

# Rates of depression, anxiety, and stress in parents of children with congenital heart disease using the Depression Anxiety Stress Scale

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## ABSTRACT

- Context and Background :** The Cardiac Neurodevelopmental Outcome Collaborative has recommended using the Depression Anxiety Stress Scale (DASS) to evaluate for depression, anxiety, and stress in parents of children with congenital heart disease (CHD). There has not been a longitudinal study investigating its utility in these parents.
- Aims :** The aim of this study was to determine the trend of depression, anxiety, and stress in parents of patients with CHD.
- Methods :** Our center uses this self-reported survey at every visit between 6 and 36 months of age. This was a single-centered, retrospective study from January 1, 2018, to June 1, 2020.
- Statistical Analysis :** Cox regression analysis was conducted using a composite end point of having an abnormal score in any of the three domains.
- Results :** Two hundred and seventy-three mothers and 139 fathers were included in the study. For mothers, scores in each domain were elevated at 12 and 24 months. For fathers, scores in each domain were elevated at 6 months, followed by a decrease before peaking again, with depression increasing at 36 months and anxiety and stress increasing at 30 months. Increased length of stay for the index surgery was associated with an abnormal score for mothers ( $B = 0.02$ ,  $P < 0.01$ ) and fathers ( $B = 0.01$ ,  $P = 0.04$ ). Being in a relationship with the father ( $B = -0.8$ ,  $P < 0.01$ ) was associated with freedom of an abnormal score for mothers.
- Conclusions :** Scores concerning for depression, anxiety, and stress peak at different points for parents. Length of stay for the index surgery and being in a relationship are important factors in the mental health of parents.
- Keywords :** Anxiety, congenital heart disease, Depression Anxiety Stress Scale, depression, mental health, parent, stress

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## INTRODUCTION

Many advancements in caring for children with congenital heart disease (CHD) have been made to improve survival for and improve life expectancy. Unfortunately, these patients often have lengthy hospital stays, undergo multiple procedures, and have additional noncardiac defects as well. Consequently, parents of these children have been found to be at risk for psychological comorbidities. Recently, there has been increased recognition of mental health disorders for the caregivers of children with CHD. In a systematic review by Woolf-King *et al.*, it is estimated that up to 30% of these parents have posttraumatic stress disorder, up to 50% have symptoms of depression and anxiety, and up to 80% have reported psychological distress.<sup>[1]</sup>

Patients with severe forms of CHD often have one or more procedures during the 1<sup>st</sup> year of life. The 1<sup>st</sup> year of life also coincides with the postpartum period, defined as the 1<sup>st</sup> year after delivery of a newborn, which can further compound the risk for psychological disease in parents. Postpartum depression is a well-recognized entity for mothers following delivery and has been reported to have a prevalence of up to 15% in the general population and estimated to be up to 39% in mothers of children in the neonatal intensive care unit.<sup>[2]</sup> The risk for compromised mental health in mothers can persist 36 months postpartum.<sup>[3]</sup> Fewer studies exist for fathers but have shown comparable results.<sup>[1]</sup>

With increased recognition for the mental well-being of parents, the Cardiac Neurodevelopmental Outcome Collaborative has recommended screening for mental health disorders in parents of children with CHD using the Depression Anxiety Stress Scale (DASS). The DASS was developed by Lovibond and Lovibond in 1995 and is a self-reported survey that evaluates three domains: depression, anxiety, and stress.<sup>[4]</sup> The DASS has been validated previously and its psychometric properties also offers standardized norms for adults.<sup>[5]</sup> To our knowledge, there has not been a study investigating the use of the DASS in parents of CHD in a longitudinal manner.

Our institution has been routinely screening parents with the DASS since January of 2018. We have primarily screened families at each follow-up appointment in our “Neurodevelopmental” clinic, where we evaluated patients with severe CHD from 6 months of age to 36 months of age. Here, we present a single-center, retrospective study from January 2018 to June 2020 that investigated the rate of psychologic disease in parents of patients with CHD with the DASS and how these scores changed over time.

## MATERIALS AND METHODS

### Study design

This study was a single-centered, retrospective study from January 1, 2018, to June 1, 2020. This study was approved by our local Institutional Review Board and is in concordance with the Declaration of Helsinki. DASS questionnaires are utilized in the neurodevelopmental clinic at our institution. In this clinic, we evaluate patients on a half-yearly basis, so appointments are categorized as 0–6 months, 6–12 months, 12–18 months, and so forth until 36 months of age. Patients were eligible and included in the study if they had CHD and if a DASS was completed by a parent. DASS data were collected at each visit and recorded for each type of parent.

Demographic and clinical data were collected from the patient’s electronic medical record, which included gender, cardiac lesion, subsequent surgeries and cardiac catheter-based procedures, gestational age, the presence of a prenatal diagnosis of CHD, the presence of single ventricle physiology after the initial cardiac procedure, other medical conditions, family history of CHD, number of hospital admissions, duration of hospital admissions, use of extracorporeal membranous oxygenation, results of the DASS, and social history.

DASS scores were collected at each visit when available and scored using the DASS scoring rubric. For reference, a score of 10 or greater in the depression domain was concerning depression. A score of 8 or greater in anxiety and a score of 15 or greater were concerning anxiety and stress, respectively.

### Statistical analyses

Data for each parent were analyzed separately. Initially, the frequency of abnormal scores for depression, anxiety, and stress was quantified at each time point separately. Next, the frequency of depression, anxiety, or stress as a composite endpoint was quantified at each time point.

Cox regression analyses were conducted for the composite endpoint of depression, anxiety, or stress as the dependent variable. Independent variables included the following: the presence of parallel circulation, presence of functionally univentricular circulation, age at first surgery in days, primary cardiac lesion, The Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery category for the first surgery, length of admission for the first surgery, need for extracorporeal membrane oxygenation, presence of a genetic anomaly, presence of prematurity, presence of a prenatal diagnosis, presence of a family history of CHD, and if the parents were together in a relationship or not. The regression analyses were conducted using

a backward regression with 20 iterations in which a variable was entered into the next step if the  $P < 0.1$  and was kept in the equation of the  $P < 0.05$ . The regression analyses were conducted separately for each parent.

All statistical analyses were performed using SPSS Version 23.0 (IBM Corp., Armonk, N.Y., USA).  $P < 0.05$  was considered statistically significant.

## RESULTS

### Description of cohort

Table 1 shows the demographics and clinical characteristics of our patient sample. Single ventricle physiology was defined as having the patient's pulmonary blood flow and systemic blood flow dependent on the same ventricle. The Society of Thoracic Surgeons-European Association for the Cardio-Thoracic Surgery category, was determined at the timing of surgery. A genetic anomaly was defined as any genetic deviation from normal by microarray, including variants of unknown significance. Prematurity was defined as being born before 37 weeks gestation. Developmental delay was evaluated with the Bayley Scales of Infant Development 3<sup>rd</sup> edition. Developmental delay was defined as a delay in 1 or more of the following domains: motor, cognitive, and language. There was a large variety of primary lesions in our sample [Table 1].

### Depression anxiety stress scale data

In total, 273 mothers and 139 fathers completed at least one DASS. Table 2 shows the number of total responses at each appointment and the number of abnormal scores by each domain for mothers and fathers. Figures 1 and 2 show the trends of abnormal scores for parents in the depression, anxiety, and stress domains for mothers and fathers, respectively.

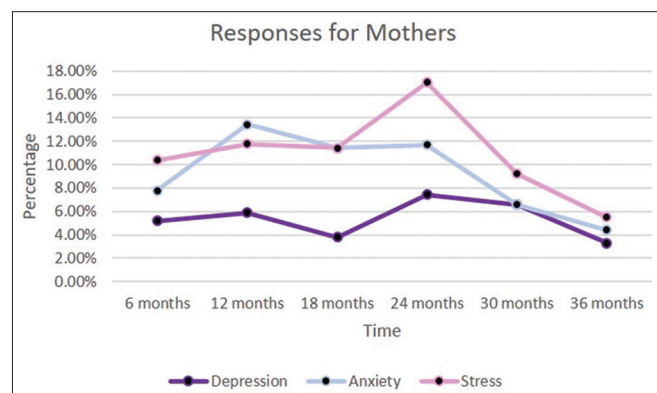
### Cox regression analyses

Figure 3 demonstrates freedom from the composite endpoint of depression, anxiety, or stress for both

**Table 1: Demographics and clinical characteristics of our patient sample (n=281)**

	n	%
Total Patients	281	
Male	158	56.23%
Female	123	43.77%
<b>Hospital Info.</b>	<b>Average</b>	<b>Range</b>
Number of Cardiac Surgeries and Catheter Procedures per Patient	2.81	0-13
Number of Cardiac Surgeries	1.68	0-6
Total Hospital Days Up Until the Time of Data Collection	47.61	3-297
Required ECMO	12	4.27%
<b>Single Ventricle Physiology</b>	<b>n</b>	<b>%</b>
After First Procedure	68	24.20%
At Most Recent Follow-Up	56	19.93%
Fontan At Most Recent Follow-Up	30	53.57%
Glenn At Most Recent Follow-Up	26	46.43%
<b>STAT Category for First Surgery</b>	<b>n</b>	<b>%</b>
5	45	16.19%
4	81	29.14%
3	57	20.50%
2	73	26.26%
1	15	5.40%
<b>Genetics</b>	<b>n</b>	<b>%</b>
Genetic Anomaly (any)	91	32.38%
Trisomy 21	26	28.57%
22q11 Deletion Syndrome	8	8.79%
Turner's Syndrome	3	3.30%
William's Syndrome	3	3.30%
Noonan's Syndrome	1	1.10%
<b>Ethnicity</b>	<b>n</b>	<b>%</b>
Caucasian	183	65.12%
African American	52	18.51%
Hispanic	34	12.10%
Asian	5	1.78%
<b>Parents</b>	<b>n</b>	<b>%</b>
In a Relationship	203	72.24%
Separated	78	27.76%
Misc.		
Developmental Delay	75	26.69%
Prematurity (born >37 weeks)	43	15.30%
Prenatal Echocardiogram	171	60.85%
Family History of CHD	36	12.81%
<b>Primary Cardiac Lesion</b>	<b>n</b>	<b>%</b>
Tetralogy of Fallot	35	12.46%
D-Transposition of the Great Arteries	35	12.46%
Atrioventricular Septal Defect	34	12.10%
Coarctation of the Aorta	26	9.25%
Hypoplastic Left Heart Syndrome	18	6.41%
Pulmonary Atresia with Intact Ventricular Septum	14	4.98%
Double Outlet Right Ventricle	14	4.98%
Total Anomalous Pulmonary Venous Return	13	4.63%
Ventricular Septal Defect	13	4.63%
Truncus Arteriosus	8	2.85%
Tricuspid Atresia	7	2.49%
Pulmonary Atresia with Ventricular Septal Defect	5	1.78%
Double Inlet Left Ventricle	5	1.78%
Critical Aortic Stenosis	4	1.42%
Ebsteins Anomaly	3	1.07%
Interrupted Aortic Arch	3	1.07%
Critical Pulmonary Stenosis	3	1.07%
Other	41	14.59%

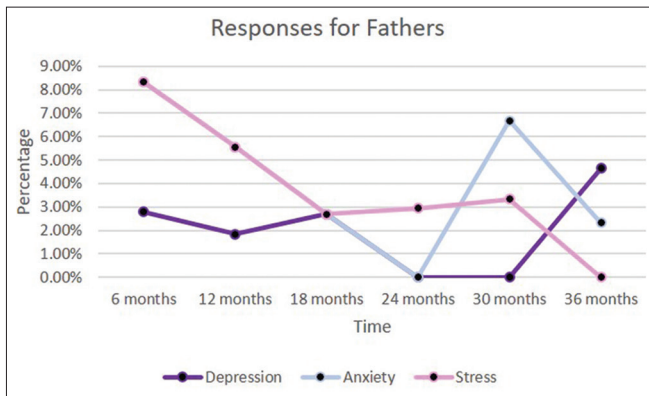
ECMO: Extracorporeal membrane oxygenation, STAT: Society of Thoracic Surgeons European Association for the Cardio-Thoracic Surgery, CHD: Congenital heart disease



**Figure 1: The percentage of abnormal scores for mothers in depression, anxiety, and stress**

**Table 2: Responses for the Depression, Anxiety, Stress Scale**

	6 months	12 months	18 months	24 months	30 months	36 months
Number of Responses						
Mother	77	119	105	94	76	91
Father	36	54	37	34	30	43
Depression						
Mother	5.19%	5.88%	3.81%	7.45%	6.58%	3.30%
Father	2.78%	1.85%	2.70%	0.00%	0.00%	4.65%
Anxiety						
Mother	7.79%	13.45%	11.43%	11.70%	6.58%	4.40%
Father	8.33%	5.56%	2.70%	0.00%	6.67%	2.33%
Stress						
Mother	10.39%	11.76%	11.43%	17.02%	9.21%	5.49%
Father	8.33%	5.56%	2.70%	2.94%	3.33%	0.00%

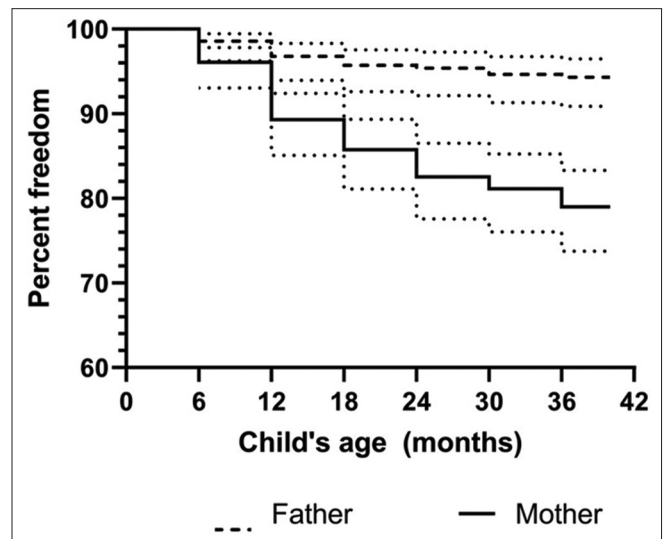

**Figure 2: The percentage of abnormal scores for fathers in depression, anxiety, and stress**

fathers and mothers. There was a statistically significant difference in freedom from the composite endpoint between mothers and fathers ( $P < 0.01$ ).

With respect to mothers, freedom of the composite endpoint was 96.0%, 89.3%, 85.7%, 82.6%, 81.1%, and 79.0% at 6, 12, 18, 24, 30, and 36 months, respectively. Factors significantly associated with the development of the composite endpoint were increased length of stay for the index surgery (beta-coefficient-0.02,  $P < 0.01$ ), while factors significantly associated with freedom from the composite endpoint were being in a relationship with the father (beta-coefficient-0.8,  $P < 0.01$ ).

With respect to fathers, freedom from the composite endpoint was 98.5%, 96.7%, 95.7%, 95.3%, 94.6%, and 94.3% at 6, 12, 18, 24, 30, and 36 months, respectively. Factors significantly associated with the development of the composite endpoint were increased length of stay for the first surgery (beta-coefficient-0.01,  $P = 0.04$ ). No factors were significantly associated with freedom from the composite endpoint.

Factors that were not associated with the development of the composite endpoint included the use of single ventricle palliation, genetic syndrome, developmental delay, prematurity, the use of extracorporeal membrane oxygenation, and ethnicity.


**Figure 3: Cox regression analysis of freedom from the composite endpoint of depression, anxiety, or stress for both fathers and mothers**

## DISCUSSION

Our observed rates of abnormal scores for depression, anxiety, and stress are lower than the rates previously reported by other authors who have used the DASS, but those studies evaluated parents at different time points.<sup>[6,7]</sup> Tallon *et al.* evaluated 91 mothers at the timing of cardiac surgery and reported that 20% of these mothers had scores concerning for depression, 25% had anxiety, and 30% had stress.<sup>[6]</sup> Another study by Kasparian *et al.* was a cross-sectional study which evaluated 91 mothers and 20 fathers with reported rates of depression, anxiety, and stress being 26%, 27%, and 32%, respectively.<sup>[7]</sup> Rates for mothers and fathers were not reported separately in these studies. Although our results are different, our study contributes longitudinal data to the current literature of the utility of DASS in parents of patients with CHD.

When combined with the data from Tallon *et al.*,<sup>[6]</sup> scores appear to improve over time, but there are



critical time points at which scores tend to increase. The trend of improving mental health with time in these parents is also similar to findings from a recent study conducted by Golfenshtein *et al.*, where 129 mothers of infants with CHD were evaluated with the Parenting Stress Index Long Form and compared with a group of mothers of infants without heart disease. Golfenshtein *et al.* found that stress for mothers of infants with CHD decreased over time; and that the levels of stress in mothers of infants with CHD were lower when compared to mothers with infants without CHD.<sup>[8]</sup> Although our study did not have a control group, both depression and anxiety have been well studied. Unipolar depression has an estimated 12 months prevalence of 10% and a lifetime prevalence of 21%.<sup>[9]</sup> Generalized anxiety disorder has an estimated prevalence of 12 months prevalence of 1.7%–3.4% and a lifetime prevalence of 4.3%–5.9%.<sup>[10,11]</sup> Compared with our sample, the rates of scores concerning for depression are lower than the prevalence in the general population, while the findings for scores in the anxiety domain have the opposite finding. Future studies are required in the depression and anxiety domain to better understand this phenomenon in these parents.

Having a mental health professional available at each appointment for these parents would be ideal, but as mental health professionals are increasing in demand, a targeted approach is required, either by an abnormal DASS or by the age of the patient. From our study, the number of abnormal DASS scores for mothers peaked at 12 months of age and again at 24 months of age for all three domains. In contrast, the number of abnormal DASS scores for fathers peaked initially at 6 months, improved, and then peaked again later at 30–36 months. The late peak in stress scores for fathers is small and may be due to the small sample size. Nonetheless, these time points may represent appointments, for which timely mental health evaluations could be offered to our families. Currently, our institution evaluates patients with CHD with a multidisciplinary approach consisting of a physician, nursing staff, physical, occupational, and speech therapists. Moving forward, it would be beneficial to incorporate psychologic services during these outpatient visits, especially at 6, 12, and 24 months. In the current COVID-19 pandemic, we have limited outpatient visits to one parent at a time. Other practices are likely following the same guidelines, so it is imperative to also communicate with the other parent or caregiver(s), which can be accomplished with a brief phone call.

Length of stay during the index surgery was found to be significantly associated with the development of mental distress for parents. Although we did not evaluate parents during their index surgery, it has previously been reported that symptoms of depression,

anxiety, and stress are elevated around the time of the child's first surgery.<sup>[6,12–15]</sup> The peak of symptoms varies between studies, but it is critical that we also offer psychological services to these families during the index surgery admission and before discharge, especially during lengthy hospital admissions following an index surgery.

If the parents were in a relationship, the mother was found to have a lower incidence of mental distress. This implies that support from a spouse is important and may be protective against the development of mental distress in parents. Conversely, studies in pediatric oncology found that 25%–40% of couples experienced relationship stress at the time of diagnosis of cancer in their children.<sup>[16]</sup> Future studies are required for parents of patients with CHD as it is currently unknown if this phenomenon exists for these parents. Nonetheless, social support is likely beneficial to parents, and we recommend taking a thorough social history to identify other friends or family members available to provide emotional support for these parents.

While this study contributes novel, relevant data to the existing body of literature, there are limitations. The retrospective nature of this study and the single-center design are key limitations. Mental health issues can vary geographically and with this study being a single-center study; the majority of the patients in this study were from a similar geographic part of the country. Another limitation of this study is that the DASS is a screening tool and should not be used as a replacement for an evaluation by a mental health professional. Although there have been studies verifying the validity of the DASS for the general population, studies for parents of patients with CHD do not exist.<sup>[5]</sup> Thus, an abnormal DASS does not equate to a diagnosis of depression, anxiety, or stress. For this reason, we recommend using the DASS to help guide which parents to refer to a mental health professional for an appropriate evaluation.

Future studies should evaluate the degree of concordance between an abnormal DASS and a diagnosis of depression, anxiety, or stress by a mental health professional. Given the nature of our study, this association was not evaluated for in our study. Future studies should also evaluate the etiology behind the fluctuating DASS scores for parents. This was beyond the scope of our study and will likely require an evaluation from a mental health professional.

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Nil.

### Conflicts of interest

There are no conflicts of interest.

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