTSS explained 74% of the variance in quality-of-life scores.³⁷ Emergency room visits and unplanned visits to the cardiologist and primary care provider were associated with increased symptoms of PTSD (see Table 1).³

Parent PTSS were also associated with overprotective parenting and subsequent emotional and behavioural problems among their children.²⁴

Discussion

A stress response to a traumatic experience can be adaptive; however, persistent or intense symptoms may interfere with daily life and impact overall well-being and quality of life of parents of children with heart disease. The purpose of this scoping review was to report on what is known about traumatic stress in parents of children with heart disease. Studies sought to describe the prevalence, timing, associated factors, and consequences of traumatic stress. Periods of heightened traumatic stress for parents were identified at the time of diagnosis, during the hospitalization, and at the time of discharge. While the majority of parents report reduced PTSS over time, 16–25% of parents experience persistent PTSS lasting longer than 16 months.^{16,27,32} These findings reflect slightly higher rates than those recently reported by Whyte-Nesfield *et al.*, who found that 12.5% of parents of children with unexpected PICU admissions experience PTSS 18–30 months post-discharge.³⁹ In a group of 159 parents of children from the PICU, oncology, or cardiology divisions, Muscara identified three distinct profiles of parents over an 18-month period and termed them resilient, recovery and chronic. Thirty-three percent of parents were described as resilient and experienced low distress through all time points. The recovery group accounted for 52% of parents who had high distress at the diagnosis that

decreased with time over several months. The chronic group accounted for 13% of parents, and they experienced high levels of distress at all time points through 18 months.³²

Recognizing particularly vulnerable time points and factors associated with parent traumatic stress may prompt timely screening to facilitate risk stratification and tailored individualized interventions that optimize outcomes for parents and children with heart disease. Given the consequences of poor adjustment to the diagnosis, additional screening and psychological support may be warranted when communicating the diagnosis to parents. In their review paper, Tacy and colleagues illuminate the complex nature of counselling parents through a prenatal diagnosis of CHD, from the perspective of the provider and parents.⁴⁰ During these conversations, parents are processing new medical information, managing uncertainty, and experiencing psychological distress. These early conversations significantly influence the adjustment and psychological well-being of parents and families; however, training for providers and best practice have not been established. Empathetic and trauma-informed communication may support psychological adjustment to the diagnosis and a collaborative and trusting partnership between parents and providers.⁴⁰

The prevalence of PTSS during hospitalization and the sustained nature of these symptoms throughout admission warrant attention.^{3,30} Given the impact of the acute stress response on PTSD, the inpatient admission is an opportunity to identify parents at risk for ASD and PTSD and provide additional support to cope with the stress of the hospitalization. Psychosocial risks, including baseline anxiety, depression, poor coping, parental role alteration, parenting stress, lower education, and acute stress response, were commonly reported. While the complexity of the disease was not consistently reported as a risk factor, parents of children with single ventricle heart disease, tube-assisted feedings, and a high medication burden were at higher risk of developing PTSS.^{6,20,19,31} Early recognition of risk can be achieved by building standardized screening and subsequent support programmes (see Table 1).^{4,6,13,14,16,21–23,33,34,17}

Specific triggers of stress are also important to guide interventions. Infants and children in the ICU are fragile, require continuous monitoring, and are often connected to life-saving equipment. While necessary, this environment poses many barriers to healthy bonding and parenting and can trigger both traumatic and parenting stress. Consistent with qualitative findings,^{12,15,28} the Paediatric Cardiac Intensive Care Unit Parental Stress Model asserts that parental stress emerges from three specific categories of stressors: infant, parent, and environment.⁴¹ Exposure to these common stressors in the ICU setting combined with the significant challenges to one's adaptation resources and the existential threats to their child's well-being are a likely precursor to traumatic stress.^{15,28,29} This framework may be useful to employ in the development of parent support programmes aimed at addressing acute stress in parents during their child's hospitalization.

Finally, given the subset of parents that experience persistent PTSS, and even meet the diagnostic criteria for PTSD, screening and ongoing support are needed after hospital discharge. Screening for PTSS and recognition of psychosocial risk factors and specific sources of stress may help inform a tailored approach to providing necessary support. Addressing these specific needs of parents experiencing PTSS may reduce unplanned utilization of healthcare and support healthy parenting and child development.^{24,38}

Few psychological support interventions for parents of children with heart disease have been developed and tested, and only one

measured traumatic stress.⁴² Medoff-Cooper and colleagues tested the effect of a telehealth home monitoring programme for parent-infant dyads discharged after neonatal cardiac surgery. Four months post-discharge, there was no significant difference in PTSD scores between the intervention and control group who received usual care.²⁵

Other intervention studies focused on anxiety, depression, parenting stress, coping, worry, and quality of life. For example, Callahan et al. described the effect of early palliative care on parenting stress, anxiety, and depression. The intervention focused on four specific domains including bonding, feeding, memories and emotional support, and psychological and spiritual support.⁴³ Overall stress in the intervention group was decreased; however, there was no difference between anxiety and depression scores between the groups.⁴³ McCusker and colleagues developed a psychoeducational intervention that supported the mother-infant relationship, parenting skills, and emotional processing of their experience. Six months after the intervention, mothers in the intervention group demonstrated improvement in anxiety, worry, and appraisal of their situation.⁴⁴

In the neonatal intensive care unit (NICU), Ghaedi-Heidari and colleagues found that the mindfulness-based stress reduction intervention was associated with higher post-traumatic growth scores.⁴⁵ The application of trauma-informed care and Adverse Child Experiences framework are emerging in the NICU literature; however, very few results are available related to the implementation of these strategies.^{46–48}

A significant gap exists with regard to interventions that support parents of children with heart disease through acute stress responses and traumatic stress symptoms. Additional research is needed to develop programmes to support parents through trauma and address the other known psychological consequences of parenting a child with heart disease, including parenting stress, anxiety, and depression.² Given the impact of psychosocial factors on psychological outcomes, interventions tested in particularly vulnerable populations, for example, those with low levels of education, low resources, poor social support, and non-English speakers, are needed.⁴⁹

Limitations

There are limitations of this scoping review to be acknowledged. Given that this was a scoping review and not a systematic review, the quality of the studies was not critically appraised, including the potential for bias. Various methodological approaches to studies were included, and different measures of traumatic stress were used across studies making comparisons difficult.

Future research

While research about traumatic stress in parents of children with CHD is limited, the body of evidence has grown substantially over the past 5 years, and findings are concerning for both parents and their children. Rates of traumatic stress among parents of children with heart disease are considerably higher than national rates^{3,4,6,13,14,16,18,20,21,19,23,24,27,38,17,50} and contribute to negative outcomes for both parents and children.^{6,18,21,24,35,37,17} Developing an understanding of the full psychological profile, including the factors related to post-traumatic growth in parents of children with heart disease, may help inform interventions that support trajectories towards healthy coping and growth.^{24,49,51} Testing interventions that are informed by screening results and

knowledge of the trajectory and triggers of traumatic stress will be important next steps.⁴² Interventions should aim to improve parent self-efficacy and support healthy coping when faced with acute stressors.⁴⁹ Given the high rates of traumatic stress symptoms and the known triggers of stress during the hospitalization, this period of time may be an opportunity to modify the subjective experience and reduce the risk of developing traumatic stress symptoms.⁴² While impossible to alleviate the lifelong impact of CHD on parents and children, targeted interventions may create a foundation that fosters healthy adaptation to traumatic medical experiences.

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