Trauma Reactions in Mothers and Fathers After Their Infant's Cardiac Surgery

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Objective To investigate the prevalence and nature of trauma symptoms in mothers and fathers of infants who had cardiac surgery. **Method** Parents of infants who underwent cardiac surgery before 3 months of age were recruited at the time of surgery. 77 mothers and 55 fathers completed the Acute Stress Disorder Scale 1 month after their infant was discharged from hospital. **Results** 26 of 77 (33.8%) mothers and 10 of 55 (18.2%) fathers satisfied criteria for acute stress disorder. For all symptom clusters, except dissociation, mothers had significantly higher mean scores (and therefore higher levels of symptoms) than did fathers, $ps = .01, -.02$. 83 percent of parents endorsed at least 1 trauma symptom and 11.4% endorsed only 1 symptom at a clinical level. Symptoms of dissociation were the most commonly endorsed by both parents, with each symptom in that cluster being endorsed at a clinical level by at least 26% of parents. **Conclusions** Consistent with our hypotheses, approximately one-third of parents overall, as well as one-third of mothers and close to one-fifth of fathers, experienced trauma symptoms consistent with a diagnosis of acute stress disorder. Most parents experienced at least one symptom at a clinical level, with symptoms of dissociation being the most commonly endorsed symptom cluster. These findings highlight the need for clinical supports for parents.

Key words adjustment; cardiology; children; parent stress; posttraumatic stress.

Introduction

Congenital Heart Disease

The term ''congenital heart disease'' (CHD) refers to abnormalities of the heart that are present from birth and includes conditions such as hypoplastic left heart syndrome, coarctation of the aorta, transposition of the great arteries, and ventricular septal defect. Cardiac conditions comprise the greatest proportion of all birth defects, are a major cause of fetal and infant mortality, and are the most common group of structural malformations in children (Lissauer & Clayden, 2001; Riley & Halliday, 2008). Many defects do not require correction; however, a proportion need one or more major surgical interventions (Lissauer & Clayden, 2001).

Infants requiring surgery for CHD experience an acute medical crisis similar to that of a critical illness (e.g., burn, accidental injury). Surgery for CHD may be followed by a number of medical check-ups, restrictions in daily activities, and changes in quality of life similar to that of a chronic illness (e.g., cancer, cystic fibrosis). Thus, for

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purposes of gauging the impact on the family, CHD requiring surgery may be considered both a critical and a chronic illness. There is evidence that parents of children with chronic illness are at increased risk for depression, anxiety, and stress (Davis, Brown, Bakeman, & Campbell, 1998; Lawoko, Joaquim, & Soares, 2006; Lawoko & Soares, 2002; Pelchat et al., 1999). Clinicians have also long recognized that many parents experience trauma symptoms in response to their child's chronic illness, with much of the research focused on children with cancer and their families (Kazak, Alderfer, Rourke, et al., 2004; McCarthy, Ashley, Lee & Anderson, 2012; Patino-Fernandez et al., 2008). More recent research has also included investigating trauma symptoms in parents of children with a critical illness, such as those with burns and accidental injury (Hall et al., 2006; Le Brocque, Hendrikz, & Kenardy, 2010).

To date, no published study has investigated parental trauma reactions in infants with CHD requiring surgical intervention. However, for these parents, there are many stages of the infant's illness that could be traumatic for both them and their infant, such as receiving the diagnosis, fear of future disability or death, hospital admissions (which may require separation from the infant), waiting for the surgery to occur, witnessing medical procedures and paraphernalia, waiting throughout the operation, and possible setbacks and new medical crises in the time after until the infant's medical status is stable. In addition, parents may experience vicarious trauma as they witness the medical course of other patients. For first-time parents, these traumatic events come on top of the psychological challenge of adjusting to new parenthood.

Acute Stress Disorder

Acute stress disorder (ASD) is a recognized psychiatric entity (Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition Revised [DSM-IVR]; American Psychiatric Association, 2000) that describes symptoms that occur as part of an individual's response within 4 weeks of exposure to a traumatic event. These symptoms last from 2 days to 4 weeks and can be a precursor to longer-term symptoms, such as posttraumatic stress disorder (PTSD). There are four clusters of trauma symptoms, with a varying number of each required for a diagnosis of ASD or PTSD. These symptom clusters are dissociation, re-experiencing, avoidance, and arousal. Symptoms of dissociation include feeling numb, detached from one's surroundings, and ''in a daze.'' Re-experiencing symptoms include experiencing recurrent images, thoughts, and dreams of the trauma. Arousal symptoms include difficulty sleeping, irritability, poor concentration, and hypervigilance. Avoidance symptoms include avoiding activities, places, and people that are likely to remind an individual of the trauma.

Parents of hospitalized children have been found to experience trauma symptoms consistent with a diagnosis of ASD. In a study of families of children admitted to a pediatric intensive care unit (PICU), 32% of parents met criteria for ASD while their child was an inpatient (Balluffi et al., 2004). In addition, Shaw et al. (2006) reported that 28% of parents of infants who were admitted to a neonatal intensive care unit (NICU) met ASD criteria 2–4 weeks after their infant's hospitalization. Higher rates of ASD were reported by McCarthy et al. (2012), who found that 63% of mothers and 60% of fathers of children newly diagnosed with cancer met criteria for ASD. Slightly lower rates of 51% of mothers and 40% of fathers were found in another study of parents of children newly diagnosed with cancer (Patino-Fernandez et al., 2008).

In addition to examining symptom levels consistent with a diagnosis of ASD, some researchers have explored the prevalence of ''subthreshold'' ASD, which is when an individual experiences clinically relevant trauma symptoms but not a sufficient number of symptoms to satisfy DSM-IV criteria for a diagnosis of ASD (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Kazak et al., 1997). For example, Winston et al. (2002) examined the prevalence of parents experiencing at least one symptom from each trauma symptom cluster after their child's traffic injury, and found 39% of parents to experience at least one symptom of dissociation, 54% to experience a symptom of re-experiencing, 43% to experience a symptom of avoidance, and 73% to experience a symptom of arousal. The importance of examining subthreshold ASD and individual trauma symptoms has been noted by Kazak and colleagues, who found that in 99% of families of adolescent survivors of cancer, at least one parent reported trauma symptoms and that this impacted the family's functioning (see Kazak, Alderfer, Streisand, et al., 2004 as reported in Kazak, Alderfer, Rourke, et al., 2004). This was supported by Le Brocque et al. (2010), who tracked the trajectory of trauma symptoms in parents after their child's accidental injury and noted that there was a group of parents who had consistent levels of moderate trauma symptoms. The authors of that study proposed that families with trauma symptoms (as opposed to diagnosis) should also be considered as potential high-risk families.

In one of the few published studies investigating trauma reactions in parents of children with a cardiac condition, Helfricht, Latal, Fischer, Tomaske, and Landolt (2008) explored the prevalence of trauma symptoms in parents of children (aged: 0–16 years) who had

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cardiopulmonary bypass surgery. Assessed immediately after discharge, 16.4% of mothers and 13.3% of fathers met diagnostic criteria for PTSD. An additional 15.7% of mothers and 13.3% of fathers experienced significant posttraumatic stress symptoms. The presence of symptoms at discharge was found to be a risk factor for PTSD 6 months later.

Current Study

With the current study, we seek to advance the literature in several ways. First, there is little research on trauma symptoms in parents of infants or children with CHD. Congenital heart disease is a unique medical condition, in that it can include an acute medical crisis (e.g., surgery) and the long-term aftermath of a chronic illness (e.g., continuous medical care). Thus, although the existing literature on trauma symptoms in parents of infants with either a chronic (e.g., cancer) or a critical (e.g., burn, accidental injury) illness is informative, the unique medical sequelae of CHD are expected to impact parents differently.

Second, the age range of children in the literature on symptoms of trauma in parents of unwell children is broad. Most studies previously described include children between 0 and 18 years of age (McCarthy et al., 2012; Patino-Fernandez et al., 2008; Helfricht et al., 2008), with studies of infants in NICU being the majority to examine trauma in parents of unwell infants (e.g. Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Shaw et al., 2006). Compared with parents of adolescents, parents of infants are in a different developmental period (i.e., transitioning to parenthood, forming an attachment relationship with their infant, developing their role as a caregiver, adjusting their relationship with their romantic partner, and potentially adjusting their relationship with their other children) of their parent–child relationship and thus might experience a similar traumatic event differently. Additionally, compared with older children with CHD, infants with CHD provide a unique group, in that the relative impact of diagnosis timing (prenatal vs. postnatal) can be examined.

Third, many studies examining trauma symptoms in parents of unwell children combine samples of mothers and fathers as ''parents'' (Balluffi et al., 2004; Shaw et al., 2006; Winston et al., 2002) and fail to provide detailed information on the unique characteristics of each gender. Literature on other psychopathology (e.g., depression, anxiety) in parents of unwell children often demonstrates gender differences, with generally a higher proportion of mothers than fathers experiencing symptoms at clinical risk levels (e.g., Lawoko et al., 2006; Pelchat et al., 1999). Additionally, having two parents from the same family in the sample creates interdependence, or greater similarity between some participants (i.e., a married couple) than other participants (e.g., a nonrelated mother and father), in the data. In the current study, we sought to examine the impact of CHD surgery on parents of infants in general (as to compare with the existing literature) and provide a more detailed comparison of mothers and fathers separately.

Finally, a majority of previously described comparison studies have included American samples that may not be generalizable to other cultures. In this study, we provide unique data on an Australian sample of parents of infants with CHD—a group that has yet to be examined.

To explore these ideas, we investigated the prevalence of ASD in parents of infants who underwent cardiac surgery before 3 months of age. We specifically measured the prevalence of ASD and subthreshold ASD as well as the types of trauma symptoms experienced by both parents. The literature on trauma in parents of children (0–16 years of age) with CHD suggests the prevalence to be approximately 15% of parents (Helfricht et al., 2008), whereas the literature on trauma in parents of premature infants suggests prevalence to be around 30% (Shaw et al., 2006). Based on these percentages, we expected that the proportion of parents of infants with CHD to experience symptoms consistent with a diagnosis of ASD would be between 15 and 30%. Additionally, consistent with previous literature, we expected a majority (>50%) of parents to experience subthreshold ASD symptoms. Because there is inconsistency in the literature with which individual or cluster of symptoms are most readily endorsed, the goal of this study is to clarify the types of trauma symptoms that are most common in this population.

Method

Participants

Mothers and fathers of infants who underwent cardiac surgery at The Royal Children's Hospital before the age of 3 months were recruited between February 2005 and September 2006 as part of a larger study. Participating mothers and fathers provided written informed consent. Families were excluded if parents did not speak English, did not live in Australia, or if the infant was determined by the medical team to be medically unstable. The Royal Children's Hospital in Melbourne is one of the main cardiac surgery centers in Australia. Consequently, a proportion of families were from interstate and/or rural areas.

During the recruitment period, 198 infants aged <3 months had cardiac surgery at the hospital. Twenty-seven

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infants died before discharge, 17 infants were deemed too gravely ill to approach, three families were from overseas, seven families had insufficient English fluency, nine families were uncontactable, and 20 families could not be contacted owing to logistic difficulties, such as staff leave. The remaining 115 families were approached to participate. Seventeen of the 115 (15%) declined to participate, with ''too busy'' being the main reason given. One infant died after having been introduced to the study. Ninety-seven mothers and 79 fathers agreed to participate. All but one family were two-parent families, and in cases where only the mother consented, ''too busy'' was the main reason given for the father's nonparticipation. In total, 78 mothers and 57 fathers returned the questionnaire. However, for one mother and two fathers, the questionnaire was incomplete, so their results were excluded, leaving 77 mothers (79%) and 55 fathers (70%) returning completed questionnaires. Details of participants are presented in Tables I and II.

Measures

The Acute Stress Disorder Scale (ASDS; Bryant, Moulds, & Guthrie, 2000) is a 19-item scale developed as a self-report measure of ASD according to DSM-IV (American Psychiatric Association, 2000) criteria and is designed to measure the responses of individuals in the acute phase of a traumatic experience. The ASDS assesses four clusters of symptoms, with five items assessing symptoms of dissociation, four items assessing re-experiencing symptoms, four items assessing avoidance, and six items assessing symptoms of arousal.

Parents are asked to answer the items according to how they have felt since their infant's surgery. Responses are measured on a 5-point scale, 1 = *not at all* to 5 = *very much*. Scores range from 19 to 95, with higher scores indicating increasing severity. Bryant et al. (2000) suggested using a combined score of ≥9 for the dissociative criteria and ≥28 for the cumulative score of the other symptoms (re-experiencing, avoidance, arousal) as the most appropriate in identifying individuals with ASD. These authors calculated the alpha coefficient to be .96 when using an ASDS total score, and .84 for dissociation, .87 for re-experiencing, .92 for avoidance, and .93 for arousal symptoms. In our sample, the alpha coefficient for mothers was .91 when using an ASDS total score, and .87 for dissociation, .70 for re-experiencing, .81 for avoidance, and .83 for arousal symptoms. For fathers, the alpha coefficient was .88 when using an ASDS total score, and .84 for dissociation, .73 for re-experiencing, .75 for avoidance, and .74 for arousal symptoms.

Procedures

Eligible families were informed of the study after their infant's surgery either in person during admission to the cardiology ward or soon after discharge from hospital by telephone. Families were approached either by the research assistant or a member of the treating team, with consent then being obtained by the research assistant. Ethics approval of the study was granted by the Royal Children's Hospital Human Research Ethics Committee (21058).

The questionnaire was mailed to the family's home. Both parents were invited to complete the questionnaire, except in one instance, where the father had no contact with the infant. Families were asked to complete the questionnaire as close to 1 month after discharge from hospital as possible. Infants were considered to be home for 1 month if they had no overnight admissions to hospital during that time. The infant's medical records were accessed to determine on which date each infant was discharged from the hospital, and whether they had been readmitted and, if so, for how long. In cases where children were transferred or readmitted to other hospitals, the final discharge date was provided by parent report.

Statistical Analyses

The data were analyzed using IBM SPSS Statistics 19. Missing items for the ASDS were handled by substituting the missing item with the mean weighted score for the items answered and then rounding it to the next whole number. Repeated-measures *t*-tests were conducted to establish if there were demographic differences between mothers and fathers who completed the questionnaire and those who did not. All subsequent analyses are presented first using the entire cohort of parents, followed by separate analyses for mothers and fathers.

First, the proportion of parents, and then mothers and fathers separately, scoring above the cutoff for ASD was calculated. Chi-square tests for independence were conducted to determine if there was a statistical difference between the proportion of mothers and fathers who scored above the cutoff for current ASD (i.e., ≥9 for the dissociative criteria and ≥28 for the cumulative score of the other symptoms). The concordance of ASD diagnosis within parent dyads was also examined. Means and standard deviations were calculated and then repeated-measures *t*-tests were used to establish if there were any differences in means between mothers and fathers.

Second, subthreshold ASD was explored. To identify the symptom clusters most frequently endorsed by parents at a clinical level, we dichotomized responses to items as either clinical or nonclinical using criteria established by

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Table I. *Descriptive Characteristics of the Study Cohort—Parents*

	Mothers ($n = 77$)		Fathers ($n = 55$)	
Characteristic	Mean (*SD*)	Range	Mean (*SD*)	Range
Days since infant's discharge at assessment	52.2 (18.08)[a]	14–96[b]	58.68 (24.51)[c]	26–149
Age (years)	32.9 (4.9)[a]	19.9–42.0	35.5 (5.5)[d]	23.2–48.9
Occupational status[e]	4.38 (1.04)	2.30–7.00	4.35 (1.11)	1.70–6.60
	n (%)		*n* (%)	
Place of birth				
Australia	63 (81.8)		43 (78.2)	
Other	9 (11.7)		11 (20.0)	
Missing	5 (6.5)		1 (1.8)	
Language spoken at home				
English	74 (96.1)		52 (94.6)	
Other	2 (2.6)		2 (3.6)	
Missing	1 (1.3)		1 (1.8)	
Education				
Secondary school < year 12	15 (19.5)		20 (36.36)	
Secondary school year 12	13 (16.9)		0 (0)	
Trade qualification/diploma	7 (9.1)		13 (23.64)	
University education	30 (39.0)		15 (27.27)	
Missing	12 (15.6)		7 (12.73)	
Financial worries				
Yes	23 (29.87)		18 (32.73)	
Government benefit as main source of income				
Yes	9 (11.69)		3 (5.45)	
Missing	1 (1.30)		0 (0)	

Note. ''Missing'' = Parents did not provide details.

[a]$n = 64$.

[b]One infant had a brief interim admission for bronchiolitis, which was not revealed until after completion of the questionnaire, hence time since last discharge was 14 days.

[c]$n = 50$.

[d]$n = 45$.

[e]Daniel Scale of Occupational Prestige (Daniel, 1983) was used to determine socioeconomic status. This Australian scale ranks occupations and assigns a score from 1 to 7, with lower numbers indicating higher socioeconomic status. $n = 71$ mothers, $n = 55$ fathers.

Winston et al. (2002) and Patino-Fernandez et al. (2008). Using these criteria, responses of greater than or equal to 3 on a 5-point scale (i.e., ''medium,'' ''quite a bit,'' or ''very much'') were considered clinical levels. This provided percentages for parents who experienced one or more symptoms of each cluster at a clinically significant level. Chi-square analyses were then used to compare differences in the proportion of mothers and fathers who endorsed at least one trauma symptom at a clinical level.

Third, we examined the proportion of parents who endorsed each item at a clinical level and, using chi-square analyses, compared differences in the proportion of mothers and fathers who endorsed each item. Finally, independent-samples *t*-tests and logistic regressions were used to examine differences in scores on the ASDS (total and symptom clusters) based on diagnosis timing (prenatal vs. postnatal) and birth order of the infant (first-born vs. later-born).

Questionnaires were returned between 1 and 3 months after discharge. A Pearson *r* was calculated to see if timing of questionnaire return was correlated with ASD scores; timing of questionnaire return did not influence results ($p > .05$) and therefore was not considered.

Results

Sociodemographic characteristics of mothers and fathers are presented in Table I. Fathers were older than mothers (*M:* 35.55 years [*SD*: 5.92] vs. *M:* 33.41 [*SD*: 4.40] $p < .001$). Fathers also completed the questionnaire later than mothers (*M*: 54.80 days after discharge [*SD*: 19.96] vs. *M:* 51.54 [*SD*: 17.91], $p < .001$, respectively).

Acute Stress Disorder

Of the 135 parents, 36 (27%) scored above the cutoff identified by Bryant et al. (2000) for ASD, indicating that

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Table II. *Descriptive Characteristics of the Study Cohort—Infants*

Characteristic	Mean (*SD*)	Range
Age (days) at discharge	51.74 (42.07)	10–182
	n (%)	
Gender		
Male	37 (51.9)	
Female	40 (48.1)	
Birth order[a]		
First-born child	27 (35.1)	
Second-born child (or higher)	43 (55.8)	
No data	7 (9.1)	
Location		
Victoria (state where hospital located)	52 (67.5)	
City	28 (36.4)	
Rural Victoria	24 (31.2)	
Other Australian state	25 (32.5)	
Timing of diagnosis		
Prenatal	34 (44.2)	
Postnatal	43 (55.8)	
Diagnosis/procedure		
Coarctation of the aorta	14 (18.2)	
Hypoplastic left heart syndrome/Norwood procedure	10 (13.0)	
Transposition of the great arteries, complex	11 (14.3)	
Ventricular septal defect	9 (11.7)	
Tetralogy of Fallot/Pulmonary atresia with ventricular septal defect	5 (6.5)	
Transposition, intact ventricular septum	7 (9.1)	
Interrupted aortic arch	5 (6.5)	
Tricuspid atresia	2 (2.6)	
Pulmonary atresia, intact ventricular septum	4 (5.2)	
Patent ductus arteriosus	3 (3.9)	
Total anomalous pulmonary venous drainage	2 (2.6)	
Other	5 (6.5)	
Surgery		
Corrective	55 (71.4)	
Palliative	22 (28.6)	
Total number of days admitted to hospital (across all admissions)		
1–14 (0–2 weeks)	21 (27.3)	
15–28 (2–4 weeks)	25 (32.5)	
29–42 (4–6 weeks)	12 (15.6)	
43–56 (6–8 weeks)	5 (6.5)	
57–84 (8–12 weeks)	4 (5.2)	
84+ (>12 weeks)	10 (13.0)	

[a]One baby was a triplet and three babies were one of a twin.

they experienced trauma symptoms consistent with a diagnosis of ASD. Twenty-six of the 77 mothers (33.8%) and 10 of the 55 fathers (18.2%) scored above the cutoff. This difference between mothers and fathers was not demonstrated to be significant, χ^2 (1) = 3.26, $p = .071$.

We then examined the concordance within parent dyads. Only dyads where both parents completed the ASDS ($n = 55$) were examined. Of these dyads, one (2%) had both parents score above the cutoff for ASD, 18 (33%) had just mothers score above the cut-off, nine (16%) had just fathers score above the cut-off, and 27 (49%) had neither parent score above the cut-off.

Using paired-samples *t*-tests, comparisons were made between mean scores for mothers and fathers based on each symptom cluster. For all symptom clusters, except dissociation, mothers had significantly higher mean

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scores (and therefore higher level of symptoms) than fathers. See Table III for details.

Subthreshold Acute Stress Disorder

Eighty-three percent of parents endorsed *at least* one trauma symptom and 11.4% endorsed *only* one symptom at a clinical level. By symptom cluster, 64.4% of parents endorsed at least one dissociative symptom, 45.2% endorsed at least one re-experiencing symptom, 47.4% endorsed at least one avoidance symptom, and 53.3% endorsed at least one arousal symptom at the clinical level.

The percentage of mothers and fathers who endorsed at least one item of each of the symptom clusters at a clinical level (i.e., ≥3) is presented in Figure 1. Eighty-seven percent of mothers and 79.6% of fathers experienced at least one trauma symptom at a clinical level. Eight percent of mothers and 16.4% of fathers experienced only one symptom at a clinical level. Dissociative symptoms were the most frequently endorsed symptom cluster by both mothers and fathers, with 68.8% of mothers and 61.8% of fathers rating at least one of the five items from the dissociative cluster at a clinical level. Re-experiencing symptoms were the least endorsed by both mothers and fathers, with 52.7% and 41.5%, respectively, experiencing at least one symptom. There were no differences in the proportion of mothers and fathers who endorsed at least one trauma symptom at a clinical level, all $ps > .05$.

Trauma Symptoms

For parents in general, the item with the highest proportion (51.0%) of endorsement at a clinical level was ''During or after the surgery, did you ever feel in a daze?'' The item with the lowest proportion (6.7%) of endorsement at a clinical level was ''Have you felt as if the surgery was about to happen again?'' For all parents, and when examining mothers and fathers separately, symptoms of dissociation were the most frequently endorsed (all items endorsed by at least 26%); see Figure 2. Chi-square analyses were used to compare differences in the proportion of parents who endorsed each item at a clinical level. Compared with fathers, a significantly higher proportion of mothers reported that they felt numb or distant from their emotions (χ^2 (1) = 5.93, $p = .015$), feel upset when they are reminded of the surgery (χ^2 (1) = 10.14, $p = .002$), have tried not to think about the surgery (χ^2 (1) = 5.34, $p = .021$), and have become jumpy since the surgery (χ^2 (1) = 4.61, $p = .032$). These items are noted in Figure 2.

As part of an exploratory analysis, we examined relations between timing of diagnosis (prenatal vs. postnatal) and birth order (first-born vs. later-born) of the infant on trauma symptoms. Thirty-four (45%) mothers and 21 (40%) fathers were given a prenatal diagnosis of their infant's CHD. For 37 (41%) mothers and 26 (42%) fathers, the participant infant was their first-born child.

Mothers were 2.68 times more likely to experience at least one symptom of avoidance at a clinical level if they received a prenatal diagnosis than if they received a postnatal diagnosis, $p = .047$ (95% CI 1.01, 7.10). Additionally, fathers were 3.32 times more likely to experience at least one symptom of avoidance at a clinical level if they received a prenatal diagnosis than if they received a postnatal diagnosis, $p = .037$, (95% CI 1.07, 10.27). Finally, fathers were 5.33 times more likely to experience at least one symptom of arousal at a clinical level if they received a prenatal diagnosis than if they received a postnatal diagnosis, $p = .006$, (95% CI 1.63, 17.44). There were no additional relations between diagnosis timing or birth order and scores for total or subscale scores of the ASDS (measured continuously and using clinical cutoffs).

Discussion

The aims of this study were to examine the prevalence of ASD, as well as subthreshold ASD, and the types of trauma symptoms experienced by parents of infants who underwent cardiac surgery. Consistent with our

Table III. *ASD Symptom Cluster Scores*

	M (*SD*)				
Symptom cluster	Overall (*n* = 132)	Mothers (*n* = 77)	Fathers (*n* = 55)	*t* (*df*)	*p*
Dissociative	12.23 (5.27)	12.84 (5.36)	11.36 (5.06)	1.41 (54)	.164
Re-experiencing	7.36 (3.08)	7.91 (3.15)	6.60 (2.83)	2.53 (54)	.015
Avoidance	7.17 (3.57)	7.69 (3.82)	6.44 (3.08)	2.32 (54)	.024
Arousal	10.22 (4.12)	10.95 (4.48)	9.20 (3.35)	2.37 (54)	.021
Total	36.99 (12.71)	39.42 (13.38)	33.60 (10.96)	2.62 (54)	.011

Note. Paired-samples *t*-tests used to compare mothers and fathers.

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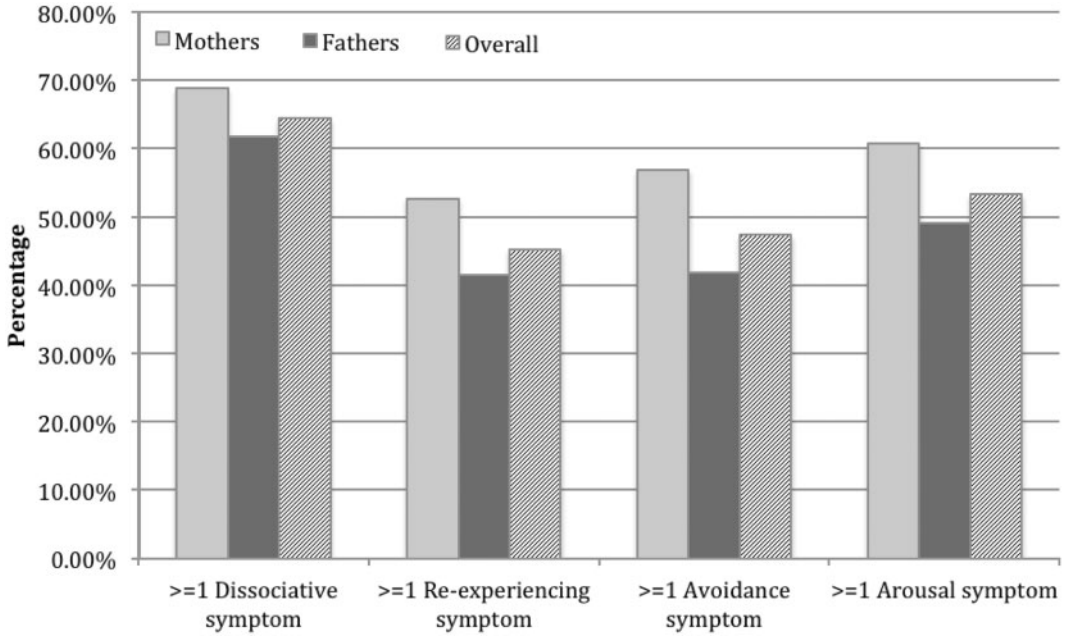

Figure 1. Percentage of mothers and fathers who endorsed at least one item in each of the symptom clusters at a clinical level. Chi-square analyses were used to compare differences in the proportion of parents who endorsed at least one trauma symptom at a clinical level; there were no differences for any of the symptom clusters, all *p*s>.05.

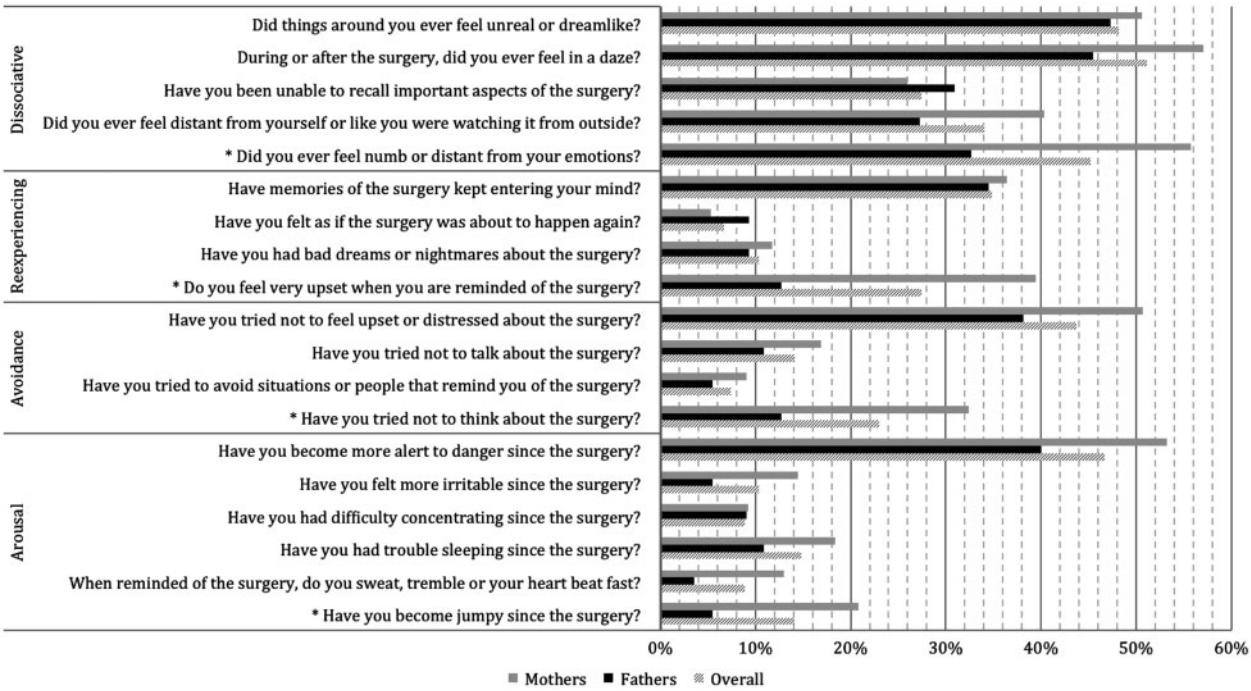

Figure 2. Percentage of mothers and fathers who endorsed each item at a clincal level. *Indicates items where proportions of mothers and fathers are statistically significantly different. Some questions were shortened for this graph.

hypotheses, nearly one-third of all parents experienced trauma symptoms consistent with a diagnosis of ASD. Furthermore, one-third of mothers and close to one-fifth of fathers were identified as meeting criteria for ASD. It was uncommon for both parents within a dyad to meet criteria for ASD.

For all symptoms clusters (except dissociation), mothers had higher mean scores than did fathers. Consistent with

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our hypotheses, a majority of all parents endorsed *at least* one trauma symptom and close to 10% experienced *only* one symptom at a clinical level. All symptoms of dissociation were frequent, both overall and for mothers and fathers separately.

Acute Stress Disorder

The prevalence of ASD in parents within this sample is higher than rates of PTSD reported in parents of children (0–16 years of age) with CHD (Helfricht et al., 2008), lower than rates of ASD that have been reported in parents of children newly diagnosed with cancer (McCarthy et al., 2012; Patino-Fernandez et al., 2008), and comparable with that of parents of children in PICU (Balluffi et al., 2004) and NICU (Shaw et al., 2006). The higher rates of ASD in this sample than those found by Helfricht et al. (2008) could be related to the age difference of the children in the samples. The postpartum period is a time during which parents are at increased risk of developing psychological disorders such as postnatal depression and anxiety and postpartum psychosis (Bergink, Lambregtse-van den Berg, Koorengevel, Kupka, & Kushner, 2011; Buist et al., 2008). Thus, parents of infants with CHD might be at greater risk for developing ASD than parents of children and adolescents with CHD. Another reason for the difference in prevalence rates may be that we used a measure of ASD, whereas Helfricht et al. used a measure of PTSD, each of which has slightly different diagnostic criteria.

The lower rates of ASD in parents of children with CHD compared with parents of children newly diagnosed with cancer may reflect the perception of higher levels of threat to the child and increased rates of exposure to traumatic events (i.e., more procedures) found with pediatric cancer patients. In addition, compared with infants with CHD, there may be greater uncertainty regarding the medical prognosis for children newly diagnosed with cancer. Owing to ethical considerations, families in our study were excluded if their infant was too gravely ill to approach. Using these exclusion criteria, we may have missed those families who would have experienced the greatest uncertainty regarding their infant's prognosis and thus would be at greatest risk for ASD. In some sense, the infants in our sample had achieved at least a preliminary solution to their medical illness at the time of completion of the questionnaire, and therefore, parents of these infants may be less likely to experience trauma compared with their counterparts. Future studies might benefit from approaching families when the outcome is less clear. This area of research is warranted, but as it was anticipated that these infants were not likely to survive, the trauma symptoms would be potentially confounded by bereavement and loss for some families.

Similar rates of ASD between our sample and NICU and PICU samples may be because patients who are admitted to NICU and PICU have a variety of medical conditions, including both critical and chronic illness. Further, all infants in our sample would have been admitted to PICU at least once, subsequent to their cardiac surgery. Therefore, there would be similarities in parent experiences (e.g., exposure to intensive care environment, vicarious trauma) between the samples.

There were limited differences between mothers and fathers in rates of ASD. Although, compared with fathers, nearly twice the percentage of mothers met criteria for ASD, this result did not reach statistical significance. Differences in mean scores on the ASDS were evident between mothers and fathers for all symptom clusters, except dissociation. Shaw et al. (2006) similarly found gender differences in ASD, which they attributed to mothers having more practical and emotional involvement with their children while hospitalized, and possibly also once discharged home, whereas fathers may have had less involvement, as they needed to return to work.

Subthreshold Acute Stress Disorder

A more comprehensive picture is obtained when looking at individual items for the ASDS rather than focusing on the presence or absence of ASD. Symptoms of dissociation (e.g., feeling numb, distant) were the most commonly endorsed among both parents in our sample. This finding is important, as Hall et al. (2006) found that parent dissociative symptoms (as measured during their child's hospitalization after burns) were predictors of future PTSD. Further, there was a relationship between size of the burn and parent trauma symptoms, which the authors explained by linking greater trauma severity (i.e., burn size) with symptoms of dissociation.

Knowledge of common trauma symptoms in parents after neonatal cardiac surgery can inform clinical practice. It is possible, for example, that trauma symptoms may impair a parent's ability to understand medical information, which in turn may affect medical decisions (as suggested by the items ''Have you tried not to think about the surgery?'' and ''Have you been unable to recall important aspects of the surgery?''), or cause parents to be hypervigilant (as suggested by the item ''Have you become more alert to danger since the surgery?''), and consequently increase health care utilization and cost. Symptoms of dissociation could also impair parents' capacities to be emotionally available for their ill child and/or their other children (e.g., Alisic, Boeije, Jongmans, & Kleber, 2011), which can further impact their children's adjustment and parent–child interactions.

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Unique to our sample, we were able to explore whether there were differences for parents who received a prenatal (rather than postnatal) diagnosis for their infant's cardiac condition, and whether symptoms were exacerbated for first-time parents. Parents were more likely to experience at least one symptom of avoidance at a clinical level if their infant had a prenatal rather than postnatal diagnosis. Additionally, fathers were also more likely to experience at least one symptom of arousal if their infant had a prenatal rather than postnatal diagnosis. One of the differences between infants diagnosed prenatally and those diagnosed postnatally is that infants with a prenatal diagnosis are likely to have one of the more severe forms of CHD, such as hypoplastic left heart syndrome. This severity might in turn increase the risk for parents developing ASD. As the significant findings were limited to the avoidance and arousal clusters, caution should be used when speculating about the relation between diagnosis timing and development of ASD. Future studies could help elucidate these relations. There were no relations between birth order of the infant and parental ASD, suggesting first-time parents and experienced parents are similarly affected by their infant's CHD surgery.

Areas for Intervention

There are multiple times that could act as points of entry for intervention, such as at the time of diagnosis (either prenatally or postnatally) during the hospital admission for the infant's surgery, and once an outpatient. The type and focus of treatment might differ depending on the timing and needs of the family; however, providing psychoeducation about possible psychological sequelae, information about services in their area, identifying families who might be at risk, and/or parent–child psychotherapy focusing on the parent–child relationship or other familial relationships may all decrease the parent's risk for PTSD.

Shaw et al. (2006) found that alteration of the parent role, such as not being able to protect their infant, hold or care for their infant, or share their infant with family members, was an important factor in the adjustment process. Evidence has also shown that reducing the impact of other daily hassles may reduce stress and consequent adjustment difficulties. Therefore, continuing services such as parent accommodation, meals for breast-feeding mothers, and Internet access for parents, in addition to social workers who are able to assist parents and identify those needing further assistance, could be invaluable in preventing poor adjustment.

In response to the high levels of ASD symptoms found in parents of injured children, Winston et al. (2002) suggested that educating parents on the normalcy of their symptoms and reactions is an important practice for clinicians. Those authors recommended that pediatricians routinely call the family or have them visit after discharge so that they can ask about ASD symptoms and explore the potential impact of these symptoms on the family's and the parents' ability to provide support to their children. Winston et al. also proposed that because approximately one-quarter of parents experience traumatic stress reactions, pediatric care providers could prepare all parents for this possibility. This could enable parents to monitor their own well-being for possible traumatic stress symptoms. Referral to appropriate services and supports could then be provided as part of the medical follow-up, where necessary.

A model for intervention has been developed by Kazak et al. (2007) for families of children diagnosed with cancer, where there are three levels of intervention available depending on the family's level of psychosocial risk. The first level is a universally targeted treatment that aims at preventing trauma symptoms and psychological distress in all families. The next level is targeted for families who experience some distress, with the aim of reducing current symptoms and preventing escalating distress. The final level of intervention is targeted for those families who are experiencing clinical levels of distress and require targeted psychological intervention.

Strengths and Limitations

A limitation of this study was that many parents struggled to return the questionnaire within the time frame requested, with questionnaires returned between 1 and 3 months after discharge from hospital. This time frame was problematic as the measurement of ASD relates specifically to acute traumatic stress symptoms 1–4 weeks after trauma. Higher prevalence of ASD and ASD symptoms may have been found if the questionnaire was completed within the 1-day to 4-week period, given that traumatic stress symptoms are reported to decrease with time (Ambrosino, 2002). However, number of days after discharge for questionnaire completion was not significantly associated with the presence of ASD for mothers or fathers in this study.

Strengths of this study included examining a developmentally homogenous sample of infants who underwent and survived cardiac surgery before 3 months of age, providing descriptions of and making direct comparisons in rates of ASD between mothers and fathers, and providing one of the samples of trauma in Australian parents of infants with CHD. These study characteristics enabled a comprehensive understanding of the traumatic impact of CHD on the family.

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Conclusion

In summary, the majority of parents of infants who undergo and survive cardiac surgery before 3 months of age experience some trauma symptoms, with nearly one-third experiencing enough to warrant a diagnosis of ASD. Ongoing trauma responses may impair parents' ability to be available to their infant, or other children, and to provide their infant with sensitive and responsive care that forms the basis of a secure attachment relationship. Clinical services while the infant is in hospital and as an outpatient involving psychoeducation for these parents may help alleviate these symptoms, prevent future PTSD, and promote positive adjustment of both parents and the family as a whole.

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