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# Parents of children with congenital heart defects during the COVID-19 pandemic: An examination of mental health variables, risk factors, and protective factors

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## ABSTRACT

**Background:** Little is known about the mental health burden or the factors that contribute to mental health variables in parents of children with congenital heart defects (CHD) during the COVID-19 pandemic.

**Objective:** The purpose of this study was to examine risk and protective factors associated with anxiety symptoms, depression symptoms, and perceived stress in parents of young children with CHD during the COVID-19 pandemic.

**Methods:** A nonexperimental design was used in this study of 127 parents of children aged newborn to five years with CHD during the COVID-19 pandemic. Regression analyses were conducted to examine associations between COVID-19 stressors, CHD care-related factors, parental resilience, external support, and mental health variables.

**Results:** Parental resilience, emotional support, and informational support were key protective factors for anxiety, depression, and stress. However, resilience was remarkably low in CHD parents. Increased levels of anxiety symptoms, depression symptoms, and perceived stress were associated with 1) Exposure to a greater number of COVID-19-related stressors, 2) Distress from family visitation restrictions during healthcare encounters, 3) Worry related to the perceived risk of their CHD child's exposure to COVID-19 during healthcare encounters, and 4) Worry about their CHD child's risk of death or serious illness from COVID-19.

**Conclusions:** The additive impact of the COVID-19 pandemic plus CHD care-related worries on this parent population's mental health is significant. Interventions that promote resilience, address the effect of healthcare system changes, and support the needs of parents of young children with CHD during this and future pandemics are needed.

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## Introduction

Researchers estimate over one million children in the U.S. have a congenital heart defect (CHD).<sup>1</sup> Having a child with CHD is challenging — concerns about feeding, growth, oxygenation, perfusion, cardiac surgery, procedures, and hospitalizations all contribute to the complexity and stress of parenting a young child with a life-threatening condition.<sup>2–5</sup> Approximately 25% of CHD families have a child with a critical cardiac defect who will need heart surgery in their first year of life.<sup>1</sup> During the pandemic, the parents of these children had to cope not only with the risks of heart surgery, but also with the risks of contracting COVID-19 inside and outside of the hospital.<sup>6</sup> These threats were exacerbated by the social isolation caused by risk reduction mandates and fewer available in-person medical appointments.<sup>7</sup> Caregiver challenges faced by parents of young children with

CHD during the COVID-19 pandemic may have placed them at increased risk for adverse mental health outcomes.<sup>8</sup> In addition to the lifestyle disruption caused by pandemic risk reduction mandates, parents of children with CHD were exposed to the stressors associated with caring for a child with a life-threatening condition, navigating the pandemic-affected healthcare system, and the knowledge that their child may have an increased risk of COVID-19 severity due to their cardiac defect.<sup>1,6,7</sup> Ultimately, the demands of caring for a child with CHD during a pandemic may have triggered the need for protective isolation, diminished access to respite care, and resulted in increased caregiver burden for parents.

Although hospitals enacted policies to reduce the risk of exposure to COVID-19 infection, the newly implemented limitations on the number of family members who could be present with a sick child during medical encounters likely increased social isolation for CHD parents.<sup>9</sup> The presence of family and friends can be a critical source of support for parents during the stress of a child's hospitalization.

*Abbreviations:* COVID-19, Coronavirus disease 2019; CHD, Congenital Heart Defect

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Thus, while necessary, these COVID-19-related healthcare policy changes added additional stress to parents of children with CHD.

Even prior to the COVID-19 public health crisis, CHD parents represented a vulnerable population at greater risk for adverse mental health outcomes. Pre-pandemic studies have demonstrated that parents of children with CHD have elevated levels of anxiety, depression, post-traumatic stress symptoms, and perceived child vulnerability.<sup>1,10–13</sup> Less is known about how individual traits like resilience impact the psychological burden of parents caring for a child with CHD. Resilience can be protective against stress and has been associated with better mental health outcomes during times of adversity.<sup>14</sup> A better understanding of the role of resilience in mental health outcomes for CHD parents during the COVID-19 pandemic is needed.

An examination of the impact of COVID-19 on CHD parents provides a window for understanding how stressors associated with a once-in-a-century pandemic exacerbate the already challenging experience of being a CHD parent. Obtaining a deeper understanding of risk factors, external support, and resilience in the context of COVID-19 and CHD care-related experiences can help healthcare professionals identify those at higher risk for anxiety, depression, and stress during times of heightened adversity. This information can inform future interventions directed toward supporting vulnerable families during pandemics, natural disasters, or other circumstances outside of individual family's control.

#### *Study purpose*

The purpose of this study was to examine anxiety symptoms, depression symptoms, perceived stress, emotional support, informational support, and resilience in parents of young children with CHD during the COVID-19 pandemic.

#### *Specific aims*

**Aim 1:** Describe the presence and severity of anxiety symptoms, depression symptoms, perceived stress, emotional support, informational support, and resilience levels in parents of young children with CHD during the COVID-19 pandemic and compare findings to U.S. adult population norms.

**Aim 2:** Examine the associations between risk factors (COVID-19 stressors and CHD care-related factors), protective factors (emotional support, informational support, resilience), and mental health (anxiety symptoms, depression symptoms, perceived stress) in parents of young children with CHD during the COVID-19 pandemic.

### **Methods**

#### *Research design*

This study employed a cross-sectional, nonexperimental survey design to examine symptoms of anxiety, depression, and stress in parents of young children with CHD during the COVID-19 pandemic. Standardized instruments were used to measure parental reports of symptoms of anxiety and depression, perceived stress, resilience, and external support factors. COVID-19-related and CHD care-related factors were measured by researcher-developed instruments.

#### *Sample and setting*

A convenience sample of 175 participants was recruited from social media platforms for parents of children with CHD. The study sample consisted of parents/caregivers in the western, midwestern, northeastern, and southern regions of the U.S. and Canada. The parent support groups Mended Little Hearts, Heart Moms, and the Canadian Congenital Heart Alliance were chosen for this non-probability

sampling as they are nationally recognized community organizations that provide support, outreach, and education for parents of children with CHD. A notification of the research study was posted on the Facebook sites of these CHD parent support groups for recruitment. Additionally, snowball sampling was implemented during recruitment to expand enrollment through networking. The inclusion criteria for participants were parents or caregivers 1) of a child with CHD aged newborn to 5 years, and 2) who could read, write, and understand English. A key intention of the study was to recruit families of very young children. This narrowed the scope of the study to capture parents who were caring for children more likely to have had recent heart surgery and more frequent contact with the healthcare system. Due to the extraordinary levels of uncertainty, morbidity, or grief associated with CHD, exclusion criteria were parents of a child with CHD that 1) was deceased, 2) had a heart transplant, or 3) was on an extracorporeal membrane oxygenation (ECMO) machine at the time of the study.

#### *Recruitment*

The University of Washington Institutional Review Board (IRB) approved the study prior to the recruitment of participants. The primary investigator (PI) contacted CHD parent support group regional coordinators via email to provide an introduction and overview of the study. After receiving approval from individual CHD parent support group administrators, a study announcement was posted on the group's Facebook social media page. The study announcement included the study name, a brief description, inclusion criteria, approximate time commitment, and the university name. A secure link to the digital study site (REDCap) was embedded in the posting. Interested parents could learn more about the study, be screened for eligibility, and gain access to the anonymous online survey by clicking on the secure link.

#### *Variables and measures*

Demographic variables including caregiver relationship to the child, caregiver gender, race/ethnicity, socioeconomic status, education level, marital status, number of other children in the household, state of residence, CHD child age, and CHD diagnosis were collected by parent self-report via question items in the online survey.

#### *Mental health variables*

**Anxiety.** Anxiety symptoms measured by the PROMIS Anxiety instrument short form 4a are defined by self-reported fear, worry, concern, or hyperarousal.<sup>15</sup> The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores indicate more anxiety.

**Depression.** Depression symptoms measured by the PROMIS Depression instrument short form 4a are defined by self-reported negative mood, negative views of self, decreased positive affect, and decreased engagement.<sup>15</sup> The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores indicate more depression.

**Perceived Stress.** Perceived stress measured by the NIH Toolbox Perceived Stress Survey is defined by individual perceptions (i.e., thoughts or feelings) about the nature of events and their relationship to an individual's values and coping resources.<sup>14</sup> It is the extent to which the demands of a situation exceed an individual's perceived capabilities. The measure includes ten items scored on a five-point Likert scale ranging from "never" to "very often." Higher scores indicate more perceived stress.

#### *Risk factors*

**COVID-19 Stressors.** A COVID-19-related stressor survey was developed by the PI for the study (Appendix A). The survey addresses

five significant domains of COVID-19-related stressors including direct exposure & perceived risk of COVID-19, financial insecurity, food insecurity, access to healthcare, and lifestyle changes due to the pandemic. The measure includes eight yes or no items indicating exposure to COVID-19-related stressors and ten items indicating the level of worry about COVID-19-related stressors scored on a five-point Likert scale ranging from “never” to “very often.” Higher scores indicate greater exposure to and worry about COVID-19-related stressors.

**CHD Care Variables.** A CHD care-related variables survey was developed by the PI for the study (Appendix B). Survey items include timing of diagnosis, extent of exposure to healthcare services (i.e., hospitalization, clinic visits, care delay) during the pandemic, perceived risk of COVID-19, and impact of COVID-19-related healthcare policy changes. The measure has four “yes” or “no” items indicating exposure to CHD care-related variables and four items indicating the level of distress from CHD care-related variables scored on a four-point Likert scale ranging from “no distress” to “severe distress.” Higher scores indicate greater exposure to and distress from CHD care-related variables.

The survey items for both PI-developed tools were adapted or informed by NIH-supported COVID-19-related measurement tools, current COVID-19 peer-reviewed publications, and the CHD literature. (Appendix C) These sources provided the key domains represented in the survey items.

**CHD Complexity.** Utilizing guidelines from the RACHS-1, Aristotle, and STS-EACTS CHD complexity scoring, the children’s CHD diagnoses were categorized as simple or complex defects.<sup>16</sup>

#### Protective factors

External support is a construct defined in this study by two concepts: informational support and emotional support.<sup>15</sup>

**Informational Support.** Informational support measured via the PROMIS Informational Support instrument is defined by the individual’s perception of the availability of helpful information or advice.<sup>15</sup> The measure includes four items scored on a five-point Likert scale ranging from “never” to “always.” Higher scores indicate greater perceived informational support.

**Emotional Support.** Emotional support measured via the PROMIS Emotional Support instrument is defined by an individual’s perceived feelings of being cared for and valued as a person.<sup>15</sup> The measure includes four items scored on a five-point Likert scale ranging from “never” to “always.” Higher scores indicate greater perceived emotional support.

**Resilience.** Resilience measured via the Connor-Davidson Resilience Scale (CD-RISC-10) is defined by an individual’s perceived ability to adapt to change, cope with stress, handle unpleasant feelings (e.g., anger, pain, sadness), not get discouraged, stay focused, and think clearly.<sup>17</sup> The CD-RISC-10 instrument captures self-perceptions of adaptability, self-efficacy, and hardiness.<sup>17</sup> The measure includes ten items scored on a five-point Likert scale ranging from “not true at all” to “true nearly all the time.” Higher scores indicate higher levels of resilience.

Use of the PROMIS measures, NIH toolbox measure, and Connor-Davidson Resilience scale have been used in other research studies in the U.S. with similar populations such as parents of healthy young children, parents of children with chronic conditions, parents of children with life-threatening conditions, and parents of critically ill infants.<sup>18–23</sup> Reliability and validity for these instruments have been established in previous studies.<sup>15,17,24</sup> Reference scores for anxiety, depression, stress, informational support, emotional support, and resilience in the general adult population are available for statistical comparison.<sup>15,17,24</sup>

In the current study, the reliability of these measures was assessed by calculating Cronbach’s alpha. Cronbach’s alpha for items in the measures were as follows: Anxiety = .89, Depression

instrument = .90, Perceived Stress = .90, Emotional support = .94, Informational support = .96, Resilience scale = .91. All of these values indicate a high level of internal consistency.

#### Data collection

Data were collected digitally via an anonymous online survey from February 26, 2021, through April 9, 2021. Upon arrival at the study site digital platform, participants were given consent information (i.e., purpose, procedures, risks/benefits, PI contact information) and asked questions to confirm inclusion criteria. The average time to complete the survey was 10–15 minutes. Participants had the option to stop the survey at any time. All data were self-reported and collected anonymously via Research Electronic Data Capture (REDCap), a web-based application developed by Vanderbilt University for clinical research projects. REDCap is a secure internet-based platform that is HIPAA compliant and provides restricted access to surveys and data collection. Storage of data for this study is located on the University of Washington’s protected server.

#### Data analysis

All participant survey data was downloaded from REDCap to an SPSS (Statistical Package for Social Sciences, version 27.0) software program for data analysis. Cases that did not meet eligibility criteria were deleted from the imported study data set. Individual survey responses were examined for missing or errant data. Participants that did not complete one or more of the survey measures were excluded from the data analysis (Figure 1). An alpha level of .05 was used in all statistical tests.

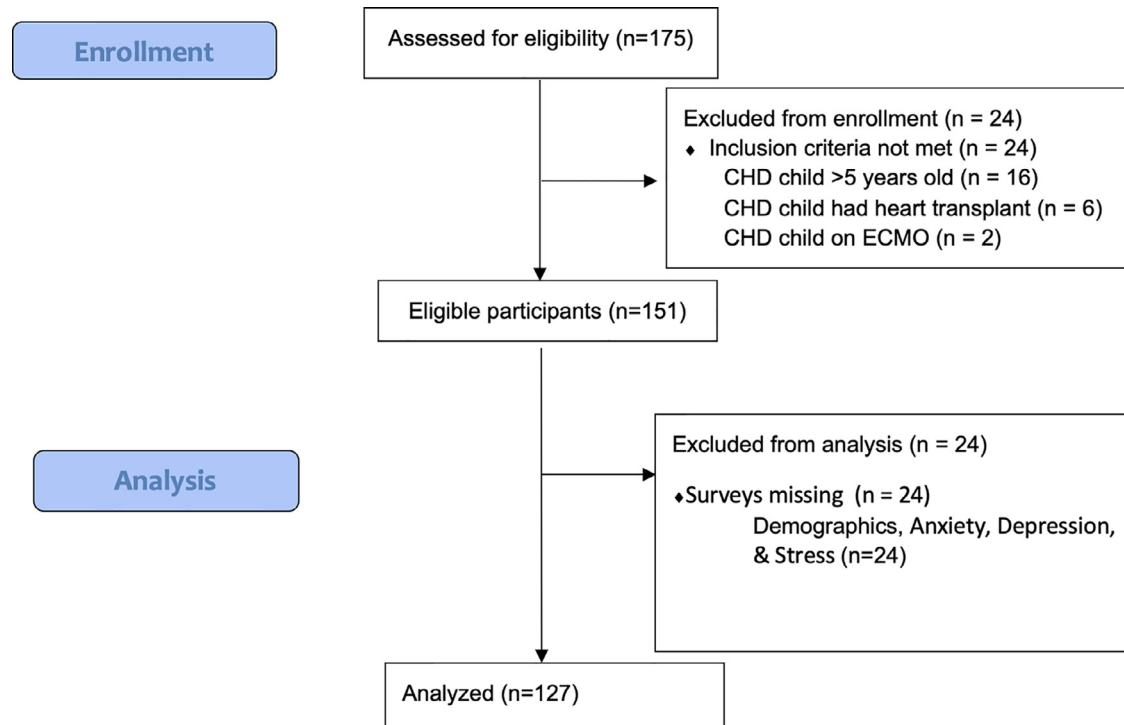
Descriptive statistics were used to describe the prevalence and severity of mental health variables, potential risk, and protective factors. A one-sample *t* test was used to compare CHD parent anxiety, depression, stress, support, and resilience scores during the COVID-19 pandemic to pre-COVID-19 general adult population norms. A Chi-square goodness of fit test was used to compare anxiety and depression symptom levels in CHD parents to anxiety and depression symptom levels in the U.S. general adult population during the COVID-19 pandemic.

Relationships among variables were tested through a series of three multivariate linear regression analyses. Regression was used to test whether key risk factors (i.e., COVID-19 stressors and CHD care-related factors) and key protective factors (i.e., resilience and external support) were predictors for anxiety, depression, or perceived stress. Utilizing evidence from the literature, the following risk factors were chosen as predictors tested in the regression models: COVID-19 stressors exposure, visitation restriction worry, COVID-19 exposure risk worry, and COVID-19 morbidity worry. Similarly guided by literature, the protective factors of resilience and external support were chosen as predictors tested in the three regression models. The total number of predictors used in the models was limited to six in accordance with the guidelines of having at least 20 cases per predictor. In all three regression models, assumptions were tested for and met the following conditions: 1) Absence of multicollinearity, 2) Normality, 3) Linearity, 3) Sample size adequacy, and 4) Absence of outliers.

## Results

#### Participant demographics

Greater than 90% of the CHD parent participants were married, white, non-Hispanic, female, and mothers. More than half had a college degree and approximately half had a middle-class income (Table 1). Over 80% of the study participants lived in the U.S. (across 30 different states), some (12%) lived in Canada, and a few (2%) lived outside of the U.S. and Canada.



**Fig. 1.** Study Participant Flow Diagram  
Note: Adapted from CONSORT 2010 Flow Diagram<sup>36</sup>

**Table 1**  
Demographic Characteristics of Parent Participants

	N	%
Relationship		
Mother	120	94.5
Father	3	2.4
Grandparent	4	3.1
Gender		
Female	121	96.8
Male	4	3.2
Marital Status		
Married/Partnered	116	92.1
Single <sup>a</sup>	10	8.0
Education		
High school graduate	8	6.3
Some college	38	30.1
Bachelor's degree	42	33.3
Graduate degree <sup>b</sup>	38	30.2
Income <sup>c</sup>		
Less than 50K	28	23.0
50K–150K	64	52.5
More than 150K	25	20.5
Other children		
No other children	35	27.8
1 other child	50	39.7
2 or more other children <sup>d</sup>	41	32.5
Race <sup>e</sup>		
American Indian	1	0.8
Asian	5	4.0
White	113	89.7
Black	0	0
More than one race	4	3.2
Ethnicity <sup>f</sup>		
Hispanic or Latino	9	7.1
Not Hispanic or Latino	115	90.6

Note. Relationship N = 127; Gender, Marital Status, Education, Other children N = 126; Income N = 117, Race N = 123, Ethnicity N = 124

<sup>a</sup> Divorced N = 2, Widowed N = 1

<sup>b</sup> Master's N = 13, Doctorate N = 7

<sup>c</sup> Rather not say N = 5

<sup>d</sup> Three or more other children N = 16

<sup>e</sup> Unsure or rather not say N = 3

<sup>f</sup> Unknown N = 2

### Mental health

CHD parent participants experienced significant anxiety symptoms, depression symptoms, and high levels of perceived stress one year into the COVID-19 pandemic. Most (82%) reported anxiety and over half (64%) confirmed depression symptoms. High levels of stress were experienced by almost all participants (97%) (Figure 2).

Anxiety symptoms ( $M = 60.6$ ,  $SD = 8.4$ ),  $t(126) = 14.21$ ,  $p < .001$ , depression symptoms ( $M = 55.4$ ,  $SD = 8.6$ ),  $t(126) = 7.06$ ,  $p < .001$ , and perceived stress ( $M = 59.1$ ,  $SD = 10.2$ ),  $t(126) = 10.00$ ,  $p < .001$  were significantly higher in CHD parents compared to U.S. general population norms<sup>37</sup> ( $M = 50.0$ ,  $SD = 10.0$ ).

When compared to the U.S. general population during COVID-19, moderate to severe anxiety symptoms,  $\chi^2(1) = 21.43$ ,  $p < .001$  were significantly higher in CHD parents. However, moderate to severe depression symptoms,  $\chi^2(1) = .44$ ,  $p = .51$  in CHD parents were not statistically significantly different compared to the U.S. general population one year into the COVID-19 pandemic. Comparison data were obtained from the U.S. Household Pulse Survey<sup>38</sup> (N = 64,443) during March 17–29, 2020.

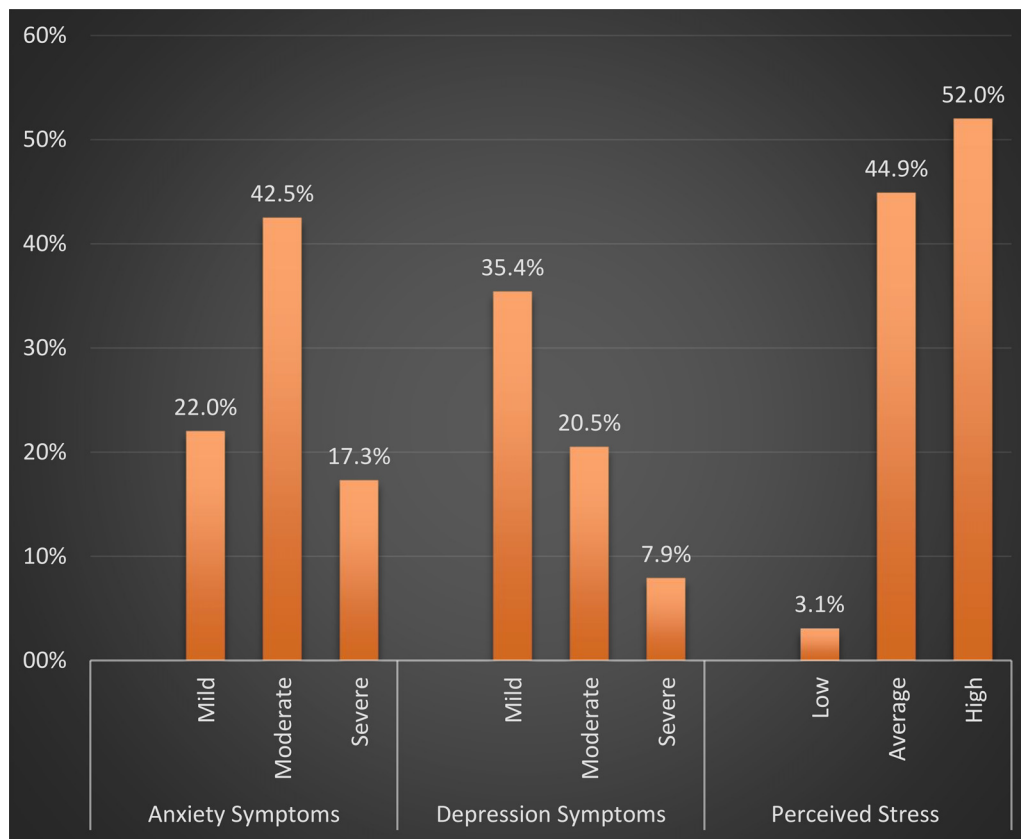
### Risk factors

#### COVID-19 stressors

Many participants experienced pandemic-related stressors that are known to be associated with mental health burden. Over half reported COVID-19 diagnosis in family, healthcare delay, childcare disruption, and decreased social contact (Table 2).

#### CHD care

Over 90% of the study participants had a child with a complex CHD diagnosis (Table 3). Most had experienced at least one in-person medical appointment and over half had a hospitalization during the pandemic. Worry or distress related to healthcare system encounters for CHD care was a consistent finding (Table 4).



**Fig. 2.** Mental Health in CHD Parents During the COVID-19 Pandemic  
 Note: N = 127; Category assignment of variable levels was based on PROMIS score cut points<sup>37</sup>

*Protective factors*

CHD parents reported average or high levels of emotional support (89%) and informational support (91%). However, over half (69%) of the CHD parents were found to have low resilience levels (Figure 3).

There was no significant difference in emotional support ( $M = 51.4, SD = 8.9, t(126) = 1.71, p = .09$ ) between the CHD parents and general population norms<sup>37</sup> ( $M = 50.0, SD = 10.0$ ). However, informational support ( $M = 53.7, SD = 9.9, t(126) = 1.71, p < .001$ ), was significantly higher in the CHD parents. In contrast, resilience scores ( $M = 26.4, SD = 6.4, t(125) = -9.70, p < .001$ ) were significantly lower in the CHD parents compared to U.S. general population<sup>17</sup> ( $M = 32.0, SD = 5.4$ ).

**Table 2**  
 Participant Reported COVID-19 Stressors

	N	%
COVID diagnosis (self)	14	11.0
COVID diagnosis (family/friend)	73	57.9
COVID death (family/friend)	13	10.4
Loss of income	50	39.4
Healthcare delay (self or family)	78	61.4
Health insurance loss (self or family)	7	5.6
Childcare disrupted	94	75.2
Decreased social contact	121	96.8
Total number of COVID-19 stressors experienced		
Less than four	65	51.2
Four or more	62	48.8

Delay N=126; Insurance, Childcare, Social contact N=125; Otherwise, N=127

*Associations between risk / protective factors and mental health*

Regression analysis demonstrated an increased exposure to COVID-19 stressors and worry related to CHD healthcare experiences were associated with increased anxiety symptoms, depression symptoms, and perceived stress. In contrast, increased resilience and external support were predictive of decreased anxiety symptoms, depression symptoms, and perceived stress (Tables 5–7).

**Discussion**

CHD parents experienced substantial mental health burden during the COVID-19 pandemic. Anxiety, depression, and stress were reported at higher levels than general population norms. These results validate previous findings that parents of young children with CHD are a population at higher risk for poor mental health outcomes.<sup>5,13</sup> The additive impact of the COVID-19 pandemic plus CHD care-related worries on this parent population’s mental health is significant.

*Impact of CHD care and COVID-19 risk factors*

The study results demonstrate a relationship between parents’ CHD care-related worries and their mental health during the pandemic. Increased levels of anxiety symptoms, depression symptoms, and perceived stress were associated with 1) Exposure to a greater number of COVID-19-related stressors, 2) Distress from family visitation restrictions during healthcare encounters, 3) Worry related to the perceived risk of their CHD child’s exposure to COVID-19 during healthcare encounters, and 4) Worry about their CHD child’s risk of death or serious illness from COVID-19. This finding aligns with previous studies demonstrating that parents of children with complex

**Table 3**  
Participant CHD Child Diagnosis by Complexity

Simple CHD	Complex CHD
Atrial Septal Defect	Anomalous coronary artery
CoArctation of the Aorta	Aortic Valve Stenosis
Patent Ductus Arteriosus	Atrioventricular Septal Defect
Vascular Ring	Cardiomyopathy
Ventricular Septal Defect	Double Inlet Left Ventricle
	Double Outlet Right Ventricle
	Heart block
	Heterotaxy and Dextrocardia
	Hypoplastic Left Ventricle (i.e., Hypoplastic Left Heart Syndrome)
	Hypoplastic Right Ventricle
	Interrupted Aortic Arch
	Mitral Valve Stenosis
	Pulmonary Atresia
	Pulmonary Valve Stenosis
	Tetralogy of Fallot
	Total or Partial Anomalous Pulmonary Venous Return
	Transposition of the Great Arteries
	Tricuspid Valve Atresia
	Truncus Arteriosus

CHD have elevated levels of perceived child vulnerability and practice vigilant parenting<sup>2,4,26,27</sup> It is likely that these characteristics would be heightened within the context of the COVID-19 pandemic. This may explain the high correlation between the CHD care-related variables of worry/distress and parental depression, anxiety, and perceived stress seen in the study. Considering the critical role of family-centered care in pediatrics, the negative impact of changes in health-care policies that limit family access to sick children is concerning. Careful attention to promoting family-centered care while COVID-19-related restrictions are in place is essential.

### Protective factors

#### Resilience

Resilience emerged as a significant protective factor for anxiety, depression, and stress. This outcome is consistent with early pandemic studies of non-CHD parents that reported the mitigating impact of resilience on anxiety, depression, and COVID-19-related stressors.<sup>28–30</sup> However, in contrast to a pre-pandemic study that showed moderate levels of resilience in mothers of children with CHD<sup>31</sup>, the CHD parents in this study had remarkably low levels of resilience. This is especially concerning as low resilience in parents of children with life-threatening conditions can be a predictor of psychological distress.<sup>22</sup>

Interventions to support resilience may be critical for mitigating the mental health burden of stressful life events in this population. Resilience is a particularly important variable because, unlike CHD and COVID-19, resilience may be modifiable with the use of resilience-enhancing strategies. Evidence in the literature indicates that problem-focused coping, optimism, and social support are key factors for fostering resilience in parents of children with disabilities.<sup>32</sup> Exercise, outside sun exposure, and support from family and friends were predictors of higher resilience in U.S. adults during the pandemic.<sup>33</sup> Research on parents during the COVID-19 pandemic has suggested that strategies addressing social isolation and promoting support help enhance individual resilience.<sup>29,31</sup> Further research is needed to expand our understanding of resilience in CHD parents and how to best support resilience in this population.

#### Support

External support, a composite variable for emotional and informational support, was also found to be a protective factor for anxiety, depression, and stress. The majority of study participants reported a relatively high level of support and, notably, were connected to a CHD parent support group. This finding suggests participation in an

**Table 4**  
CHD Care Variables

	N	%
CHD child age		
Birth to 2 months	25	22.3
13 to 24 months	30	26.8
2 to 5 years	57	50.9
CHD diagnosis complexity <sup>a</sup>		
Simple	8	6.3
Complex	118	93.7
CHD healthcare during pandemic		
CHD diagnosed	28	22
In-person appt	119	93.7
Hospitalization	69	54.3
CHD care delay	59	46.8
Morbidity worry <sup>b</sup>		
Never	2	1.6
Almost Never	3	2.4
Sometimes	17	13.6
Fairly Often	28	22.4
Very Often	75	60
Perceived exposure risk <sup>c</sup>		
No distress	25	19.7
Mild distress	38	29.9
Moderate distress	42	33.1
Severe distress	22	17.3
Visitation restrictions <sup>d</sup>		
No distress	16	12.7
Mild distress	30	23.8
Moderate distress	33	26.2
Severe distress	47	37.3
CHD care delay distress <sup>e</sup>		
No distress	56	49.1
Mild distress	28	24.6
Moderate distress	21	18.4
Severe distress	9	7.9

Appt = appointment; Dx = Diagnosis; CHD care delay = Appt, procedure, or surgery; CHD age N=112; Complexity N=126; CHD care delay N=126; others N=127.

<sup>a</sup> Guidelines from RACHS-1, Aristotle, and STS-EACTS CHD complexity scoring

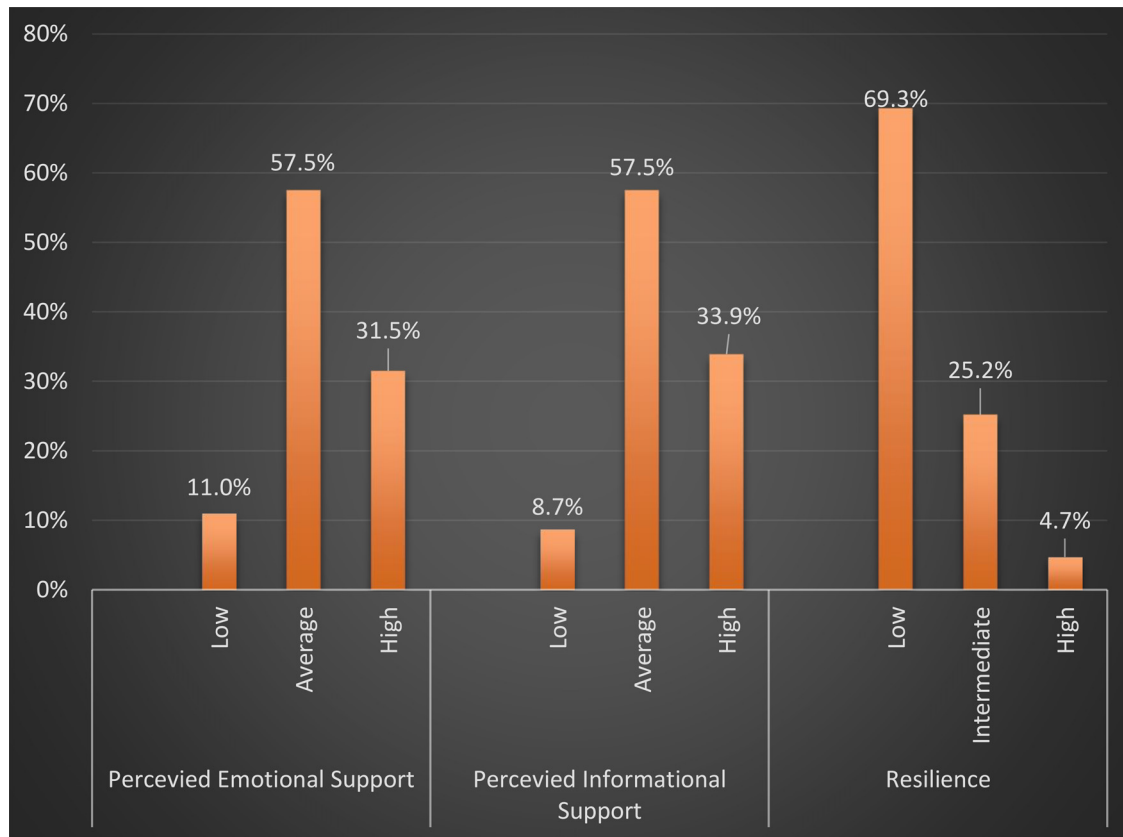
<sup>b</sup> Worry about CHD child risk of death or serious illness from COVID-19 (N=125).

<sup>c</sup> Distress about CHD child risk of exposure to COVID-19

online support group may be an effective strategy for enhancing support among CHD parents. Although average to high levels of support were reported by CHD parents, the correlation between exposure to a higher number of COVID-19 stressors and lower perceived support in this study is also an important finding. CHD parents with higher exposure to COVID-19 stressors may be at greater risk for poor mental health outcomes and may also have higher support needs. Furthermore, since the participants were predominantly members of an online support group, it is not known if support would have been reported differently by those who were not connected to a CHD parent support group. Emotional support and informational support have been found to be predictors of resilience in parents of children with cancer.<sup>34</sup> Thus, healthcare professionals should consider an approach to promoting resilience with strategies that enhance positive protective factors, such as external support, in addition to focusing on how to decrease risk factors.

### Limitations

The use of non-probability sampling presents a selection bias and resulted in a limited or absent representation of some population subgroups in this analysis. Over 90% of the participants had a child with complex CHD. This is in contrast to prevalence study data that estimates only 9% of children have complex CHD in the U.S.<sup>35</sup> As a result, there was poor representation of parents of children with simple CHD.



**Fig. 3.** Support and Resilience in CHD Parents During the COVID-19 Pandemic  
 Note: N = 127; Category assignment of variable levels based on PROMIS score cut points and CD-RISC-10 scoring guidelines<sup>37,17</sup>

**Table 5**  
 Regression Model for Predictors of Anxiety Symptoms

	B	SE	β	95% CI		p
				LL	UL	
(Constant)	72.47	5.57		61.44	83.5	<.001
Resilience	-.39	.11	-.30	-.60	-.18	<.001
External support <sup>a</sup>	-.19	.08	-.21	-.35	-.03	.017
# of COVID stressors	.17	.56	.02	-.93	1.28	.755
Visitation worry <sup>b</sup>	.83	.62	.11	-.39	2.06	.18
Exposure worry <sup>c</sup>	1.75	.77	.21	.22	3.28	.026
Morbidity worry <sup>d</sup>	1.06	.86	.12	-.64	2.76	.22

This group of predictors explained a significant proportion of the variance in anxiety scores,  $R^2 = .38$ ,  $F(6, 117) = 12.16$ ,  $p < .001$ .

Note. B = unstandardized coefficient, β = standardized coefficient, CI = confidence interval, LL = lower limits, UL = upper limits.

<sup>a</sup> Composite variable reflects the mean of emotional support and informational support T scores

<sup>b</sup> Distress about family visitation restrictions during CHD healthcare encounter (N = 126)

<sup>c</sup> Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter

<sup>d</sup> Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

**Table 6**  
 Regression Model for Predictors of Depression Symptoms

	B	SE	β	95% CI		p
				LL	UL	
(Constant)	70.76	5.59		59.68	81.83	<.001
Resilience	-.46	.11	-.34	-.67	-.24	<.001
External support <sup>a</sup>	-.20	.08	-.21	-.36	-.04	.013
# of COVID stressors	.96	.56	.13	-0.15	2.07	.088
Visitation worry <sup>b</sup>	.29	.62	.04	-.94	1.52	.638
Exposure worry <sup>c</sup>	2.01	.78	.23	0.47	3.54	.011
Morbidity worry <sup>d</sup>	.052	.86	.01	-1.66	1.76	.952

This group of predictors explained a significant proportion of the variance in depression scores,  $R^2 = .41$ ,  $F(6, 117) = 13.31$ ,  $p < .001$ .

Note. B = unstandardized coefficient, β = standardized coefficient, CI = confidence interval, LL = lower limits, UL = upper limits.

<sup>a</sup> Composite variable reflects the mean of emotional support and informational support T scores

<sup>b</sup> Distress about family visitation restrictions during CHD healthcare encounter (N = 126)

<sup>c</sup> Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter

<sup>d</sup> Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

Likewise, fathers were underrepresented, and limited racial diversity was noted in the sample. Research studies with CHD parents who are racially diverse, fathers, or single parents and caring for a CHD child during a pandemic are needed. There is a paucity of information in the literature on the mental health burden of non-white parents of children with CHD. Specifically, the relationship between race as a health disparity variable and parental stress has not been extensively examined in the pediatric cardiac literature.<sup>25</sup>

Recruiting from CHD parent support groups also contributed to the selection bias. The CHD parents in the study sample may have greater access to support resources compared to CHD parents who are not a part of a support group. This is particularly of interest considering the role of support as a protective factor for negative mental health outcomes. Snowball sampling was implemented during recruitment to expand enrollment through networking. Despite these efforts, the sample's homogeneity limits the generalizability of the study results. Additional research is needed to evaluate the



**Table 7**  
Regression Model for Predictors of Perceived Stress

	B	SE	$\beta$	95% CI		p
				LL	UL	
(Constant)	82.44	6.37		69.82	95.05	<.001
Resilience	-.76	.12	-.48	-1.00	-.51	<.001
External support <sup>a</sup>	-.21	.09	-.18	-.38	-.03	.024
# of COVID stressors	.81	.64	.09	-.45	2.07	.207
Visitation worry <sup>b</sup>	1.06	.71	.11	-.34	2.46	.136
Exposure worry <sup>c</sup>	1.45	.89	.14	-.30	3.21	.103
Morbidity worry <sup>d</sup>	.11	.98	.01	-1.84	2.06	.912

This group of predictors explained a significant proportion of the variance in perceived stress scores,  $R^2 = .46$ ,  $F(6, 117) = 16.44$ ,  $p = <.001$ .

Note. B = unstandardized coefficient,  $\beta$  = standardized coefficient, CI = confidence interval, LL = lower limits, UL = upper limits.

<sup>a</sup> Composite variable reflects the mean of emotional support and informational support T scores

<sup>b</sup> Distress about family visitation restrictions during CHD healthcare encounter (N = 126)

<sup>c</sup> Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter

<sup>d</sup> Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

validity and reliability of the PI developed COVID-19 and CHD care surveys in this population. Lastly, the absence of qualitative data limits access to the full breadth and depth of the CHD parent experience.

#### Implications for practice and future research

The additive impact of the COVID-19 pandemic plus CHD care-related worries on this parent population's mental health is significant. This research offers insight into the risk and protective factors affecting CHD parents who interacted with the healthcare system during a global pandemic. Notably, novel data has been provided on parental distress from CHD-related care and historic changes in healthcare policy limiting family visitation. A greater focus on how to circumvent healthcare system changes that conflict with family-centered care is warranted.

This research contributes to previous work demonstrating the protective role of resilience and external support during stressful life events. Of particular importance, this study introduces data that shows low resilience in CHD parents during a pandemic. Further work needs to be done to expand our understanding of resilience in CHD parents and to explore strategies that may enhance individual resilience. Strategies that promote individual resilience, identify external support resources, promote family-centered care, and provide timely referral to mental health services are needed for parents of young children with CHD during this and future pandemics.

#### Conclusion

This research offers evidence that CHD parents may be at higher risk for adverse mental health outcomes during the COVID-19 pandemic. Elevated levels of anxiety, depression, and stress were reported in parents of young children with CHD from the U.S. and Canada. This data supports early pandemic study reports of associations between experience of specific COVID-19-related stressors and anxiety, depression, & stress. More broadly, the study findings may enhance our understanding of the mental health burden experienced by parents of children with life-threatening conditions during a public health crisis.

#### Declaration of Competing Interest

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#### Appendix A

##### COVID-19 Related Stressors Survey

##### **COVID stressor exposure**

During the COVID-19 pandemic (from March 2020 to the present day) ...

1. I was diagnosed with COVID-19

**Yes No**

2. Someone close to me (family or close friend) was diagnosed with COVID-19

**Yes No**

3. Someone close to me (family or close friend) died from COVID-19

**Yes No**

4. I (or my partner) lost my job or have had a decrease in income

**Yes No**

5. Someone in our family had a medical appointment, procedure, or surgery that was delayed or canceled during the COVID-19 pandemic

**Yes No**

6. Someone in our family temporarily or permanently lost their health insurance during the COVID-19 pandemic

**Yes No**

7. Childcare or school for our child(ren) was disrupted during the COVID-19 pandemic

**Yes No**

8. I have had to decrease my social contact with family or friends during the COVID-19 pandemic due to social distancing mandates

**Yes No**

##### **COVID stressor worry**

In the past month...

9. I worry about getting the COVID-19 infection.

**Never Almost Never Sometimes Fairly Often Very Often**

10. I worry about someone in my family getting the COVID-19 infection.

**Never Almost Never Sometimes Fairly Often Very Often**

11. I worry that my child with CHD could become seriously ill or die if he/she got the COVID-19 infection

**Never Almost Never Sometimes Fairly Often Very Often**

12. I worry about being able to pay the rent/mortgage/ bills

**Never Almost Never Sometimes Fairly Often Very Often**

13. I worry about being able to get the food needed for my family

**Never Almost Never Sometimes Fairly Often Very Often**

14. I worry about being able to get the medication(s) needed for my child with CHD

**Never Almost Never Sometimes Fairly Often Very Often**

15. I worry about being able to make childcare or school arrangements for my child with CHD

**Never Almost Never Sometimes Fairly Often Very Often**

16. I worry about my other child(ren)'s education during the COVID-19 pandemic

**Never Almost Never Sometimes Fairly Often Very Often**

17. I worry about being able to manage working from home

**Never Almost Never Sometimes Fairly Often Very Often**

18. I worry about not having enough social contact with family or friends

**Never Almost Never Sometimes Fairly Often Very Often**

## Appendix B

### CHD Care Variables Survey

1. The age of my child with CHD is:

\_\_\_\_ (weeks, months, years) old

2. The name of my child's CHD is: (Check all that apply)

**Patent Ductus Arteriosus Atrial Septal Defect Ventricular Septal Defect CoArctation of Aorta Vascular Ring Transposition of Great Arteries Truncus Arteriosus Tetralogy of Fallot Hypoplastic Right Ventricle Hypoplastic Left Ventricle Atrioventricular Septal Defect Total Anomalous Pulmonary Venous Return Other \_\_\_\_\_**

3. My child was diagnosed with a congenital heart defect (CHD) during the COVID-19 pandemic (anytime from March 2020 to the present day)

**Yes No**

4. My child with CHD had a cardiac clinic appointment during the COVID-19 pandemic (anytime from March 2020 to the present day)

**Yes No**

If yes, what type of visit? (Check all that apply)

**In-person visit Virtual visit Telephone visit**

5. My child with CHD was admitted to the hospital during the COVID-19 pandemic (anytime from March 2020 to the present day)

**Yes No**

If yes, for what reason? (Check all that apply)

**Heart surgery Cardiac procedure Medical management of the cardiac condition**

6. My child with CHD had a medical appointment, procedure, or surgery that was *delayed or canceled* during the COVID-19 pandemic (anytime from March 2020 to the present day)

**Yes No**

If yes, what type of medical encounter was delayed or canceled: (check all that apply)

**Cardiac clinic appointment Cardiac procedure Cardiac surgery CHD care-related distress**

7. How much distress have you experienced related to the delay or cancellation of your child's CHD medical appointment, procedure, or surgery

**1 2 3 4 5**

**No Distress Extreme Distress**

8. How much distress have you experienced related to the restrictions on family visitation during a cardiac clinic visit or hospitalization

**1 2 3 4 5**

**No Distress Extreme Distress**

9. How much distress have you experienced related to having to wear a mask during a cardiac clinic visit or hospitalization

**1 2 3 4 5**

**No Distress Extreme Distress**

10. How much distress have you experienced related to worrying about you or your child getting the COVID-19 virus during a cardiac clinic visit or hospitalization

**1 2 3 4 5**

**No Distress Extreme Distress**

## Appendix C

### Study Survey Development Resources

**COVID-19-19 OBSSR Research Tools** (NIH Office of Behavioral and Social Sciences)

[https://www.nlm.nih.gov/dr2/COVID-19-19\\_BSSR\\_Research\\_Tools.pdf](https://www.nlm.nih.gov/dr2/COVID-19-19_BSSR_Research_Tools.pdf)

**COVID-19 19 Exposure and Family Impact Survey** (CEFIS), Kazak, A (2020) Nemours Children's Health Center

**Psychological Stress Associated with the COVID-19-19 Crisis**, Adamson, M (2020) Stanford University

**Understanding America Study: Health Tracking Long Survey**, Darling, J (2020) University of Southern California

### Vanderbilt Child Health COVID-19-19 Poll

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### COVID-19 Stress Scale

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