Anxiety, Depression, and Stress in Parents of Children with Congenital Heart Defects During the COVID-19 Pandemic: An Examination of Risk and Protective Factors

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Abstract

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Little is known about the mental health burden or the risk and protective factors that have impacted mental health outcomes in parents of children with congenital heart defects (CHD) during the COVID-19 pandemic. Exposure to COVID-19 related stressors plus CHD care related stressors may have had an additive effect on this parent population's mental health. 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. The study used a cross-sectional, nonexperimental survey design that focused on parents of children aged newborn to five years with CHD one year into the COVID-19 pandemic. The findings reveal CHD parents experienced significant anxiety, depression, and stress during the COVID-19 pandemic at levels higher than the US general population norms. Regression analyses were conducted to examine associations between COVID-19 stressors, CHD care related factors, parental resilience, external support, and mental health outcomes.

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. Parental resilience, emotional support, and informational support were shown to be key protective factors for anxiety, depression, and stress. However, resilience was remarkably low in CHD parents. Further research is needed to expand our understanding of resilience in CHD parents and to explore strategies that may support resilience in this population.

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Finally, I would like to express my gratitude for my family and friends-- Don, Karol, Golda, Sheri, Mike, Eric, Cleita, and Sandy who have lovingly stood by me during my PhD journey.

Dedication

I dedicate this dissertation to my daughter, Elliana. You have inspired me to grow. I am honored to have been chosen to walk by your side in this journey of life. I am humbled by the human experience of simultaneous joy and pain. My precious warrior, I wish to leave you a legacy of wonder. I love you and I believe in you.

Chapter 1. Introduction

Researchers estimate over one million children in the US have a congenital heart defect (CHD) (CDC, n.d.). 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 (Cantwell-Bartl & Tibballs, 2017, Meakins et al., 2015, Rempel & Harrison, 2007, Woolf-King et al. 2017). During COVID-19, these challenges were exacerbated by the social isolation caused by risk reduction mandates, fewer in-person medical appointments, and concerns about the CHD child's risk for contracting the virus (Marino et al., 2020). These additional 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. 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 and the knowledge that their child may have an increased risk of COVID-19 severity due to their cardiac defect (CDC, n.d.). 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.

Approximately 25% of CHD families have a child with a critical cardiac defect who will need heart surgery in their first year of life (CDC, n.d.). 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 (CDC, 2020). Additionally, parents had

to navigate the pandemic-affected healthcare system for the medical appointments and hospitalizations needed to monitor and treat their child's cardiac condition (CDC, n.d.).

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 (American Academy of Pediatrics, n.d.). The presence of family and friends can be a critical source of support for parents during the stress of a child's hospitalization. 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 (Biber et al., 2019; Vrijmoet-Wiersma et al., 2020; Lawoko & Soares, 2002; Soulvie et al., 2012; Woolf-King et al., 2017). 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 (Tam et al., 2020). Thus, an examination of resilience in CHD parents during the COVID-19 pandemic can help us better understand the role of resilience in protecting these parents from negative mental health outcomes.

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. To do so, this study addressed three research questions: "What is the severity of anxiety and depression symptoms reported by parents of young children with CHD during the COVID-19 pandemic?", "How are COVID-19 factors and CHD care factors related to CHD parents' anxiety symptoms, depression symptoms, and perceived stress?", and "How were individual resilience levels and perceived external support related to anxiety, depression, and perceived stress in CHD parents 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.

1a) Compare anxiety symptoms, depression symptoms, perceived stress, emotional support, informational support, and resilience levels in parents of young children with CHD with the US adult population pre-pandemic norms.

1b) Compare anxiety symptoms and depression symptoms in parents of young children with CHD with the US adult population COVID-19 pandemic norms.

1c) Compare anxiety symptoms, depression symptoms, and perceived stress in parents of young children with CHD among sample subsets grouped by demographic factors (i.e., education, income, number of other children), COVID-19 related stressors, and CHD care related factors.

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.

Significance

This study's 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 clinicians 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. Ultimately, exploring the risk and protective factors associated with increased mental health burden for CHD parents in the context of a pandemic may contribute to our understanding of parents of children with other life-threatening conditions who must also navigate the healthcare system while exposed to increased adversity.

Chapter 2. Review of the Literature

Mental Health During the COVID-19 Pandemic

Data collected in the first few months of the pandemic revealed increased anxiety, depression, and stress related to COVID-19 in American households (Daly & Robinson, 2020; Holingue et al., 2020; Kapteyn et al., 2020). Parents in the US reported increased stress during the pandemic when compared to their pre-COVID-19 stress levels (Adams et al., 2021).

Furthermore, parental stress was a risk factor for negative mental health outcomes. An investigation of parental stress by Brown et al. (2020) found most parents experienced high levels of anxiety symptoms and depression symptoms during the early weeks of the COVID-19 pandemic in the US. The worsening of parental mental health and children's behavioral health were at times intertwined, with nearly one in ten families reporting the worsening of both (Patrick et al., 2020).

Psychological Distress in Parents of Young Children

Parents of infants and young children experienced particularly high rates of psychological distress during the COVID-19 pandemic. In a Canadian study, researchers investigated the presence and risk factors of anxiety and depression in mothers of young children six weeks into the COVID-19 pandemic (Cameron et al., 2020). The findings revealed maternal anxiety and depression were significantly elevated compared to population norms prior to the pandemic. In their analysis, Cameron et al. (2020) reported variables such as employment loss and/or financial strain, recent stressful experiences in the past month, and stressful experiences in the past year were significant risk factors for anxiety and depression in mothers of infants and young children.

In the US, researchers explored the impact of the COVID-19 pandemic on mental health in the perinatal period and found elevated rates of stress and mood disorders such as anxiety and depression (Farewell et al., 2020). Uncertainty and lack of support were found to be major sources of stress for mothers of infants. Specifically, the risk of infant exposure to COVID-19 and the lack of consistent communication and guidelines from providers were reported as the most common causes of uncertainty. Moreover, the absence of daycare and caregiver support as well as social isolation were described as sources of stress for these mothers.

COVID-19 Related Risk Factors

Pandemic Risk Reduction Strategies

Pandemic risk reduction strategies during the COVID-19 pandemic caused significant lifestyle disruption and imposed isolation by mandating the mass restriction of individual activities and social contact. Government leaders employed risk reduction strategies such as mask wearing, social distancing, and confinement (i.e., stay-at-home orders and quarantine) (CDC, n.d.). Substantial changes took place in all areas of industry and service settings. Families had to cope with new parenting demands created when COVID-19 related directives affected the function of schools and childcare as well as altered the work-place environment. Many parents experienced psychological distress from COVID-19 related confinement, lifestyle disruption, and increased caregiver burden due to social restrictions and changes in the community infrastructure. Reasons for this distress are presented below.

Confinement

Historically, the use of confinement measures such as quarantining and stay-at-home orders have contributed to increased stress and adverse mental health outcomes during epidemics. Brooks et al. (2020) described the distress experienced due to quarantine in a report of 24 studies representing people from 10 countries with SARS, Ebola, H1N1, MERS, or Equine Influenza. The review found that people who were quarantined reported emotional disturbance, depression, stress, low mood, irritability, insomnia, post-traumatic stress symptoms, anger, and emotional exhaustion. Low mood and irritability had the highest prevalence (>50%). The dominant sources of stress from quarantine, extrapolated from the review, were the duration of quarantine, fear of infection, frustration and boredom, inadequate supplies, and inadequate

information (Brooks et al., 2020). The duration of quarantine (especially >10 days) was associated with higher post-traumatic stress symptoms. Notably, mothers with young children were more concerned about becoming infected or transmitting the virus to others. Frustration, boredom, and feeling isolated were reported as a result of reduced social and physical contact, loss of routine, and confinement. Inadequate food/shelter and lack of access to medication or medical care were also sources of stress that were associated with prolonged (i.e., 4-6 months after quarantine) anxiety and anger. Lastly, unclear guidelines from health authorities, confusion about the purpose of quarantine, and uncertainty about levels of risk increased fear and predicted post-traumatic stress symptoms for some mothers.

Early studies during the COVID-19 pandemic revealed that quarantine was associated with elevated stress levels, contributed to psychological distress in parents, and had a negative impact on family functioning. Researchers examined the impact of COVID-19 on parenting stress in the early stages of the pandemic. In a study conducted by Chung et al. (2020), online surveys were used to collect data from parents of young children living in Singapore during the two months that mandatory mass quarantine orders were instituted by the government. The findings from this work demonstrated a positive correlation between parents' perception of the impact of the COVID-19 pandemic and their measured stress level. In another study, researchers explored the impact of COVID-19 on parental and couple functioning during the first few weeks of Spain's regulated lockdown (Günther-Bel et al., 2020). Data was collected via online surveys to examine psychological distress (i.e., anxiety and depression), relationship functioning, and perceived changes in family dynamics during confinement. Günther-Bel et al. (2020) noted that most participants reported high levels of uncertainty and situational (state) anxiety, but a relatively small percentage demonstrated evidence of clinical depression. In their analysis of the

qualitative data regarding perceptions of family change during the confinement, females reported more conflict (e.g., increased tension, arguments, resurfacing of old issues). Deterioration themes such as loneliness (e.g., emotional isolation between family members, less time with significant others, missing extended family) and unbalanced family needs (e.g., uneven task distribution, overwhelming childrearing burdens, no personal space) were associated with the presence of young children and with the need to cope with health problems in the household. Thus, COVID-19 related stressors arising from confinement early in the pandemic were found to influence relationship functioning, lead to changes in family dynamics, and act as a mediator for anxiety, depression, and stress in parents.

In the US, stay-at-home orders were implemented in the first few months of the pandemic (Moreland et al., 2020). Stay-at-home orders stipulated that people stay in their residence except for essential activities, such as shopping for food or medication. Also known as sheltering in place, this was a "community mitigation strategy used to reduce the spread of COVID-19" (CDC, n.d.). Public health officials in the US and internationally also used quarantine as a strategy to prevent the spread of COVID-19. Quarantine mandates the separation and restriction of movement of people who have potentially been exposed to the virus (CDC, n.d.). However, even as nation-wide shelter-in-place orders were lifted, families of children with underlying medical conditions, such as cardiac conditions, were still advised to stay at home as much as possible as they were at increased risk for severe illness from COVID-19 (American Heart Association, 2020). Consequently, the risk and uncertainty of COVID-19 combined with prolonged isolation posed additive sources of stress for parents of children with high-risk conditions. While previous epidemics revealed adverse mental health outcomes, COVID-19 was

an unprecedented global pandemic that spanned more than a year. Consequently, COVID-19 has had a profound impact on families, the extent of which is not yet fully realized.

Lifestyle Disruption

Several national surveys of US families in the early months of the COVID-19 pandemic demonstrated the relationship between lifestyle disruption from the pandemic and psychological distress. Perceived risk of COVID-19 infection, economic impact, and lifestyle changes related to the pandemic were mediating factors of psychological distress in one of the largest pandemic observational studies in the US (Daly & Robinson, 2020). Among parents, worsening mental health was reported in those who experienced increased food insecurity, decreased insurance coverage, or loss of regular childcare (Patrick et al., 2020). For low-income families, parenting-specific challenges, such as changes in family structure and routine, were associated with higher perceived stress levels during the pandemic (Adams et al., 2021). Differences among racial or ethnic groups were seen in one study that examined the impact of the pandemic on parental stress. Brown et al., (2020) reported Hispanic parents experienced a higher number of COVID-19 related stressors compared to white and Black parents. The authors posit this finding may be related to conflict between following social distancing mandates and the value placed on family proximity and contact in the Hispanic culture. In contrast, Patrick et al. (2020) reported worsening parental mental health in the early pandemic was similar among white, Black, and Hispanic groups. Moreover, the additive effect of the accumulation of stressors, such as changes that impacted health, safety, and economic well-being due to COVID-19, was a key risk factor for higher perceived stress in parents (Brown et al., 2020). As the research has shown, the level and type of disruption in daily life due to COVID-19 were important risk factors for mental health outcomes in parents during the early months of the pandemic.

Caregiver Burden

Caregiver burden has been linked to negative mental health outcomes in parents during the COVID-19 pandemic. Researchers in the US examined the patterns of parents' reported experiences during the early months of the COVID-19 pandemic. Utilizing quantitative methods, Russell et al. (2020, p. 673) explored the research questions, "Are there associations from the sustained burden created by the COVID-19 pandemic on parents' relationships with their children?" and "What role do mental health symptoms play?" They recruited a sample of 420 parents for data collection through an anonymous online survey. Unlike many family-focused research projects, fathers were equally represented in this study. Male caregivers reported higher rates of depression symptoms, caregiver burden, and perceived child stress. Parents of young children (i.e., age 0 to 5 years) experienced higher levels of stress and caregiver burden than parents of older children. Furthermore, caregiver burden was shown to be a direct predictor of anxiety and depression for both mothers and fathers during the COVID-19 pandemic.

CHD Care Related Risk Factors

Anxiety and Depression in CHD Parents

Pre-pandemic studies have shown the presence of psychological distress and parenting challenges among parents of children with CHD. In a quantitative study of over 1000 families, researchers in Sweden reported that distress, measured by anxiety and depression scores, was higher in parents of children with CHD when compared to parents of healthy children (Lawoko & Soares, 2002). Specifically, they found a greater risk of anxiety, depression, and post-traumatic stress disorder (PTSD) in parents of young children (age 0-5 years old) with CHD. Similarly, elevated distress, anxiety, worry, and concern have been described in systematic

reviews examining the mental health impact of parenting a child with CHD (Biber et al., 2019; Soulvie et al., 2012).

Qualitative researchers have highlighted some of the unique parenting challenges reported by parents of children with CHD. Carey et al. (2002) conducted a mixed method study to compare the early child parenting practices of 30 mothers of children with CHD aged 2 to 5 years to a group of 30 mothers of healthy children of the same age. Specific themes that represented the parenting practices of mothers of children with CHD in the interviews included the following: experiencing the unexpected, fear, and uncertainty, maintaining vigilance, trying to keep a positive outlook, attempting to normalize, and adapting to the presence of stress. A key finding revealed a higher level of vigilance in mothers of children with CHD compared to mothers of healthy children. Thus, research has demonstrated that mothers of children with CHD faced psychological distress and uncertainty during pre-pandemic times. These previous studies indicate that CHD mothers are a vulnerable population and suggest they may have an elevated risk for mental health problems during times of adversity.

Uncertainty, Vigilance, and Perceived Child Vulnerability

Fear for their child's health and uncertainty about the future were among the most prevalent sources of stress and anxiety in parents of children with CHD (Vrijmoet-Wiersma et al., 2020). When compared to parents of healthy children, parents of children with CHD scored significantly higher on measurements of perceived child vulnerability, anxiety, and stress. In one systematic review of the literature representing several countries, Woolf-King et al. (2017) revealed an increased presence of psychological stress in parents of young children with CHD. In this review, the concept of psychological distress was assessed through measures or reports of stress, worry/concern, anxiety, and depression. The review cited studies reporting a high (30-

50%) prevalence of symptoms of depression and PTSD associated with hospitalization for surgery in parents of children with CHD. Longitudinal studies in the review noted that symptoms may persist for months or even years. Consequently, the fear, uncertainty, and traumatic stress of hospitalization associated with parenting a child with a life-threatening condition have been shown to be factors that contributed to psychological distress in parents of children with CHD during pre-pandemic times.

Complex CHDs such as Hypoplastic Left Heart Syndrome (HLHS) have a particularly high risk of morbidity and mortality. As such, researchers have explored the concepts of vigilance and hypervigilance in this population of families. Cantwell-Bartl and Tibballs (2017) conducted a retrospective mixed methods study with semi-structured interviews and psychometric testing of 29 parents of 16 children (age 1 to 19 years) who had undergone surgery for HLHS. The central theme identified was the stress parents felt due to worrying about their child's health. Hypervigilance was described by parents as "always watching to make sure they are alright" and "fear that the child would die imminently" after discharge from the hospital (Cantwell-Bartl & Tibballs, 2017, p.1344). In another study, Meakins et al. (2015) performed a secondary analysis of 55 interviews from two studies of parents of young children with HLHS to further explore the theme of parental vigilance. They found parental action was characterized by both vigilance and exaggerated vigilance in areas such as protection (e.g., from infection) and monitoring (e.g., the child's health status, nutrition, and medication tolerance). Parental actions like being unable to leave the child, over-focusing on the child's care, being unable to break routines, sleeping in the same bed as the child, or frequent physical monitoring of the child were coded as exaggerated vigilance. Some parents acknowledged the use of exaggerated vigilance but reasoned it was in the best interest of the child. The authors suggested that persistent

uncertainty about a child's long-term survival and the medical demands of the complex condition of HLHS directed and required vigilant parental actions. This study introduced the notion that hypervigilance may perform a vital function in parenting a child with particularly complex types of CHD.

The process of parenting a child with a complex cardiac disease (i.e., HLHS) was further explored by Rempel and Harrison (2007). The authors conducted interviews with 16 parents of 9 children age 2 months to 5 years old with HLHS. The major theme identified in the findings was referred to as "extraordinary parenting in the context of uncertainty" (p. 827). This parenting style was characterized as a process of safeguarding their child's survival (p. 833). This research builds on previous studies' findings of the potential functionality of vigilant parenting behaviors and the presence of a high parent perceived child vulnerability state of mind (Cantwell-Bartl & Tibballs, 2017, Meakins et al.2015).

Navigating the COVID-19 Affected Healthcare System

Risk of Exposure to COVID-19. In addition to coping with pandemic related lifestyle changes, parents of children with CHD also had to navigate the COVID-19 affected healthcare system during the medical encounters needed to monitor and treat their child's cardiac condition (CDC, n.d.). Evidence from the early pandemic suggests that young children with CHD are at higher risk for cardiac involvement from COVID-19, such as heart failure, and that these children should be monitored closely (Bezerra et al., 2020; Salik & Mehta, 2020; Simpson et al., 2020; Tan & Aboulhosn, 2020). However, some parents reported delaying medical care for their CHD child due to parental fear of exposing them to COVID-19, the unavailability of healthcare providers due to the pandemic, or being discouraged to access hospitals because of the risk of infection (Lazzerini et al., 2020). In a study of school age children with CHD, over 80% of

parents reported fear of COVID-19's potential impact on their child's cardiac health, felt they had not received adequate information from their cardiac providers, and wanted information specific to their child's cardiac diagnosis (Marino et al., 2020). The majority of these parents reported they did not rely on official advice and decided to isolate their child at home based on their own instincts. Many worried about health care professionals coming into their homes and felt hospitals were no longer safe. Thus, parents of children with CHD were forced to risk exposure to COVID-19 by bringing their child into the healthcare system while reconciling that action with the knowledge that individuals with pre-existing conditions, such as cardiac disease, were at high risk for mortality and morbidity from the virus (CDC, 2020).

Care Delays and Family Visitation Restrictions. The pandemic created a significant burden to the healthcare system. Hospitals in the US reported challenges in the areas of 1) COVID-19 testing, supplies, and equipment, 2) workforce allocation, and 3) capacity (Department of Health and Human Services, 2020). Clinic closures and surgery delays were implemented nationally for the preservation or redirection of limited resources and to decrease COVID-19 exposure (Diaz et al., 2020). Many individuals with non-COVID-19 medical conditions needing healthcare during the pandemic experienced limited access to in-person care and were directed to telehealth services. Furthermore, risk reduction efforts led to healthcare policy changes during the pandemic. Early COVID-19 related healthcare policy changes limited the availability of many pediatric cardiac services (Cardinal et al., 2020; Faraoni et al., 2020; Nicoara et al., 2020; Wood et al., 2020). For example, an estimated 90% of pediatric cardiology office visits, procedures, and scheduled corrective heart surgeries in the Puget Sound region were canceled by providers during the first three months of the COVID-19 pandemic to minimize patient risk for COVID-19 infection (C. Bellotti, personal communication, September 25, 2020;

J. Penalver, personal communication, September 23, 2020; T. Seick, personal communication, September 19, 2020). Similarly, in an early pandemic study in the UK, over 80% of parents of school age children with CHD reported their child's healthcare appointments or surgeries had been rescheduled (Marino et al., 2020).

As the pandemic moved from an acute to a chronic phase, medical and surgical services fluctuated between various stages of reopening, and hospitals implemented historic changes in pediatric healthcare policies that mandated restrictions on family attendance during children's healthcare visits and hospitalizations (American Academy of Pediatrics, n.d.). COVID-19 related policy changes were implemented by hospitals in an effort to reduce public health risk by limiting visitation of family members during hospitalizations, procedures, and clinic appointments. As a result of these changes, parents of children with CHD had to navigate healthcare organizations that no longer allowed siblings to be present and that stipulated only one adult caregiver could accompany the child during medical encounters.

Protective Factors

Emotional and Informational Support

For many parents, external support, comprised of emotional and informational support, was a protective factor for parental stress during the early months of COVID-19 (Brown, et.al., 2020). Brown et al. (2020) found level of external support and perceived control act as protective factors and were associated with a decrease in parents' perceptions of stress. Moreover, adults who reported greater perceived family support and support from a significant other were associated with greater ability to cope in the first few weeks of the pandemic (Killgore, 2020).

Lack of support has been explored as a variable that can contribute to CHD parents' experience of distress. Lawoko & Soares (2003) found mothers of children with CHD experienced low levels of emotional support compared to mothers of healthy children. Moreover, they reported an association between low support and psychological distress. For CHD parents, important sources of informational support from their healthcare team include access to services, provider availability, and communication/information sharing (Marino, et al., 2020).

Resilience

The trait of resilience, the ability to cope with stress and adapt to change when faced with adversity (e.g., the challenges of the COVID-19 pandemic), is of interest as a potential protective factor in this study (Connor & Davidson, 2003). According to resilience theory, this trait affects the psychological impact of adversity, a chronic or acute process experienced when an individual encounters significant life stress (Van Breda, 2018).

After a scoping literature review, studies that measured resilience in CHD parents during the COVID-19 pandemic were not found. However, one study examined resilience in US adults during the first few weeks of the COVID-19 pandemic and reported significantly low levels of resilience (Killgore et al., 2020). Moreover, lower resilience scores were associated with higher levels of anxiety and depression. In other early pandemic studies, the role of resilience as a protective factor for anxiety, depression, and COVID-19 related stressors was documented in non-CHD parents (Barzilay et al., 2020; Mikocka-Walus et al., 2021; Song et al., 2021).

Two components of resilience, coping and optimism, were mentioned in one study of mothers early in the COVID-19 pandemic (Farewell et al., 2020). In this study, coping strategies such as getting outdoors, focusing on gratitude, managing expectations, maintaining structure,

and establishing a routine were identified as supportive for mothers of infants. Optimism, or having a positive outlook, is another aspect of resilience. Mothers with optimism described increased connection with their families and partners, shared caregiver responsibilities, and increased access to remote healthcare as positive impacts of the COVID-19 pandemic (Farewell et al., 2020).

Lack of diversity in research samples

It is important to note the paucity of research that includes non-white CHD parents. While 36% of children with CHD are non-white (Gilboa et al., 2016), they are underrepresented in research. See Appendix F for the percent of non-white participants in the CHD studies reviewed.

Conceptual Framework

The image of a seesaw illustrates the contribution of risk factors and protective factors to the dynamic nature of mental health outcomes in CHD parents (**Figure 1**). Anxiety, depression, and stress are the mental health outcomes of interest in this study. Having a child with CHD is challenging due to the additional health related care demands and uncertainty associated with parenting a child with a serious health condition. CHD care factors affecting the mental health of parents include the stressful experience of receiving the CHD diagnosis, the trauma of hospitalizations, and ongoing concerns about safeguarding their child's survival. This study addresses the added impact of the global COVID-19 pandemic on these parents. COVID-19 factors that contribute to increased anxiety, depression, and stress include lifestyle disruption, financial strain, social isolation, caregiver burden, and fear of themselves or their child contracting the COVID-19 infection. Potential protective factors for CHD parents are perceived

external support and individual resilience. Thus, the seesaw model shows how risk factors, including COVID-19 stressors and CHD care factors, can tip the scale towards negative mental health outcomes, while protective factors, support and resilience have the potential to tip toward more positive outcomes. Resilience is a particularly important variable because unlike CHD and COVID-19, resilience is modifiable.

Chapter 3. Methods

Research Design

This study employed a cross-sectional, nonexperimental survey design to examine symptoms of anxiety and depression 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. Twenty-four of the individuals recruited were not enrolled in the study as they met one or more of the exclusion criteria. An additional twenty-four participants were excluded from analysis due to missing survey or demographic data. Thus, the final sample size for the study was 127 participants (**Figure 2**). 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 (also known as chain-referral sampling) was implemented during recruitment to expand enrollment through networking. A message was added at the end of the survey encouraging participants to share the link to the study with other CHD families. 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 study met the criteria for exempt status. 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. Enrollment took place from February 26, 2021, through April 9, 2021, approximately one year into the COVID-19 pandemic.

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. Anxiety symptoms, depression symptoms, perceived stress, external support, resilience, COVID-19 related stressors, and CHD care related factors were obtained from self-report measures embedded in the online survey. A table listing the study variables and instruments is provided in Appendix A.

Outcome Variables

Anxiety. Anxiety symptoms measured by the PROMIS Anxiety instrument short form 4a are defined by self-reported fear, worry, concern, or hyperarousal (HealthMeasures, n.d.). The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores indicate more anxiety. Reliability and validity have been established, and reference scores for anxiety in the general adult population are available for statistical comparison (Cella et al., 2010; HealthMeasures, n.d.).

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 (HealthMeasures, n.d.). The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores

indicate more depression. Reliability and validity have been established, and reference scores for depression in the general adult population are available for statistical comparison (Cella et al., 2010; HealthMeasures, n.d.).

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 (HealthMeasures, n.d.). 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. Reliability and validity have been established, and reference scores for stress in the general adult population are available for statistical comparison (Salsman et al., 2013; HealthMeasures, n.d.).

Risk Factors

COVID-19 Stressors. A COVID-19 related stressor survey was developed by the PI for the study. The survey items (**Appendix B**) were adapted or informed by NIH-supported COVID-19 related measurement tools and peer-reviewed publications (**Appendix D**). 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 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. The five significant domains of COVID-19 related stressors are as follows.

1. COVID-19 infection

    Perceived risk of contracting COVID-19 infection

    Perceived risk to CHD child's health from a COVID-19 infection

  Direct exposure

    Participant diagnosed with COVID-19

    Friend or family member diagnosed with COVID-19

    Friend or family member death due to COVID-19

2. Financial insecurity

    Loss of employment or decrease in income

3. Food insecurity

    Worry about getting the food needed for the household

4. Reduced access to healthcare

    Delay or cancellation of medical care appointment, procedure, or surgery

    Disruption or loss of health insurance

    Worry about getting needed prescription medications

5. Lifestyle changes

    Disruption or loss of childcare

    Managing school for a child(ren) at home

    Navigating working from home

    Limitations on social contact with family or friends

CHD Care Variables. A CHD care related variables survey was developed by the PI for the study. The survey items (**Appendix C**) were adapted or informed by CHD literature, NIH-supported COVID-19-related measurement tools, and peer-reviewed publications (**Appendix D**). CHD care related factors associated with parental psychological distress in previous studies were used to identify domains of CHD care related variables for this study. 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 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 domains of CHD care related variables are as follows.

1. CHD diagnosis during COVID-19
2. Cardiac clinic in-person appointment during COVID-19
3. Cardiac related hospitalization during COVID-19
4. Delay or cancellation of a cardiac clinic appointment, procedure, or surgery

Distress related to:

5. Delay in a medical appointment, procedure, or surgery
6. Family visitation restrictions during a clinic visit, procedure, or hospitalization
7. Mask-wearing requirements during a clinic visit, procedure, or hospitalization
8. Worry about child getting COVID-19 during a clinic visit, procedure, or hospitalization

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 (Jacobs et al., 2008). Simple defects include Patent Ductus Arteriosus, Atrial Septal Defect, Ventricular Septal Defect, CoArctation of the Aorta, and Vascular Ring. Complex defects include Transposition of the Great Arteries, Truncus Arteriosus, Atrioventricular Septal Defect, Hypoplastic Right Ventricle, Hypoplastic Left Ventricle, Total Anomalous Pulmonary Venous Return, and Tetralogy of Fallot.

Protective Factors

External support is a construct defined in this study by two concepts: informational support and emotional support (HealthMeasures, n.d.).

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 (HealthMeasures, n.d.). The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores indicate greater perceived informational support. Reliability and validity have been established, and reference scores for informational support in the general adult population are available for statistical comparison (Cella et al., 2010; HealthMeasures, n.d.).

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 (HealthMeasures, n.d.). The measure includes four items scored on a five-point Likert scale ranging from "never" to "always." Higher scores indicate greater perceived emotional support. Reliability and validity have been established, and reference scores for emotional

support in the general adult population are available for statistical comparison (Cella et al., 2010; HealthMeasures, n.d.).

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 (Davidson, n.d.). The CD-RISC-10 instrument captures self-perceptions of adaptability, self-efficacy, and hardiness (Davidson, n.d.). 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 greater resilience. Reliability and validity have been established, and reference scores for resilience in the general adult population, parents of healthy children, and parents of children with chronic medical conditions are available for statistical comparison (Davidson, n.d.).

Data Collection

Data was collected digitally via an anonymous online survey from February 26, 2021, through April 9, 2021. This captured data approximately one year into the COVID-19 pandemic. 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. After inclusion criteria were established, participants were asked to indicate digital consent. Once consent was obtained, participants were directed to complete the study survey. A stop-action feature was embedded in the digital application to prevent participants who did not meet study criteria or did not sign the consent from beginning the survey. The average time to complete the survey was 10-15 minutes. Participants had the option to stop the survey at any time. All data was 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 to create the study data set. 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. Descriptive statistics and inferential statistics tests were run in SPSS to examine participant demographics, COVID-19 related stressors, CHD care related factors, and sample scores from the anxiety, depression, perceived stress, informational support, emotional support, and resilience measures.

Use of the PROMIS measures, NIH toolbox measure, and Connor-Davidson Resilience scale have been used in other research studies in the US 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 (Salsman, et al., 2013, Carter, 2019, Hilliard, et al., 2017, Baron Nelson, et al., 2018, Rosenberg et al., 2013, Busse, et al.,2013). In the current study, the reliability of these measures was assessed by calculating the 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.

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.

Individual item scores from the anxiety, depression, perceived stress, emotional support, and informational support measures for each participant were downloaded from the SPSS study data set into an excel file. The excel file with item scores for the PROMIS (anxiety, depression, emotional support, and informational support) and the NIH Toolbox (perceived stress) measures were sent to the HealthMeasures scoring site (https://www.HealthMeasures.net/score-and-interpret/calculate-scores/scoring-instructions). The HealthMeasures scoring service utilized the raw data to calculate sum scores, T scores, and standard error values that were adjusted for missing items. The T score values were imported into the study data set in SPSS. Frequency distribution (i.e., sample number and percent), measures of central tendency (i.e., means), and measures of variability (i.e., standard deviation) were obtained for anxiety, depression, perceived stress, emotional support, and informational support T scores. In addition, the varying levels of severity of these variables in the sample participants were described. Using the PROMIS and Toolbox T score cut points (HealthMeasures, n.d.), anxiety, depression, perceived stress, and support levels were calculated, and new variables that labeled anxiety level (i.e., within normal limits, mild, moderate, severe), depression level (i.e., within normal limits, mild, moderate, severe), perceived stress level (i.e., low, average, high) emotional support level (i.e., low, average, high), and informational support level (i.e., low, average, high) were created. Frequency distributions (i.e., sample number and percent) were obtained and reported for CHD parent anxiety, depression, perceived stress, emotional support, and informational support levels.

Individual item scores from the resilience measure for each participant were downloaded from the SPSS study data set into an excel file. The calculation of participant resilience scores and handling of missing items were addressed by following the scoring guidelines for the CD-RISC-10 resilience measure (Davidson, n.d.). Item scores were summed for each participant, creating a variable labeled sum resilience score. Participants with less than seven out of ten items completed were considered invalid and were excluded from the data analysis. For those missing one to three items, the missing items were scored as the mean of the other items. Frequency distribution (i.e., sample number and percent), measures of central tendency (i.e., means), and measures of variability (i.e., standard deviation) were obtained for sum resilience scores. In addition, the varying levels of resilience in the CHD parent sample were described. Using the CD-RISC-10 scoring guidelines, a new variable labeling resilience level (i.e., low, intermediate, high) was created. The resilience levels were calculated using score cut points outlined in the CD-RISC-10 scoring guidelines (Davidson, n.d.). Frequency distribution (i.e., sample number and percent) was obtained and reported for the CHD parent resilience levels.

Aim 1a) Compare anxiety symptoms, depression symptoms, perceived stress, emotional support, informational support, and resilience levels in parents of young children with CHD with the US adult population pre-pandemic norms. The null hypothesis being tested in this aim posits that there is no difference in anxiety, depression, stress, support, or resilience mean scores between CHD parents one year into the COVID-19 pandemic and the pre-COVID-19 US general adult population norms.

A one-sample *t* test in SPSS 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. Higher T scores indicated higher anxiety symptoms, depression symptoms,

perceived stress, emotional support, informational support, or resilience. A T score of 50 reflects the mean (SD = 10) for anxiety, depression, stress, and support in the US general adult population (HealthMeasures, n.d.). A sum score of 32 reflects the mean (SD = 5.4) for resilience in the US general adult population (Davidson, n.d.). Skewness was measured to evaluate for the normality of data distribution. Levene's test was used to confirm homogeneity of variances. An alpha level of .05 was used in this statistical test. The T score means, standard deviation, *t* statistic value, level of significance, and effect size were calculated and reported.

Aim 1b) Compare anxiety symptoms and depression symptoms in parents of young children with CHD with the US adult population COVID-19 pandemic norms. The null hypothesis being tested in this aim posits that there is no difference in anxiety or depression symptom levels between CHD parents one year into the COVID-19 pandemic and the US general adult population one year into the COVID-19 pandemic.

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 US general adult population during the COVID-19 pandemic. The percent of moderate to severe anxiety and depression symptoms in the US general adult population one year into the COVID-19 pandemic was obtained from the results of the March 2021 CDC US Household Pulse Survey (CDC, n.d.). These percent estimates from the US general adult population (labeled as expected values) were compared to the percent of moderate to severe anxiety and depression symptoms in the CHD parent sample (labeled as observed values), which were obtained during the same time. Percentages, Chi square statistic values, and significance levels were reported. An alpha level of .05 was used in this statistical test.

Aim 1c) Compare anxiety symptoms, depression symptoms, and perceived stress in parents of young children with CHD during the COVID-19 pandemic among sample subsets grouped by demographic factors (i.e., education, income, number of other children), COVID-19 related stressors, and CHD care related factors. The null hypothesis being tested in this aim is that there is no difference in anxiety, depression, or stress mean scores between CHD parent subgroups defined by demographic factors, COVID-19 related stressors, or CHD care related factors.

Frequency distribution (i.e., sample number and percent) were obtained for subgroups defined by 1) demographic factors, 2) CHD care related factors, and 3) number of COVID-19 stressors experienced. The COVID-19 stressor variable was further divided into two subgroups. Participant sum scores (range 0-8 stressors) were categorized into two levels of exposure: 1) less than four COVID-19 stressors and 2) four or more COVID-19 stressors. Frequency distribution (i.e., sample number, percent, range, minimum, and maximum), measures of central tendency (i.e., means), and measures of variability (i.e., standard deviation) were obtained for the sample and categorized by the two levels of COVID-19 stressor exposure defined above.

Independent *t* tests were run in SPSS to compare differences in the anxiety, depression, and stress mean scores between subgroups (divided into two levels) defined by demographic factors, COVID-19 stressors level, and CHD care related factors. The anxiety, depression, and stress T score means, standard deviation, *t* statistic value, level of significance, and effect size were calculated and reported. An alpha level of .05 was used in these statistical tests. Skewness was measured to evaluate for the normality of data distribution. Subgroups with skewed distribution and subsequently very small sample sizes were not included in the data analysis. The

homoscedasticity assumption was confirmed using either the Levene's test or Welch's test of HOV (homogeneity of variance).

ANOVA tests were run in SPSS to compare differences in the anxiety, depression, and stress mean scores between subgroups with more than two levels. The anxiety, depression, and stress T score means, standard deviation, *F* statistic value, level of significance, and effect size were calculated and reported. Tukey post hoc testing was performed to examine differences between levels among the subgroups. An alpha level of .05 was used in these statistical tests. Skewness was measured to evaluate for the normality of data distribution. Subgroups with skewed distribution and subsequently very small sample sizes were not included in the data analysis. The homoscedasticity assumption was confirmed using either the Levene's test or Welch's test of HOV (homogeneity of variance).

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. The following hypotheses were tested:

Hypothesis 1: A higher number of COVID-19 stressors will be positively associated with higher levels of anxiety, depression, and perceived stress.

Hypothesis 2: Higher levels of distress from CHD care related factors (i.e., family visitation restrictions, perceived COVID-19 risk to CHD child, morbidity/mortality worry) will be positively associated with higher levels of anxiety, depression, and perceived stress.

Hypothesis 3: Resilience will be inversely related to anxiety, depression, and perceived stress.

Hypothesis 4: External support (emotional support and informational support) will be inversely related to anxiety, depression, and perceived stress.

The relationships between anxiety, depression, stress, support, resilience, COVID-19 stressors exposure, and CHD care related factors were first examined with a correlation matrix in SPSS. The Pearson *r* coefficient values and significance levels were reported to reflect the strength and direction of the relationships among the variables of interest. A high correlation coefficient indicating multicollinearity was noted between the emotional support and informational support variables in the correlation matrix. Thus, a composite variable reflecting the mean of the emotional support and informational support T scores was created and labeled "external support" for use as an independent variable in the regression analysis.

In the final step, posited hypothesized relationships were tested through a series of three multivariate linear regression analyses. In this study, regression analysis 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. Unstandardized coefficients, standard error, standardized coefficients, and significance levels were reported to represent the amount of variance in the outcome variable that could be accounted for by each

predictor variable in each of the three regression models. The semi-partial correlation value was calculated to identify which predictors had a unique contribution to the variance in the outcome variable. R^2 values were obtained to explain the amount of variance in the outcome variable that was accounted for by the group of predictors in each of the regression models. The ANOVA *F* statistic and significance level were reported to indicate if the regression model was a statistically significant predictor of the outcome variable.

In all three regression models, assumptions were tested for and met the following conditions: 1) Absence of multicollinearity, which was assessed by confirming that there were no IVs with an *r* value >.70 or VIF (variance inflation factor) of 10 or greater; 2) Normality, which was assessed by reviewing the P-P plot for distribution of standardized residuals along the bisecting line; 3) Linearity, which was assessed by reviewing the scatter plot for rectangular distribution and standardized residuals between -3 and 3; 3) Sample size adequacy, which was assessed by confirming the number of cases per predictor was at least 20; and 4) Absence of outliers, which was assessed by confirming Cook's distance was not >1.

Chapter 4. Results

Sample Demographics

Demographic characteristics of the sample are detailed in **Error! Reference source not found.**. 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. Over 80% of the study participants lived in the US (across 30 different states), some (12%) lived in Canada, and a few (2%) lived outside of the US and Canada.

Mental Health Outcomes

CHD parent participants had 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%). The frequency of mental health outcome variables and the category assignment of variable levels based on PROMIS score cut points are illustrated in **Table 2**.

COVID-19 Stressor Risk Factors

Participants' reported exposure to COVID-19 stressors is shown in **Table 3** . Almost all the participants reported decreased social contact during the pandemic. More than half experienced a disruption in childcare, a delay in healthcare, or had a family member or friend who was diagnosed with COVID-19. Approximately one-third of participants reported a loss of income. Ten percent of participants reported that they had been diagnosed with COVID-19 or had a family member or friend die from COVID-19. Very few participants reported loss of health insurance. Out of a total of eight COVID-19 related stressors, half of the study sample reported experiencing less than four COVID-19 stressors and half reported experiencing four or more COVID-19 stressors (**Table 4**).

CHD Care Risk Factors

Factors related to CHD care in the sample are presented in **Table 5**. CHD complexity, child age, healthcare system encounters, and related worries during the pandemic are described. Notably, over 90% of the study participants had a child with a complex CHD diagnosis

(Appendix E) and had attended an in-person appointment during the COVID-19 pandemic. In contrast, the age of the CHD children was fairly evenly distributed among the infant, toddler, and preschool age groups.

Data reflecting parents' encounters with the healthcare system during the pandemic revealed about one quarter (22%) had a child who was diagnosed with CHD during the COVID-19 pandemic. Approximately half (54.3%) reported their CHD child was hospitalized during the COVID-19 pandemic. In addition, about half (46.8%) reported experiencing a delay or cancellation of a CHD care appointment, procedure, or surgery during the COVID-19 pandemic.

Worry or distress related to healthcare system encounters for CHD care was a consistent finding. More than 80% of the study participants reported experiencing worry (fairly or very often) related to the risk of their CHD child's death or serious illness from COVID-19, distress (mild to severe) related to perceived risk of their CHD child's exposure to COVID-19 during a healthcare encounter, and distress related to family visitation restrictions during CHD healthcare encounters. Approximately half (50.9%) of the participants were distressed by a delay in a CHD clinic appointment, procedure, or surgery.

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. Category assignment of variable levels based on PROMIS score cut points and CD-RISC-10 scoring guidelines are illustrated in **Table 2**.

Comparison of Mental Health in CHD Parents to the US General Adult Population

Anxiety symptoms, depression symptoms, and perceived stress were significantly higher in CHD parents during the COVID-19 pandemic compared to pre-COVID-19 US general adult population norms. There was no significant difference in emotional support between CHD parents and US general population norms. However, informational support was significantly higher in CHD parents. In contrast, resilience scores were significantly lower in CHD parents compared to US general population norms. These comparisons are illustrated in **Table 6**

. Moreover, using data obtained from the US Household Pulse Survey (N = 64,443) during March 17-29, 2020 (CDC, n.d.), moderate to severe anxiety symptoms were significantly higher in CHD parents when compared to the US general adult population during COVID-19. Moderate to severe depression did not significantly differ between these groups. These comparisons are illustrated in **Table 7**.

Comparison of Anxiety, Depression, and Perceived Stress Among CHD Parent Subgroups

Demographic Factors

Sample size and distribution allowed for limited testing of differences among demographic factors. Parents' level of education was examined as a variable and no significant differences in mental health outcomes were seen among CHD parents with varying education levels (**Error! Reference source not found.**).

However, differences in outcomes were seen among CHD parents in different income groups (**Table 9**

). There was a statistically significant difference in depression and stress among low-, middle-, and high-income groups. Post-hoc analysis with Tukey testing showed depression among parents

with a low income (less than 50K) was significantly higher than in those with a middle income (50K to 150K) and a high income (greater than 150K). Similarly, post-hoc analysis with Tukey testing showed that stress among parents with a low income was significantly higher than in parents with a high income. Estimates of effect size show that 8% (a medium effect size) of the variance in depression symptoms and 6% (a medium effect size) of the variance in perceived stress can be explained by income.

Differences in anxiety were seen among parents with different numbers of children in the household (**Error! Reference source not found.**). There was a statistically significant difference in anxiety among parents with no other children, those with one other child, and those with two or more other children. Post-hoc analysis with Tukey testing showed parents with only a CHD child had significantly higher anxiety levels than parents with two or more other children. Estimates of effect size show that 5% (a small to medium effect size) of the variance in anxiety can be explained by the number of other children.

COVID-19 Stressor Risk Factors

Mental health outcomes differed among parents experiencing different numbers of the eight examined COVID-19 stressors (i.e., COVID-19 diagnosis in self, COVID-19 diagnosis in family, COVID-19 death, income loss, healthcare delay, health insurance loss, childcare disruption, decreased social contact). CHD parents who reported exposure to four or more

COVID-19 stressors had significantly higher depression symptoms and perceived stress compared to parents with exposure to less than four COVID-19 stressors (**Table 11**

).

Parents who reported experience with certain COVID-19 stressors such as financial strain or COVID-19 related death had differences in mental health outcomes. Parents who experienced a COVID-19 death of a family member or friend had significantly higher perceived stress, M = 64.7, SD = 12.4, p = .033, d = .63, compared to those that had not experienced a COVID-19 related death. Parents that reported a loss in income had significantly higher depression symptoms, M = 57.5, SD = 8.9, p = .025, d = .41, compared to those that did not report income loss.

CHD Care Risk Factors

CHD child characteristics such as age and disease complexity were explored as potential CHD care risk factors. Parents of children in different age subgroups (i.e., infant, toddler, preschooler) were not significantly different in their reported levels of anxiety, depression, or stress (**Table 12**

). Greater than 90% of the CHD parents in the sample had a child with a complex CHD. Therefore, due to poor distribution and skewness, differences in mental health outcomes between parents of children with simple vs complex CHD diagnoses were not tested.

Parent exposure to the healthcare system for CHD care during the pandemic and related worry were explored. There were no significant differences in anxiety, depression, or stress between parents of a child who was diagnosed with CHD during the COVID-19 pandemic and those of a child who was not diagnosed during the pandemic (**Error! Reference source not found.**). Similarly, there were no significant differences in anxiety, depression, or stress between

parents of a CHD child who was hospitalized during the COVID-19 pandemic and those with a child who was not hospitalized during the pandemic (**Error! Reference source not found.**). Most of the parents in the study reported attending an in-person clinic visit for CHD care during the pandemic. However, there were no significant differences in anxiety, depression, or stress between parents who experienced a delay or cancellation in CHD care (i.e., a clinic appointment, procedure, or hospitalization) and those who did not experience a CHD care delay during the pandemic (**Table 15**

).

Examination of the Relationships Among the Key Variables

Bivariate Analysis

Correlations were computed among the three outcome variables (i.e., anxiety symptoms, depression symptoms, perceived stress), two potential protective factors (i.e., support, resilience), and seven potential risk factors informed by the COVID-19 and CHD literature. The potential risk factors tested included the number of COVID-19 stressors experienced and six CHD care related factors (i.e., CHD diagnosis, hospitalization, CHD care delay, visitation worry, exposure worry, and morbidity worry). Pearson *r* values for each of the variables tested can be seen in the correlation matrix shown in **Table 16**

.

An interrelationship was seen between the mental health outcomes. There was a significant positive correlation among anxiety symptoms, depression symptoms, and perceived stress. The potential protective role of resilience and support emerged in the bivariate analysis. Resilience, emotional support, and informational support each had a significant negative correlation with anxiety symptoms, depression symptoms, and perceived stress. Resilience had a significant positive correlation with emotional support and informational support.

Exposure to COVID-19 stressors was related to mental health outcomes and support. The number of COVID-19 stressors CHD parents experienced had a significant positive correlation with depression and stress, and a significant negative correlation to emotional and informational support. In contrast, exposure to CHD care events, such as diagnosis during COVID-19, hospitalization during COVID-19, or CHD care delay, was not significantly correlated with anxiety symptoms, depression symptoms, or perceived stress.

The relationship between worry or distress related to healthcare encounters and mental health outcomes and protective factors was significant. Distress caused by family visitation restrictions during healthcare encounters had a significant positive correlation with anxiety symptoms. Parental worry about perceived CHD child risk of exposure to COVID-19 during healthcare encounters had a significant positive correlation with anxiety symptoms, depression symptoms, and perceived stress and a significant negative correlation with resilience, emotional support, and informational support. Likewise, parental worry about CHD child risk of death or serious illness from COVID-19 had a significant positive correlation with anxiety symptoms, depression symptoms, and perceived stress and a significant negative correlation with emotional support and informational support.

Regression Analysis

Multiple linear regression analysis was used to examine the relationship between potential risk and protective factors and the mental health outcome variables. A regression model for each of the three outcome variables (i.e., anxiety symptoms, depression symptoms, perceived stress) was analyzed. In each model, two potential protective factors (i.e., resilience and support) and four potential risk factors (i.e., number of COVID-19 stressors, visitation worry, exposure worry, and morbidity worry) were tested as predictors. The unique contribution

of any one predictor was further examined by calculating the squared semi-partial correlation (*sr*2) values.

In the first regression model, anxiety symptoms was the outcome variable (**Error! Reference source not found.**). This model explained a significant proportion of the variance (38%) in anxiety scores, $R^2 = .38$, F (6, 117) = 12.16, p = <.001. Resilience, external support, and exposure worry predictors had significant unique effects on anxiety. Specifically, for each point on the resilience score there was an estimated mean decrease of .39 points in anxiety scores. Likewise, for each point on the external support score there was a decrease of .19 points in anxiety scores. In contrast, for each point of exposure worry there was an estimated mean increase of 1.75 points in anxiety scores. Resilience, *sr* = .262, contributed 6.9 % of the variance, external support, *sr* = .175, contributed 3.1% of the variance, and exposure worry, *sr* = .164, contributed 2.7% of the variance in anxiety scores.

In the second regression model, depression symptoms was the outcome variable (**Error! Reference source not found.**). This model explained a significant proportion of the variance (41%) in depression symptoms scores, $R^2 = .41$, F (6, 117) = 13.31, p = <.001. Resilience, external support, and exposure worry predictors had significant unique effects on depression. Specifically, for each point on the resilience score there was an estimated mean decrease of .46 points in depression scores. Likewise, for each point on the external support score there was a decrease of .20 points in depression scores. In contrast, for each point of exposure worry there was an estimated mean increase of 2.01 points in depression scores. Resilience, *sr* = .301, contributed 9.1 % of the variance, external support, *sr* = .179, contributed 3.2% of the variance, and exposure worry, *sr* = .184, contributed 3.4% of the variance in depression scores.

In the third regression model, perceived stress was the outcome variable (**Error! Reference source not found.**). This model explained a significant proportion of the variance (46%) in perceived stress, $R^2 = .46$, F (6, 117) = 16.44, p = <.001. Resilience and external support had significant unique effects on perceived stress. Specifically, for each point on the resilience score there was an estimated mean decrease of .76 points in perceived stress scores. Likewise, for each point on the external support score there was a decrease of .21 points in perceived stress scores. Resilience, *sr* = .418, contributed 17.5 % of the variance and external support, *sr* =.155, contributed 2.4% of the variance in perceived stress scores.

In summary, 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 associated with decreased anxiety symptoms, depression symptoms, and perceived stress.

Chapter 5. Discussion

This research was conducted approximately one year into the COVID-19 pandemic. At that time, the COVID-19 vaccine was not widely available, and there were over 30 million cases of COVID-19 and over half a million deaths from COVID-19 in the US (CDC, n.d.). This work gleaned mental health data about a uniquely vulnerable parent population during this public health crisis. Specifically, this research enhanced our understanding of psychological distress in parents of children aged newborn to 5 years old with complex CHD who experienced in-person encounters with the healthcare system during the COVID-19 pandemic. Unfortunately, 90% of the sample was white, and therefore we do not know how non-white CHD parents fared during the first year of the pandemic.

Mental Health in CHD Parents During the Pandemic

The findings in this study demonstrate that parents of young children with CHD experienced significant psychological distress during the COVID-19 pandemic. CHD parents reported anxiety, depression, and stress at levels higher than the US general adult population pre-COVID-19 norms. Moreover, when compared to the data reported from the US general adult population during the COVID-19 pandemic, CHD parents had significantly higher moderate to severe anxiety symptoms. These findings are consistent with pre-pandemic studies that have demonstrated a high presence of anxiety, depression, and stress in parents of children with CHD (Soulvie et al., 2012; Wolf-King et al., 2017). The results further validate the concern that parents of young children with CHD are a population at higher risk for poor mental health outcomes. Nevertheless, several subgroups were not well represented in this study, and further investigation of CHD parents who are racially diverse, fathers, or single and caring for a CHD child during a pandemic is 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 of race as a health disparity variable and parental stress has not been extensively examined in the pediatric cardiac literature (Lisanti, 2018). Likewise, the absence of parents of color in this study supports the need for further research to enhance our understanding of anxiety, depression, and stress in non-white families during a pandemic or other stressful life events.

Risk Factors

Financial Strain

Low income or loss of income were associated with negative mental health outcomes in CHD parents during the COVID-19 pandemic. This is understandable given COVID-19's

economic impact. In the early months of the pandemic, unemployment rates were at historic highs and 23 million Americans were out of work (US Bureau of Labor Statistics, n.d.). Although this number receded over the following 12 months to 10 million by April 2021, it remained double that of pre-pandemic unemployment rates in the US. Accordingly, healthcare providers should assess the presence of financial strain in families and refer them to potential resources in order to take the first important step toward identifying and supporting higher risk parents.

COVID-19 Stressors

Exposure to COVID-19 stressors was found to have statistically significant correlations with depression and stress in CHD parents. Perceived risk of COVID-19 infection, health impact from COVID-19 infection, financial strain, and the extent of pandemic related lifestyle disruption were stressors associated with mental health burden. The negative effect of these COVID-19 related stressors on mental health in the general population has been corroborated by early pandemic studies (Robinson & Daly, 2020; Sherman et al., 2020). During the COVID-19 pandemic, many parents were faced with an exponential increase in care demands. Changes in their child's daily routine, increased work-related tasks, increased household tasks, and worry about COVID-19 were among the most commonly reported stressors by parents in early pandemic studies (Adams et al., 2021) Numerous parents had to navigate working from home while faced with widespread childcare and school closures coupled with limited access to their support networks due to confinement and social distancing mandates. Accordingly, early COVID-19 studies demonstrated that high caregiver burden can be a predictor of negative mental health outcomes (Russell et al., 2020). It seems likely that the combination of lifestyle disruption from COVID-19 and CHD care demands could increase the mental health burden

among CHD parents. In pre-pandemic studies, care burden was shown to be a predictor of distress and hopelessness in the CHD parent population (Lawoko and Soares, 2006). Consequently, a closer look at caregiver burden during the pandemic as a measured independent variable for mental health outcomes is warranted.

Care Burden

Parental anxiety was significantly higher in parents with only a CHD child compared to CHD parents who had other children. This finding may be counterintuitive considering the potential increase in care burden with more children. However, one could argue that parents with a singular focus on their solitary CHD child would feel the need for hypervigilance, which may contribute to anxiety in times of uncertainty.

From a developmental perspective, one could imagine the care burden would differ for infants, toddlers, and preschoolers. Consequently, the absence of differences in mental health outcomes between parents of different CHD child age groups is an interesting finding. Furthermore, the lack of differences between parents of CHD infants and parents of young CHD children in this study is in contrast to other research that has reported higher rates of depression and anxiety in mothers of infants with CHD (Solberg et al., 2011). Likewise, the higher rate of depression typically seen in mothers in the postpartum period in the general population was not seen in this study (CDC, n.d.). A plausible explanation may be that, since the majority of CHD children in the sample had a complex diagnosis, parent participants may have experienced a similar level of anxiety, depression, and stress regardless of child age. Further studies are needed to explore the relationship between child age and CHD parent mental health outcomes during a pandemic, especially among parents whose children do not have a complex CHD diagnosis.

Risk and Worry Related to Encounters with Healthcare

The study results indicate that there is a relationship between parent's CHD care related worries and their mental health outcomes. Parental experiences of interacting with a COVID-19 affected healthcare system for the care of a child with a life-threatening condition were explored. Parents of young children with CHD worried about the risk of CHD child death or serious illness from COVID-19. In addition, they reported distress related to perceived risk of CHD child exposure to COVID-19 during a healthcare encounter. Furthermore, these parents experienced distress related to the family visitation restrictions imposed during their CHD healthcare encounters. Previous studies have indicated that parents of children with complex CHD have elevated levels of perceived child vulnerability and practice vigilant parenting (Rempel & Harrison, 2007). It seems 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.

The impact of CHD care related worry gives rise to further questions about the role of parent perceived child vulnerability in mental health. Parent perceived child vulnerability is a measurable characteristic that has been documented in studies of parents of children with chronic conditions and is associated with vigilant parenting in the CHD parent population (Forsyth et al., 1996; Houtzager et al., 2014; Vrijmoet-Wiersma et al., 2020). Likewise, life-threatening congenital defects, such as heart disease, have been identified as a risk factor for the development of vulnerable child syndrome (VCS) (Duncan & Caughy, 2009). VCS is a set of fear-based behaviors that evolve from a parents' belief that, despite recovery, their child might die (Green, 1986). Duncan and Caughy (2009) explained that these parent behaviors (and

subsequent child behaviors) manifest from and are related to experiences and interactions of hypervigilance prompted by a rekindling of parents' fear of morbidity. Furthermore, the role of CHD parents as attentive protectors has been described in the literature (Cantwell-Bartl & Tibballs, 2017; Carey et al., 2002; Gower et al., 2017). This may explain why most of the CHD parents in this study reported distress related to the family visitation restrictions initiated in the healthcare system during the COVID-19 pandemic. As explained by attachment theory researchers, parents have a biological drive to protect their young children (Ainsworth et al., 1971; Bowlby, 1969/1973/1980). From an attachment perspective, the parent's primary role is to provide comfort and protection for the child during times of perceived threat or danger (Farnfield & Holmes, 2014). Notably, the distress from family visitation restrictions during healthcare encounters had a significant correlation with CHD parent anxiety. In many cultures, parents care for their hospitalized children with the help of other family members. Thus, it would be interesting to see further data about family visitation restrictions in a sample that included more parents from cultures in which the extended family is an integral part of the caregiving team.

CHD Related Trauma

It is surprising that CHD care variables recognized as traumatic in the literature, such as the experience of receiving a CHD diagnosis or a CHD child being hospitalized (Bronner et al., 2008; Colville and Pierce, 2012; Davydow et al., 2010; Rees et al., 2004; Rennick et al., 2002), were not associated in this study with higher levels of anxiety, depression, or stress during the pandemic. It is possible that differences among the groups may have been found if data was captured about the number of hospitalizations experienced during the pandemic or whether the CHD diagnosis was discovered prenatally vs postnatally. Most of the CHD care variables were measured as discrete variables, capturing whether or not a parent had the experience. The

contribution of CHD care variables to anxiety, depression, or stress could possibly have been better represented if they were measured via an assessment of impact (level of worry or distress) instead of exposure (did it happen or not). This approach would be supported by the pediatric medical traumatic stress (PMTS) model, which posits that *subjective experience* determines whether or not an event will be perceived as a traumatic stressor (Kazak et al., 2006; Price et al., 2016). Thus, qualitative data from parent responses to questions about the impact of their experiences may be more revealing.

Protective Factors

Resilience

Resilience was a significant predictor variable in the multivariate analysis and emerged as a protective factor for anxiety, depression, and stress. However, the CHD parents in this study had remarkably low levels of resilience. These findings were in contrast to a pre-pandemic study that showed moderate levels of resilience in mothers of children with CHD (Sanayeh et al., 2021). In the regression analysis, resilience contributed a significant amount of the variance in anxiety, depression, and stress. As seen in pre-COVID-19 studies, low resilience in parents of children with life-threatening conditions can be a predictor for psychological distress (Rosenberg et al., 2014). The mitigating impact of resilience on anxiety, depression, and COVID-19 related stressors has been documented by early pandemic studies of non-CHD parents (Barzilay et al., 2020; Mikocka-Walus et al., 2021; Song et al., 2021). Exercise, outside sun exposure, and support from family and friends were predictors of higher resilience in US adults during the pandemic (Killgore et al., 2020). Further research is needed to expand our understanding of resilience in CHD parents and how to support resilience in this population.

Support

External support (the composite variable for emotional and informational support) emerged as a protective factor and was a significant predictor variable in the multivariate analysis 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 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, as the sample was predominantly white, married, female members of an online support group, it is not known if support would have been reported differently by fathers, single parents, parents of other racial groups, or 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 (Mezgebu et al., 2020). Thus, providers 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 US (Gilboa, 2016) As a result, there was poor representation of parents of children with simple CHD. Likewise, fathers were underrepresented, and limited racial diversity was noted in the sample. 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. In addition, the relatively small sample size limited the extent of subgroup analysis and the number of predictors in the regression models. A larger sample may have allowed for better distribution among several of the variables of interest. In addition, the proportion of parents who reported children diagnoses with complex congenital heart disease does not reflect the population of parents with children who have CHD diagnoses that are less complex. It may be that parents with children with complex CHD diagnoses were more motivated to participate in the study Lastly, although the quantitative approach allows for objective measurement of the variables of interest, the use of closed-ended question surveys for data collection limits the breadth and depth of the participant responses.

Implications

To PI's knowledge, this is the first study to describe anxiety, depression, and stress in parents of young children with CHD from the US and Canada during the COVID-19 pandemic. This research offers insight to the risk and protective factors affecting CHD parents who have had to interact with the healthcare system during a global pandemic. More broadly, the study

findings may contribute to our understanding of the mental health burden experienced by parents of children with life-threatening conditions during this and future pandemics. In addition, this study contributes findings that may generalize to other circumstances that are outside of parental control. Natural disasters also impact parents who have to care for a child with a complicated diagnosis, or a chronic health condition. This study contributes to the understanding of the impact of these additional circumstances that likely impact these parents. Considering the critical role of family-centered care in pediatrics, the negative impact of changes in healthcare policies that limit family access to sick children is concerning. Careful attention is needed to promote family-centered care while COVID-19 related restrictions are in place. Moreover, further exploration of the role of parental vigilance and perceived child vulnerability in mental health outcomes during times of adversity is warranted. Lastly, strategies that promote individual resilience, reduce anxiety, identify external support resources, and provide timely referral to mental health services are needed for this vulnerable population.

The consistent presence and strength of resilience as a protective factor for anxiety, depression, and stress is worthy of further exploration. Perhaps most striking of this study's findings was that resilience was remarkably low in CHD parents. Interventions to support resilience may be critical for mitigating the mental health burden of stressful life events in this population. Evidence in the literature indicates that problem-focused coping, optimism, and social support are key factors for practitioners to consider when addressing resilience in parents of children with disabilities (Peer & Hillman, 2014). Research on parents during the COVID-19 pandemic has suggested that strategies addressing social isolation and promoting support help enhance individual resilience (Mikocka-Walus et al., 2021; Sanayeh et al., 2021).

Additional consideration is needed regarding the lack of racial diversity in this predominantly white study sample. According to prevalence studies the racial diversity in CHD children is 63% white, 23% Hispanic and 13.5% Black (Gilboa, et al., 2016). Health disparities have been seen in these non-white CHD families during non-pandemic times. In particular, parental socioeconomic status has been associated with poor health outcomes and higher readmissions and Hispanic infants with congenital heart defects (Peyvandi, et al., 2018) Similarly, higher neonatal mortality has been associated with Black infants with complex CHD when compared to white infants with complex CHD (Nembhard, et al., 2011).

During the pandemic, COVID-19 data shows health disparities among different race/ethnicity groups in the US (CDC, n.d.). Specifically, Black and Hispanic families are disproportionately affected by COVID-19. Both of these groups had higher rates of severe illness, hospitalization, and death compared to white Americans (CDC, n.d.). This evidence of health disparities suggests that parents in these racial groups may be a more vulnerable population during the pandemic. Further research is needed to explore the mental health outcomes among Black and Hispanic parents of children with CHD during the COVID-19 pandemic. Moreover, an examination of the CHD parent experience of COVID-19 related stress within the context of racial or ethnic cultural values and beliefs is warranted.

Future Directions

As of the time of this dissertation, 57% of the US adult population had received a COVID-19 vaccine (CDC, n.d.). The timeline for the COVID-19 vaccine to be available for young children is yet to be determined. The level of parental endorsement, access, and subsequent impact of a pediatric COVID-19 vaccine on the mental health of CHD parents is not known. For example, given the tendency for protective isolation and parent perceived child

vulnerability, it is uncertain if the mental health burden of CHD parents will lessen once the vaccine is available for children 5 years or younger. Further research on the uptake and impact of the vaccine on mental health outcomes in this population is warranted.

Conclusions

Parents of children with CHD have been exposed to additional stressors during the COVID-19 pandemic. The risk of COVID-19 poses an added threat to their CHD child's fragile health. Accordingly, parents' efforts to protect their high-risk children from exposure may lead to extended self-imposed sequestration. Subsequent feelings of social isolation can undermine support and resilience, two critical protective factors. The care of a child with CHD requires repeated contact with the pandemic-affected healthcare system. This may fuel concerns about the risk of exposure and heighten hypervigilance in parents. COVID-19 related changes in healthcare policies that limit family access to children may increase distress in CHD parents during medical encounters. Finally, historically higher rates of depression and anxiety in this population suggest parents of children with CHD may be more vulnerable to adverse mental health outcomes during periods of heightened adversity. Thus, the potential 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 essential.

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Tables

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[a]	10	8.0
Education			
	High school graduate	8	6.3
	Some college	38	30.1
	Bachelor's degree	42	33.3
	Graduate degree[b]	38	30.2
Income[c]			
	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[d]	41	32.5
Race[e]			
	American Indian	1	0.8
	Asian	5	4.0
	White	113	89.7
	Black	0	0
	More than one race	4	3.2
Ethnicity[f]			
	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; [a]Divorced N =2, Widowed N=1; [b]Master's N = 13, Doctorate N = 7; [c]Rather not say N = 5; [d]Three or more other children N = 16; [e]Unsure or rather not say N = 3; [f]Unknown N = 2

Table 2

CHD parent levels of Anxiety, Depression, Stress, Support, and Resilience during COVID-19

		N	%
Anxiety Symptoms			
	WNL	23	18.1
	Mild	28	22.0
	Moderate	54	42.5
	Severe	22	17.3
Depression Symptoms			
	WNL	46	36.2
	Mild	45	35.4
	Moderate	26	20.5
	Severe	10	7.9
Perceived Stress			
	Low	4	3.1
	Average	57	44.9
	High	66	52.0
Emotional Support			
	Low	14	11.0
	Average	73	57.5
	High	40	31.5
Informational Support			
	Low	11	8.7
	Average	73	57.5
	High	43	33.9
Resilience			
	Low	88	69.3
	Intermediate	32	25.2
	High	6	4.7

WNL: Within Normal Limits

Table 3

COVID-19 Stressors

	N	%
COVID-19 diagnosis (self)	14	11.0
COVID-19 diagnosis (family/friend)	73	57.9
COVID-19 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

Note. Healthcare delay N = 126; Health insurance loss, Childcare disrupted, and Decreased social contact N = 125; otherwise, N = 127.

Table 4

COVID-19 *Stressor Exposure*

	Range	Min	Max	M	SD	N	%
	0-8	1	6	3.5	1.2	127	
< 4 stressors						65	51.2
4 or > stressors						62	48.8

Table 5

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[a]			
	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[b]			
	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[c]			
	No distress	25	19.7
	Mild distress	38	29.9
	Moderate distress	42	33.1
	Severe distress	22	17.3
Visitation restrictions[d]			
	No distress	16	12.7
	Mild distress	30	23.8
	Moderate distress	33	26.2
	Severe distress	47	37.3
CHD care delay distress[e]			
	No distress	56	49.1
	Mild distress	28	24.6
	Moderate distress	21	18.4
	Severe distress	9	7.9

Note. 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.[a] Guidelines from RACHS-1, Aristotle, and STS-EACTS CHD complexity scoring. [b]Worry about CHD child risk of death or serious illness from COVID-19 (N = 125). [c]Distress about CHD child risk of exposure to COVID-19 during healthcare encounter (N = 127). [d]Distress about family visitation

restrictions during CHD healthcare encounter (N = 126). [e]Distress about CHD care delay (N = 114).

Table 6

Comparison of CHD Parent Variable Measure Scores to Pre-COVID US Adult Population Norms

	CHD parent sample		US adult population				
	M	SD	M	SD	*t* (126)	*p*	Cohen's *d*
Anxiety symptoms	60.6	8.4	50.0	10.0	14.21	<.001	1.26
Depression symptoms	55.4	8.6	50.0	10.0	7.06	<.001	.63
Perceived stress	59.1	10.2	50.0	10.0	10.00	<.001	.89
Emotional support	51.4	8.9	50.0	10.0	1.71	.09	.15
Informational support	53.7	9.9	50.0	10.0	4.17	<.001	.37
Resilience	26.4	6.4	32.0	5.4	-9.70	<.001	.86

Note. Resilience *df* =125.

Table 7

Comparison of Anxiety and Depression Symptoms between CHD Parents and US Adult Population during COVID-19

	CHD parent sample	US adult population		
	%	%	χ^2 (1)	*p*
Moderate to severe anxiety	59.8	30.0	21.45	<.001
Moderate to severe depression	28.3	24.6	.44	.51

Note. Rates of anxiety and depression during the COVID-19 pandemic from 2020-2021CDC US Household Pulse Survey.

Table 8

Comparison of Anxiety, Depression, and Perceived Stress T Scores for Education Subgroups

	High school graduate		Some college		Bachelor's degree		Graduate degree		F (3,122)	Partial η^2
	M	SD	M	SD	M	SD	M	SD		
Anxiety	54.2	11.5	60.3	9.3	60.7	7.1	62.4	7.7	2.16	.05
Depression	52.7	13.5	55.9	8.3	54.9	8.6	55.9	8.0	0.40	.01
Stress	50.8	16.3	59.8	10.1	58.2	10.4	61.3	7.9	2.58	.06

Note. N = 126; p value >.05 for all measures.

Table 9

Comparison of Anxiety, Depression, and Perceived Stress T Scores for Income Subgroups

	Less than 50K		50K to 150K		More than 150K		F (2,114)	Partial η^2
	M	SD	M	SD	M	SD		
Anxiety	63.3	8.7	60.6	7.9	58.5	8.5	2.28	.04
Depression	59.2[a]	8.6	54.5	8.7	52.6	7.1	4.78*	.08
Stress	63.3[b]	12.1	58.1	9.8	56.2	8.8	3.64*	.06

Note. N = 117; **p* value <.05; K = thousands of dollars; [a]Post hoc analysis: higher depression in <50K group compared to 50K–150K group (p = .036) and compared to >150K group (p = .012). [b]Post hoc analysis: higher stress in <50K group compared to >150K group (p = .035).

Table 10

Comparison of Anxiety, Depression, and Perceived Stress T Scores for Number of Other Children Subgroups

	No other children		One other child		Two or more other children		F (2,123)	Partial η^2
	M	SD	M	SD	M	SD		
Anxiety	63.4[a]	7.9	60.7	7.7	58.6	8.7	3.26*	.05
Depression	56.5	6.9	55.3	8.6	54.9	9.7	.33	.005
Stress	60.1	9.1	60.2	9.4	57.2	11.8	1.13	.02

Note. N = 126; **p* value <.05; [a]Post hoc analysis: higher anxiety in no other children group compared to two or more children group (p = .042).

Table 11

Comparison of Anxiety, Depression, and Perceived Stress T Scores Between COVID-19 Stressor Groups

	< 4 COVID-19 stressors		4 or > COVID-19 stressors		*t* (125)	*p*	Cohen's *d*
	M	SD	M	SD			
Anxiety	59.4	8.4	61.8	8.3	1.64	.104	.29
Depression	53.1	7.8	57.7	8.8	3.13	.002	.56
Stress	57.1	10.1	61.1	10.1	2.19	.03	.39

Note. N =127.

Table 12

Comparison of Anxiety, Depression, and Perceived Stress T Scores for CHD Child Age Subgroups

	Birth to 12 months		13 to 24 months		2 years to 5 years		F (2,109)	Partial η^2
	M	SD	M	SD	M	SD		
Anxiety	61.3	6.7	61.8	9.9	60.1	8.3	.43	.008
Depression	54.9	6.7	57.9	11.1	54.3	7.8	1.76	.031
Stress	60.0	9.2	61.4	11.8	58.1	10.0	1.04	.019

Note. N = 112; p value >.05 for all measures.

Table 13

Comparison of Anxiety, Depression, and Perceived Stress T Scores for CHD Diagnosis Timing Subgroups

	Dx prior to COVID		Dx during COVID		*t* (125)	*p*	Cohen's *d*
	M	SD	M	SD			
Anxiety	60.5	8.6	60.9	7.9	.27	.788	.058
Depression	55.4	8.8	55.4	7.8	.02	.985	.004
Stress	58.9	9.9	59.9	11.4	.47	.639	.101

Note. N = 127; Dx = CHD diagnosis.

Table 14

Comparison of Anxiety, Depression, and Perceived Stress T Scores Between Hospitalization Groups

	Not hospitalized during COVID-19		Hospitalized during COVID-19		*t* (125)	*p*	Cohen's *d*
	M	SD	M	SD			
Anxiety	59.7	7.9	61.4	8.8	1.11	.271	0.2
Depression	55.5	8.7	55.3	8.6	.15	.88	.03
Stress	59.0	9.3	59.1	11.0	.05	.958	.01

Note. N = 127.

Table 15

Comparison of Anxiety, Depression, and Perceived Stress T Scores Between CHD Care Delay Groups

	No CHD care delay		CHD care delay		*t* (124)	*p*	Cohen's *d*
	M	SD	M	SD			
Anxiety	60.7	8.2	60.6	8.7	.07	.946	.01
Depression	55.6	7.7	55.4	9.5	.08	.937	.01
Stress	59.0	9.2	59.4	11.3	.19	.85	.03

Note. N = 127.

Table 16

Correlation Matrix for Variables of Interest

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Anxiety symptoms												
2. Depression symptoms	.77**											
3. Perceived stress	.81**	.75**										
4. Emotional support	-.40**	-.45**	-.42**									
5. Informational support	-.41**	-.41**	-.42**	.85**								
6. Resilience	-.47**	-.51**	-.60**	.42**	.36**							
7. # of COVID stressors	.17	.25**	.20*	-.25**	-.22*	-.04						
8. CHD diagnosis[a] (y/n)	.02	.002	.04	.16	.13	-.07	-.20*					
9. CHD hospitalization[b] (y/n)	.10	-.01	.005	.08	.09	.16	.007	.37**				
10. CHD care delay[c] (y/n)	-.01	-.007	.02	.04	.02	.04	.32**	-.23**	.005			
11. Visitation worry[d]	.18*	.10	.16	.02	.05	-.03	.15	.32**	.57**	.18*		
12. Exposure worry[e]	.44**	.43**	.38**	-.29**	-.25**	-.31**	.21*	.12	.06	.13	.15	
13. Morbidity worry[f]	.38**	.29**	.27**	-.31**	-.27**	-.15	.24**	-.07	.11	.17	.31**	.56**

** p <.01(2 tailed); *p <=.05 (2 tailed).

Note: Variable 11 N = 126; Variable 13 N = 125; Variable 14 N = 114; all other variables N = 127.
[a]CHD diagnosed during COVID-19 pandemic. [b]CHD hospitalization during COVID-19 pandemic. [c]CHD appointment, procedure, or surgery delayed or cancelled during COVID-19 pandemic. [d]Distress about family visitation restrictions during CHD healthcare encounter. [e]Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter. [f]Worry about CHD child risk of death or serious illness from COVID-19.

Table 17

Multiple Linear Regression Model for Predictors of Anxiety Symptoms

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

R^2 = .38

Note. B = unstandardized coefficient, ß = standardized coefficient, CI = confidence interval, LL = lower limits, UL = upper limits. [a]Composite variable reflects the mean of emotional support and informational support T scores; [b]Distress about family visitation restrictions during CHD healthcare encounter (N = 126); [c]Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter; [d]Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

Table 18

Multiple Linear Regression Model for Predictors of Depression Symptoms

	B	SE	ß	95% CI		*p*
				LL	UL	
(Constant)	70.76	5.59		59.68	81.83	<.001
Resilience	-.46	.11	-.34	-0.67	-.24	<.001
External support[a]	-.20	.08	-.21	-0.36	-.04	.013
# of COVID stressors	.96	.56	.13	-0.15	2.07	.088
Visitation worry[b]	.29	.62	.04	-0.94	1.52	.638
Exposure worry[c]	2.01	.78	.23	0.47	3.54	.011
Morbidity worry[d]	.052	.86	.01	-1.66	1.76	.952

$R^2 = .41$

Note. B = unstandardized coefficient, ß = standardized coefficient, CI = confidence interval, LL = lower limits, UL= upper limits. [a]Composite variable reflects the mean of emotional support and informational support T scores; [b]Distress about family visitation restrictions during CHD healthcare encounter (N = 126); [c]Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter; [d]Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

Table 19

Multiple Linear Regression Model for Predictors of Perceived Stress

	B	SE	ß	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[a]	-.21	.09	-.18	-.38	-.03	.024
# of COVID stressors	.81	.64	.09	-.45	2.07	.207
Visitation worry[b]	1.06	.71	.11	-.34	2.46	.136
Exposure worry[c]	1.45	.89	.14	-.30	3.21	.103
Morbidity worry[d]	.11	.98	.01	-1.84	2.06	.912

$R^2 = .46$

Note. B = unstandardized coefficient, ß = standardized coefficient, CI = confidence interval, LL = lower limits, UL= upper limits. [a]Composite variable reflects the mean of emotional support and informational support T scores; [b]Distress about family visitation restrictions during CHD healthcare encounter (N = 126); [c]Distress about perceived CHD child risk of exposure to COVID-19 during healthcare encounter; [d]Worry about CHD child risk of death or serious illness from COVID-19 (N = 125); N = 127 for all other predictors.

Figures

Figure 1

Conceptual Framework Diagram

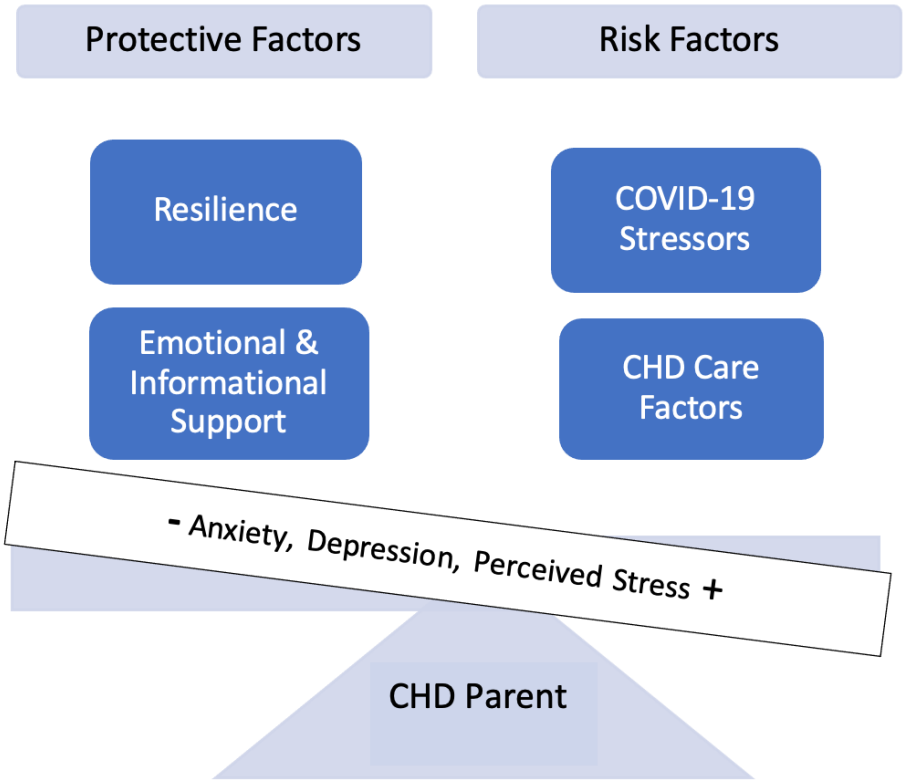
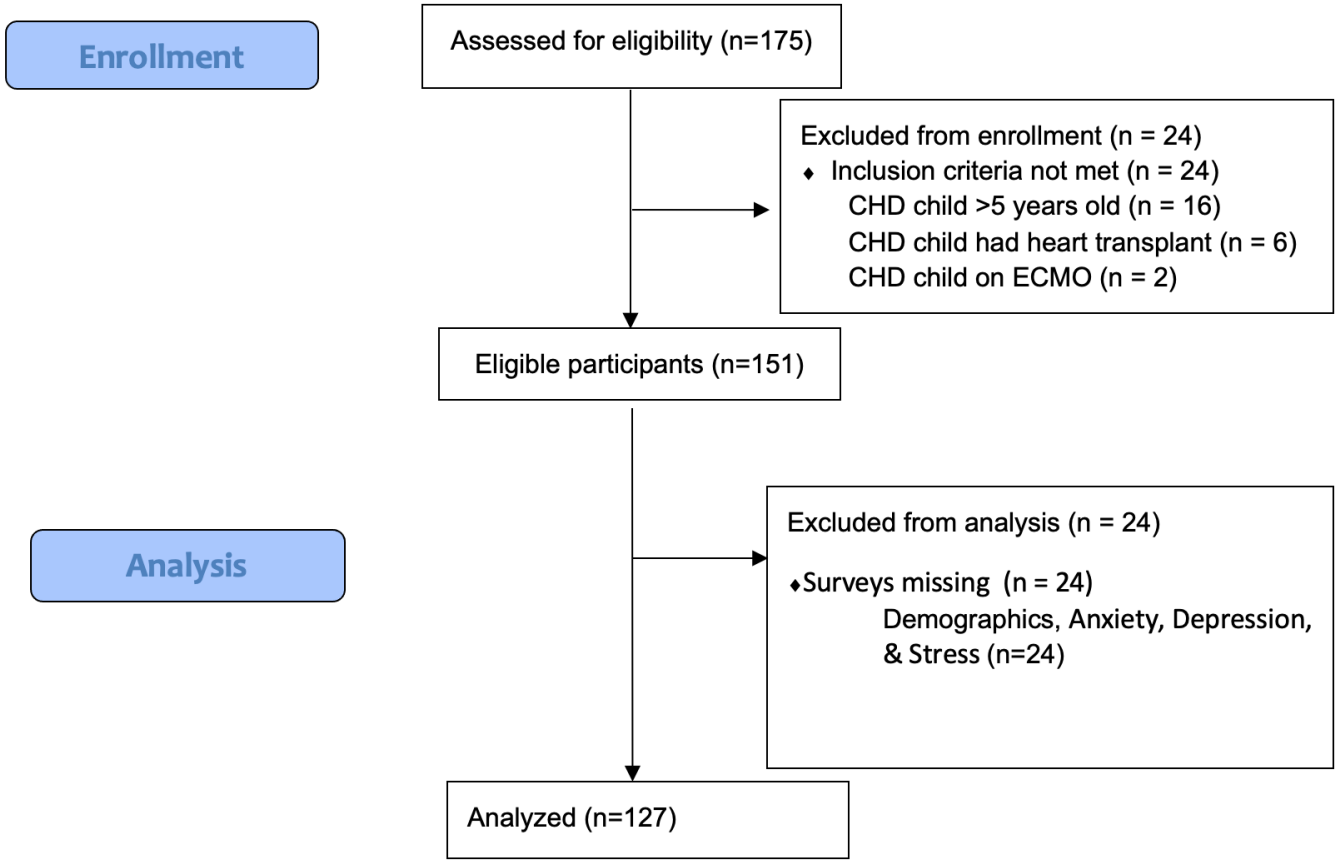


Figure 2

Study Participant Flow Diagram



Note: Adapted from CONSORT 2010 Flow Diagram.

Appendices

Appendix A

Variables and Instruments

Construct	Variable	Measure	Source	Number of items	Scale	Scoring	Method
	Anxiety	Anxiety short form instrument	Patient-Reported Outcomes Measurement Information System (PROMIS), an NIH-funded initiative to develop and validate patient reported outcomes for clinical research and practice.	4	Likert	Higher scores indicate higher levels of anxiety	Self-report
	Depression	Depression short form instrument	PROMIS	4	Likert	Higher scores indicate higher levels of depression	Self-report
	Perceived stress	Perceived stress survey	NIH Toolbox	10	Likert	Higher scores indicate higher levels of stress	Self-report
External support							
	Informational support	Informational support instrument	PROMIS	4	Likert	Higher scores indicate higher levels of informational support	Self-report
	Emotional support	Emotional support instrument	PROMIS	4	Likert	Higher scores indicate higher levels of emotional support	Self-report
	Resilience	CD-RISC-10	Connor-Davidson Resilience Scale	10	Likert	Higher scores indicate higher levels of resilience	Self-report
COVID-19 stressor exposure and worry	COVID-19 stressors	COVID-19 related stressors survey	PI developed, items adapted or informed by NIH-supported COVID-19 related measurement tools and peer-reviewed publications (see Appendix D)	18	Dichotomous & Likert	Higher scores indicate higher levels of COVID-19 related stressors	Self-report
CHD care variable exposure and related distress	CHD care variables	CHD related variables survey	PI developed, items adapted or informed by CHD literature, NIH-supported COVID-19 related measurement tools and peer-reviewed publications (see Appendix D)	11	Dichotomous & Likert	Higher scores indicate higher levels of CHD related variables	Self-report

Appendix B

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 C

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 D

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

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

Patrick et al., (2020), Well-being of parents and children during the COVID-19-19 pandemic: A national survey. *Pediatrics, Official Journal of the American Academy of Pediatrics*

COVID-19 Related Mediating Factors

Robinson, E & Daly, M (2020) Explaining the rise and fall of psychological distress during the COVID-19-19 crisis in the United States: Longitudinal evidence from the Understanding America Study. *British journal of health psychology*.

Pandemic Related Covariates

Sherman, A. C., Williams, M. L., Amick, B. C., Hudson, T. J., and Messias, E. L. (2020). Mental health outcomes associated with the COVID-19-19 pandemic: Prevalence and risk factors in a southern US state. *Psychiatry Research*, *293*, 113476. DOI.org/10.1016/j.psychres.2020.113476

COVID-19 Stress Scale

Taylor et al., (2020) Development and initial validation of the COVID-19 Stress Scales *Journal of Anxiety Disorders*)

Exposure of CHD Families to Healthcare During COVID-19

Marino LV, Wagland R, Culliford DJ, Bharucha T, Sodergren SC, D. A. (2020). No official help is available - experiences of parents and children with congenital heart disease during COVID-19-19. *MedRxiv*.

Appendix E

Participant Reported CHD Child Diagnosis

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

Appendix F

Diversity in CHD parent research samples

Author(s) & Country	Year	Title	Sample size	Percent of non-white study participants
Carey et al. (US)	2002	Maternal factors related to parenting young children with congenital heart disease.	39	16.6%
Vrijmoet-Wiersma et al. (Netherlands)	2020	A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease	196	Non-Dutch 13%
Cantwell-Bartl & Tibballs (Australia)	2017	Parenting a child at home with hypoplastic left heart syndrome: Experiences of commitment, of stress, and of love.	29	Race / Ethnicity not reported
Meakins et. al (US)	2015	Parental vigilance in caring for their children with hypoplastic left heart syndrome.	41	Race / Ethnicity not reported
Rempel & Harrison (Canada)	2007	Safeguarding precarious survival: Parenting children who have life-threatening heart disease	16	author reported "most parents were white"
Rempel et al. (Canada)	2012	Facets of Parenting a Child with Hypoplastic Left Heart Syndrome.	53	Race / Ethnicity not reported
Solberg et al. (Norway)	2011	Long-term symptoms of depression and anxiety in mothers of infants with congenital heart defects	267	Race / Ethnicity not reported
Marino et al. (UK)	2020	No official help is available - experiences of parents and children with congenital heart disease during COVID-19-19.	184	Race / Ethnicity not reported
Lawoko & Soares (Sweden)	2002	Psychosocial morbidity among parents of children with congenital heart disease: a prospective longitudinal study	632	Race / Ethnicity not reported