

A BROKEN HEART: THE IMPACT OF PEDIATRIC OPEN HEART SURGERY ON
PARENTS' WELLBEING AND PARENTING

by

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ABSTRACT

LINDA G. MCWHORTER. A broken heart: The impact of pediatric open heart surgery on parents' wellbeing and parenting. (Under the direction of DR. SHARON G. PORTWOOD)

According to the pediatric medical traumatic stress model, pediatric medical experiences can create posttraumatic stress symptoms (PTSS) in pediatric patients and in their parents and siblings. While the impact of traumatic medical experiences has been studied in parents of children with a variety of pediatric conditions, little is known about how the resulting PTSS may affect parenting. The relational PTSD model suggests that suboptimal parenting patterns can result from parental PTSS. One condition with high potential for traumatic medical events is critical congenital heart disease (CHD), which requires open heart surgery during infancy. This qualitative study examined the experience of parental PTSS and parenting in a sample of parents (N=12; 4 fathers, 8 mothers) of children with critical CHD. Using interpretive phenomenological analysis, focus group data were analyzed to determine 1) the ways in which CHD has affected parents' lives; 2) the parents' experience of PTSS related to CHD; 3) parenting patterns; and 4) the relationships between parental PTSS and parenting patterns. The following themes emerged: seeking/receiving social support, giving back, positive changes, overprotective and permissive parenting, and lasting effects of the traumatic medical experiences. Parents reported experiencing PTSS from all four PTSD symptom clusters. In addition, vicarious trauma and continuous traumatic stress were reported. Parents reported parenting patterns of overprotection and permissiveness; overprotection was

suggested by the relational PTSD model. Finally, parenting a child with CHD was found to be a gendered experience, with fathers and mothers reporting different experiences on a variety of themes. Clinical considerations include the importance of parent to parent support, the different experiences of fathers and mothers, and the need to screen for PTSS among parents of children with CHD. Future research should consider quantitative studies with larger samples to assess the relationship between PTSD and parenting in this population.

DEDICATION

This dissertation is dedicated to my family, who have supported me throughout my doctoral program. First, my sister, who paved the path toward a Ph.D. years before me, encouraging and supporting me in my application to graduate school and helping me through all the ups and downs of returning to school after many years. My husband has always been there to pick up the slack throughout my training as we raised our four children and has always had just the right thing to say whenever I doubted myself. I could not have done this without his steady presence. Our children, who were teenagers when I began this journey, were patient and helpful as I entered this new phase of my life, and as adults, are so proud of what their mother accomplished. And finally, my sweet four-year-old nephew, who was born with the most complex congenital heart defect, hypoplastic left heart syndrome. The many joys and challenges he and his family have experienced have taught me great lessons about life and love.

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A Broken Heart: The Impact of Pediatric Open Heart Surgery on Parents' Wellbeing and Parenting

Children who experience serious medical conditions and major medical procedures are at increased risk for pediatric medical traumatic stress (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006), which can result in posttraumatic stress disorder symptoms, including intrusive symptoms, avoidance of reminders of the trauma, negative changes in cognition and mood, and changes in arousal and reactivity (American Psychiatric Association, 2013). In addition to the pediatric patient, parents and siblings experience potentially traumatic medical events, including the diagnosis, procedures, and symptoms, any of which can lead to PTSD symptoms. For parents, their children's surgeries, extended hospitalizations, time in the intensive care unit (ICU), and painful and risky treatments are all potentially traumatizing. In fact, in some cases, such as childhood cancer and ICU experiences, parents have even higher rates of PTSD symptoms than do the pediatric patients (Nelson & Gold, 2012). Clearly, the PTSD symptoms that result can affect parents' wellbeing. However, the ways these medical PTSD symptoms impact parenting have not been studied thoroughly.

One fairly common pediatric disorder that may result in significant pediatric medical traumatic stress for parents is congenital heart disease (CHD). CHD is defined as "a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance" (Mitchell, Korones, & Berendes, 1971, p. 324). Critical CHD and its treatment create high mortality risks, especially in the first year of

life, and high rates of medical and developmental complications with lifelong ramifications. Parents of children born with critical CHD may experience numerous potentially traumatic events, starting with the diagnosis of this potentially life-limiting condition and the need for open-heart surgery during early infancy. Accordingly, parents of children with critical CHD are an ideal population within which to study the impact of pediatric medical trauma on parents and parenting patterns, particularly since these families have all experienced a similar set of potentially traumatic events. In addition, critical CHD is not “cured” by surgery, but continues to require long-term follow-up with cardiology, such that it presents ongoing risk for repeated exposure to medical trauma and death.

CHD is a major risk factor for both parent and child internalizing problems, including PTSD symptoms, anxiety, and depression (Landolt, Ystrom, Stene-Larsen, Holmstrøm, & Vollrath, 2014). The impact of parent PTSD symptoms on child adjustment may be explained through Scheeringa and Zeanah’s (2001) model of relational posttraumatic stress disorder (PTSD). This model describes how PTSD symptoms among parents and caregivers can affect child outcomes in young children exposed to trauma, posing that transactional processes occur between a parent and a child who have both experienced trauma, in which the symptoms of one interact with the symptoms of the other. This process can result in three different suboptimal parenting patterns: withdrawn/unresponsive/unavailable, overprotective/ constricting, and enacting/ endangering/ frightening.

Rationale and Purpose

While numerous studies have examined parental PTSD symptoms in the context of pediatric medical traumatic stress, there is very little is known about how parental PTSD symptoms may affect parenting. Parents of children with CHD faces numerous challenges related to ongoing medical treatments and health risks. Understand the impact of parental PTSD symptoms on parenting may can inform psychosocial care for children with CHD. To clarify the scope of this project, while child temperament/behavior and parenting are mutually influencing, this project will not address this interaction and will not examine the child's contribution to parenting.

As this is a relatively unexplored area of research, qualitative methods are an effective approach to begin to understand the important components of the area under study. Therefore, this dissertation sought to explore the impact of critical CHD requiring open-heart surgery during infancy on parent PTSD symptoms and parenting behavior employing focus groups of CHD parents.

Research Questions

This dissertation was guided by the following research questions:

- (1) In what ways has CHD affected the life of the parent?
- (2) What are parents' experiences of pediatric medical traumatic stress?
- (3) In what ways has CHD affected the parenting patterns of parents with a child who has undergone open-heart surgery?
- (4) What is the relationship between parent pediatric medical traumatic stress and parenting patterns?

Interpretive phenomenological analysis was selected for this dissertation because it has been increasingly used within the field of health psychology to provide understanding of the impact of medical experiences and diagnoses on the lived experience of individuals, and can inform the creation of policies and practices to improve medical experiences for families (Smith, 2011). Understanding how potentially traumatizing medical events related to CHD impact parents and their parenting abilities is an important first step in the development of interventions to reduce the negative psychosocial impact of CHD on the family.

LITERATURE REVIEW

Pediatric Medical Traumatic Stress

Families with a child undergoing complex medical treatment, such as open-heart surgery, frequently experience potentially traumatic events during diagnosis, treatment and recovery. Kazak and colleagues (2006) proposed the model of pediatric medical traumatic stress as a framework to conceptualize patients' and families' traumatic reactions to pediatric medical events. Pediatric medical traumatic stress is "a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences" (National Child Traumatic Stress Network, n.d). These responses include the four symptom clusters of posttraumatic stress disorder (PTSD) described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5): intrusive symptoms, avoidance of reminders of the trauma, negative trauma-related cognitions/affect, and trauma-related arousal/reactivity (American Psychiatric Association, 2013). Intrusive symptoms include intrusive, distressing memories or dreams of the trauma, flashbacks, and physical/psychological distress at reminders of the trauma. Avoidance is characterized by efforts to avoid distressing internal and external trauma-related experiences. Negative cognitions and affect include an inability to remember components of the traumatic event, negative beliefs and negative thoughts about the trauma, negative emotions, diminished interest in participating in activities, feelings of detachment, and an inability to experience positive emotions. Trauma-related arousal and reactivity includes

irritability, reckless behavior, hypervigilance, exaggerated startle, problems with concentration, and sleep disturbances.

Unlike posttraumatic stress disorder (PTSD), pediatric medical traumatic stress is not a clinical diagnosis and does not require the diagnostic threshold for PTSD in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision (American Psychiatric Association, 2013). Some patients and family members with pediatric medical traumatic stress meet criteria for a diagnosis of PTSD in one symptom cluster, but not another. Others may have subclinical elevations across symptom clusters or may meet full criteria for a diagnosis of PTSD. For example, Kazak and Baxt (2007) found that among parents of children with cancer who experienced pediatric medical traumatic stress, 25% to 44% of mothers met full criteria for a clinical diagnosis of PTSD, with 30% to 50% meeting criteria for one or more symptom clusters of PTSD. Further, nearly all families in the study (99%) had at least one parent who met criteria for intrusive symptoms of PTSD (e.g., flashbacks, nightmares, intrusive thoughts).

Kazak and colleagues (2006) emphasized the importance of considering the following underlying assumptions of the pediatric medical traumatic stress model when applying this framework to children and families:

- (1) Commonalities exist among the potentially traumatic medical events across various illness or injury groups;
- (2) Children and families exhibit a range of normative reactions to these events, including PTSD symptoms and posttraumatic growth; some degree of PTSD symptoms is typical and can, indeed, be adaptive;

- (3) Children and families exhibit a range of preexisting psychological functioning;
- (4) Developmental considerations are essential when examining the effects on trauma in pediatric populations; and
- (5) A social ecological or contextual approach is recommended in designing and implementing interventions.

Kazak and colleagues (2006) further delineated three phases of the pediatric medical traumatic stress model. Phase One includes the period of the initial trauma and the immediate aftermath. Phase Two includes early reactions and ongoing responses that evolve over time; this may occur during hospitalization or after hospital discharge, but in either situation, the family is still dealing with the illness or injury in a serious way. Phase Three includes long term reactions, months or years after the traumatic event is over and full medical recovery has often taken place.

As noted, a wide variety of events may be perceived as traumatic by pediatric patients and their family members, including receiving a life-changing diagnosis, such as cancer or critical CHD; undergoing painful procedures or treatment that carries high health risks; and spending time in a pediatric intensive care unit (ICU) (Woolf, Muscara, Anderson & McCarthy, 2016). Pediatric medical traumatic stress has been studied in numerous pediatric medical populations, including children with spina bifida (e.g., Vermaes, Gerris, Mullaart, Geerdink, & Janssens, 2008), burns (e.g., Bakker, Maertens, Van Son, & Van Loey, 2013), cancer (e.g., Ljungman, Cernvall, Grönqvist, Ljótsson, Ljungman, & von Essen, 2014) accidental injury (e.g., Le Brocque, Hendrikz, & Kenardy, 2010), heart transplant (e.g., Farley et al., 2007), and CHD (e.g., Helfricht,

Latal, Fischer, Tomaske, & Landolt, 2008), each of which can elicit distress in both children and their families, including mortality risk, horror, helplessness, and fear. In addition, some families experience vicarious trauma through witnessing traumatic experiences of other patients and families, which is common in the pediatric ICU (Nelson & Gold, 2012).

According to the pediatric medical traumatic stress model, certain characteristics of medical experiences influence the perception of these events as traumatic, including the onset of the illness or injury (i.e., gradual or sudden), the length of the hospitalization, the length of treatment, the course of treatment (i.e., resolving or escalating symptoms), the need for repeated procedures, the potential life threat of the diagnosis and treatment, the invasiveness and loss of control; and the pain involved (Kazak et al., 2006).

In addition to objective characteristics, a variety of preexisting and co-occurring psychosocial conditions influence the extent to which medical events are perceived as being traumatic. The subjective appraisal of the event as traumatic is a stronger predictor of parental pediatric medical traumatic stress reactions than is the objective medical risk and severity. In fact, family responses to potentially traumatic medical events are not highly correlated with the severity of the illness or treatment (Nelson & Gold, 2012). For parents, preexisting parental psychosocial conditions, including trauma exposure, depression, anxiety, coping skills, and social support, all contribute to the likelihood of perceiving an event as traumatic (Woolf et al., 2016). For the child patients, along with these preexisting conditions, separation from their parent during medical procedures increases the risk for pediatric medical traumatic stress (Kazak et al., 2006). In addition,

developmental factors, such as age and developmental level, influence a child's response to medical events, as does prior exposure to medical trauma (Kazak et al., 2006).

While traumatic medical experiences clearly can affect both pediatric patients and their families, researchers are finding that above and beyond the impact of the negative events on children, children are further affected by the impact of these events on their caregivers. The following sections describe how parental PTSD affects child wellbeing.

Parental PTSD Symptoms and Child Outcomes

Elevated parental PTSD symptoms are a risk factor for child maladjustment. Numerous studies have found an association between parental PTSD symptoms and child PTSD symptoms (e.g., Scheeringa & Zeanah, 2008). Indeed, among parents of children experiencing medical trauma, parental PTSD symptoms predicted child PTSD symptoms one year later (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Other studies have shown similar associations across a range of traumatic events. For example, in study of accidental childhood injury (Ostrowski, Christopher, & Delahanty, 2006), mothers' PTSD symptoms at 6 weeks of age predicted child PTSD symptoms at 7 months of age, but only for girls, not boys. In a study of pediatric burn patients, parental acute stress predicted child acute stress (Stoddard et al., 2006). Across a variety of different types of trauma, mothers' PTSD symptoms were more strongly associated with child PTSD than were fathers' PTSD symptoms (Morris, Gabert-Quillen, & Delahanty, 2012). Even when controlling for child trauma exposure, mothers' intimate partner violence-related PTSD was correlated with their young children's PTSD (Levendosky, Bogat, & Martinez-Torteya, 2013). In another study of mothers with PTSD from intimate partner violence,

mothers' PTSD symptoms mediated the relationship between the child's exposure to the violence and the child's trauma symptoms (Lannert et al., 2014), supporting the relational PTSD model.

In addition to the association with child PTSD, parental PTSD symptoms are associated with a variety of negative child outcomes. For example, combat veterans' PTSD symptoms were associated with increased child violence and hostility during adolescence and adulthood (Glenn, Beckham, Feldman, Kirby, Hertzberg, & Moore, 2002). A meta-analysis revealed that parental PTSD predicted child distress; this relationship was strongest when both parent and child were exposed to interpersonal trauma, but also present among parents exposed to combat and war trauma (Lambert, Holzer, & Hasbun, 2014). In an epidemiological study of the general population, parents with PTSD had children with increased rates of anxiety and depression compared to parents without PTSD (Leen-Feldner, Feldner, Bunaciu, & Blumenthal, 2011). Among a pediatric population experiencing accidental injury, parental PTSD was negatively correlated with child recovery from injury, whereas child PTSD was not correlated with recovery, indicating that parent adjustment to traumatic pediatric medical experiences influences child adjustment (Kassam-Adams, Bakker, Marsac, Fein, & Winston, 2015).

Taken as a whole, these studies clearly indicate that parental PTSD increases child risk for maladjustment. One suggested mechanism through which parents' PTSD symptoms affect children is through parenting behavior (Scheeringa & Zeanah, 2001).

Pediatric Medical Traumatic Stress and Parenting

The caregiving environment that best supports child wellbeing includes firm behavioral control; calm, consistent discipline; developmentally appropriate expectations and limits; and warm nurturance (Dishion, Shaw, Connell, Gardner, Weaver, & Wilson, 2008). Pediatric medical traumatic stress may tax parents' psychological resources, making it difficult for them to provide optimal parenting. In fact, psychological distress has been found to reduce parents' ability to respond sensitively to their children's needs (e.g., Cents et al., 2013). However, the impact of pediatric medical traumatic stress and PTSD symptoms on parenting ability has not been thoroughly explored.

The model of relational PTSD by Scheeringa and Zeanah (2001) provides one possible explanation of parents' role in children's adjustment to trauma. Traumatic events create significant risk for child maladjustment across a wide variety of development domains (NCTSN Core Curriculum on Childhood Trauma Task Force, 2012). The relational PTSD model proposes that responsive, sensitive parenting may moderate the relationship between the traumatic event and child adjustment. Parents who correctly read their child's cues and respond in healthy ways may reduce the strength of the relationship between the traumatic event and the child's PTSD symptoms. In contrast, when parents' own traumatic symptoms interfere with their ability to provide responsive parenting, their PTSD symptoms can interact with their children's symptoms, creating a compounding effect that increases child distress.

The relational PTSD model proposes three possible patterns of suboptimal parenting in the face of traumatic exposure: withdrawn/unresponsive/unavailable,

overprotective/ constricting, and enacting/endangering/frightening. The withdrawn pattern is characterized by a limited parental ability to respond sensitively to the child, resulting in emotional unavailability. It is felt to be more common among mothers with past traumas who have children with recent trauma and is exacerbated by parental depression and grief. The second pattern is overprotection, in which the parent constricts the child's freedom in an attempt to avoid further harm to the child. This pattern can be difficult to change, as the parent often feels that it is a reasonable response and a part of his or her protective role. The third pattern, enacting/endangering/frightening, involves parental preoccupation with the content of the traumatic experience, leading the parent to bring up the trauma to the child repeatedly, to frighten the child by dwelling on the trauma, or to place the child in situations that risk additional trauma exposure.

Emerging research into the impact of parental PTSD on parenting and child outcomes partially supports this model of parental PTSD, but with mixed findings across different types of trauma. PTSD symptoms have been found to have a negative effect on parents' emotional availability and effective discipline with their children in a variety of traumatic exposures, including postpartum PTSD, intimate partner violence, interpersonal violence, war trauma, and combat violence. In support of the relational PTSD model, withdrawn parenting patterns were observed in a number of studies. For example, among new mothers, post-partum PTSD symptoms were associated with less maternal interaction with the infant (Ionio & Di Blasio, 2014). Mothers with interpersonal violence histories and PTSD had high negative attribution and low reflective functioning

(Schechter et al., 2006), indicating difficulty responding in sensitive ways to their children.

Another parenting pattern found to be associated with PTSD is harsh and punitive parenting, possibly related to the enacting/frightening parenting pattern discussed in the relational PTSD model. Among mothers who had ended an intimate relationship due to violence, maternal PTSD was associated with anger expression and reactivity (Chemtob & Carlson, 2004). In an epidemiological study of the general population, parents with PTSD were more likely to report moderate to severe physical aggression with their children than were parents without PTSD (Leen-Feldner et al., 2011). Palosaari and colleagues found gender differences with the impact of war trauma exposure on parenting; fathers' exposure to war trauma was positively associated with psychological maltreatment of their children, while mothers' exposure to war trauma was negatively associated with maltreatment, however, parental PTSD was not measured in this study (Palosaari, Punamäki, Qouta, & Diab, 2013). Male military combat veterans had a negative correlation between PTSD and perceived parenting quality (Gewirtz, Polusny, DeGarmo, Khaylis, & Erbes, 2010). Parents with high exposure to the terrorist attacks on September, 11, 2001, reported parental PTSD symptoms correlated with negative changes in parenting behavior post trauma (DeVoe, Klein, Bannon Jr, & Miranda-Julian, 2011).

In contrast, other studies have failed to detect an association between PTSD and negative parenting outcomes. In a dissertation study examining a sample of mothers from a community behavioral health clinic, Bakhitova (2014) found no association between

self-reported PTSD symptoms and parenting style across several dimensions, including permissive parenting, nurturance, control, and physical discipline, when controlling for depressive symptoms. In a study of Vietnamese and Hmong immigrant mothers, PTSD was not associated with maternal sensitivity (Foss, 2001), suggesting that different types of trauma may influence parenting differentially. In a study of parents with a history of child abuse, parental PTSD was not associated with parenting when controlling for parental exposure to child abuse; however, parental history of emotional abuse was associated with poor mother-child interactions (Lang, Gartstein, Rodgers, & Lebeck, 2010). Notably, the inclusion of several potentially traumatic events, along with PTSD, in the regression analyses may have created multicollinearity problems, making it difficult to detect the influence of PTSD on parenting.

While there is relatively little research on the effect of parental PTSD on parenting, there are even fewer studies specifically addressing the impact of pediatric medical traumatic stress on parenting behavior. In a dissertation study, among parents of children with cancer, parental PTSD symptoms were negatively related to parental behavioral control of the child (Dunn, 2012), suggesting more permissive parenting. Although they did not measure parental PTSD symptoms, Brosig, Mussatto, Kuhn, and Tweddell, (2007) found that parents of children with critical CHD had more permissive parenting styles, with less discipline and lower expectations than did healthy controls, again suggesting more permissive parenting, a pattern not addressed in the relational PTSD model. In a qualitative study, parents reported that their own distress levels affected how responsive they could be with their children following a single incident

child trauma that included accidental injury or violence exposure (Alisic, Boeije, Jongmans, & Kleber, 2012). In a prospective cohort study of Norwegian mothers and their children with CHD, maternal psychological distress and child distress had mutual influences, supporting the compounding effect discussed in the relational PTSD model (Landolt et al., 2014).

Given the limited research on how parental PTSD symptoms influence parenting, it is unclear if pediatric medical traumatic stress has a differential impact on parenting patterns. For instance, the context of interpersonal and combat-related trauma differs in important ways from pediatric medical traumatic stress. Foremost among these differences is the fact that medical trauma results from efforts to diagnose, to treat, and/or to repair a pediatric injury or illness, such that the people involved in many of the traumatic events (i.e., the medical team) are the same people treating the child's condition. In contrast, interpersonal and combat trauma result from intentionally inflicted harm. Medical trauma also differs from mass trauma and natural disasters, one substantial difference being that the parent does not experience life threat during pediatric medical trauma.

While the relational PTSD model proposes a triad of suboptimal parenting patterns, the limited research into the effects of parental PTSD on parenting suggest that additional patterns may surface, including permissive parenting, particularly among parents facing medical trauma.

Congenital Heart Disease

One medical condition that creates numerous potentially traumatic events and may increase parenting risks is families of children with congenital heart disease (CHD). CHD is the most common type of birth defect, occurring in approximately 1 out of 100 live births (Centers for Disease Control and Prevention [CDC], 2014). CHD involves significant structural defects in the heart and its main blood vessel that can impair heart function (Mitchell et al., 1971). CHD ranges from minor (not requiring treatment) to critical (requiring open-heart surgery within days or weeks of birth). According to the CDC, about 25% of all CHD is classified as critical, including a variety of conditions, such as ventricular septal disease, transposition of the great vessels, tetralogy of Fallot, total anomalous pulmonary venous return, Truncus Arteriosus, and the most complex, single-ventricle disorders (e.g., tricuspid atresia, hypoplastic left heart syndrome), all of which require open-heart surgical intervention during infancy. Critical CHD carries the greatest risk of mortality. CHD is the cause of 30% of newborn deaths due to birth defects; over 41,000 deaths over a six-year period were due to CHD, with almost half of these infants under 12 months of age (Gilboa, Salemi, Nembhard, Fixler, & Correa, 2010). In fact, more children die each year from CHD than all forms of childhood cancer combined (Smith, Altekruze, Adamson, Reaman, & Seibel, 2014).

Multiple potentially traumatic medical events are common among children having open-heart surgery, including the initial diagnosis. Families may receive the diagnosis during their prenatal anatomy scan ultrasound around 19-weeks gestation. Other times, the diagnosis is not made until after the child is born, often emergently, when the

newborn is experiencing some medical distress. Research has found that the difference between psychological stress and anxiety among parents with either prenatal and postnatal diagnosis is no longer significant by 6 months after the birth if the child (Pinto et al., 2016). Initially, however, parents with prenatal diagnoses reported lower anxiety and stress at diagnosis and birth than did parents with postnatal diagnoses.

Other potential traumatic exposures for parents of children with CHD include frequent and lengthy hospitalizations, painful and risky treatments, recurring symptoms, and ongoing risk to life, health, and functioning; these all increase the likelihood of developing PTSD symptoms (Kazak et al., 2006). Further, repeated hospitalizations and medical procedures can lead to cumulative trauma, increasing symptom complexity in children (Cloitre et al., 2009) and parents (Boman, Kjällander, Eksborg, & Becker, 2013), as well as vulnerability to further traumatization (Nelson & Gold, 2012).

Open-heart procedures themselves vary in complexity, duration, and risk, but all have a strong potential to be traumatizing to the child and family. For patients with CHD, open-heart procedures, particularly during the neonatal period, carry numerous significant health risks, in addition to the typical risks associated with surgery. Open-heart surgery places children at risk for thrombi (i.e., blood clots), emboli (i.e., air bubbles in the vascular system), arrhythmia (i.e., irregular heart beat), heart attack, and stroke. These surgeries also carry a substantial risk of death, with mortality within 30 days ranging from .8% to 23.1% (O'Brien et al., 2009).

Following open-heart surgery, there is risk for numerous potential complications, including placement in intensive care for days or weeks to manage the medical

consequences of this invasive procedure. Patients are ventilator-dependent for a period of time, creating respiratory risks, including pneumonia (Foglia, Meier, & Elward, 2007). Bleeding, coagulopathy, and transfusions are expected outcomes of the surgery, with over 10% of patients experiencing infection, cyanosis (i.e., poor oxygenation of the blood), and extended time in the ICU (Feinstein et al., 2012). In addition, parents are unable to hold their children immediately following open-heart surgery due to the ventilator and surgical separation of the sternum.

Having an infant or child in a neonatal or pediatric ICU is a strong risk factor for parental PTSD symptoms. Researchers discovered that 30% to 84% of parents of children in intensive care exhibited PTSD symptoms (Bronner, Peek, Knoester, Bos, Last, & Grootenhuis, 2010). Further, 10.5% to 21% of parents with children in ICU met criteria for PTSD due to traumatic experiences with their own children and vicarious secondary trauma through witnessing experiences of other families and children in the ICU (Nelson & Gold, 2012).

For many children with CHD, additional procedures are not uncommon, but they are unpredictable, such that families can never be certain when the next cardiac procedure will be. In addition, critical CHD is potentially life-threatening, creating ongoing traumatic experiences for families. Families experience extended and often repeated hospital stays, complex medical and surgical procedures, uncertain outcomes, and uncomfortably high mortality risk. The effects of these traumatic experiences are cumulative; parents who experienced posttraumatic stress reactions during an initial surgery are at greater risk for posttraumatic stress reactions during subsequent procedures

(Bronner et al., 2010). Importantly, critical CHD is never “cured” by surgery, instead requiring ongoing care from a cardiologist and, sometimes, repeated surgeries, heart catheterizations, or heart transplant. Lifelong health risks are associated with many types of CHD, including ongoing risk of endocarditis due to shunts and prosthetics, arrhythmias, heart failure, and pulmonary hypertension (van der Bom, Zomer, Zwinderman, Meijboom, Bouma, & Mulder, 2011).

Contextual Factors

Parents of children with critical CHD face numerous psychological risks related to medical trauma that may influence parenting practices. However, parenting behavior is multidetermined, indicating that many different factors are at play in the development of parenting skills, including the parent’s own early life experiences, coping styles, current stress level, understanding of child development, education level, social support and economic resources. When considering how CHD and PTSD symptoms impact caregivers, a social ecological framework helps to understand the many interacting risk factors and protective factors that also influence family functioning. Bronfenbrenner’s (1994) ecological model of the impact of environment on human development recognizes multiple nested layers of influence, beginning with the microsystems or layer most proximal to the child, which includes the family and immediate community (e.g., school, religious affiliation, neighborhood); the mesosystem, which includes the interactions between the immediate community and the family; the exosystem, which includes factors that impact the microsystem such as local government, the parents’ employers, and the school board; the macrosystem, which includes national government, media, pop culture,

and religion; and the chronosystem (i.e., the impact of time and history on development). Clearly, for parents of a child with CHD, the impact of this serious condition is just one of many contextual factors influencing their development and adaptation. In addition, CHD-related factors interact with each of these systems to affect parenting capacity.

It is important to determine the impact of this serious pediatric condition on parents and their ability to care for their children. By identifying ways in which CHD impacts parental well-being, parents can be assessed and treated to reduce the negative effects on the parents as well as other family members. Further, if dysfunctional parenting patterns are an outcome of parental pediatric medical traumatic stress, this is a modifiable risk factor for child well-being that can be directly addressed through prevention and intervention efforts, reducing the number of risks faced by children in these families. The proposed study represents an initial step in examining how CHD impacts family functioning and is designed to inform future research on understanding the ways pediatric medical traumatic stress can disrupt parent well-being, parenting patterns, and child adjustment.

Current Study

This dissertation used focus groups to conduct a qualitative exploration of the impact of CHD on parents, including their experiences of posttraumatic stress and their parenting patterns, using interpretive phenomenological analysis.

Research questions. Through an examination of the psychosocial impact of CHD on parent functioning, this study addressed the following research questions:

(1) In what ways has CHD affected the life of the parent?

(2) What are parents' experiences of pediatric medical traumatic stress?

(3) In what ways has CHD affected the parenting patterns of parents with a child who has undergone open-heart surgery?

(4) What is the relationship between parent pediatric medical traumatic stress and parenting patterns?

METHODS

Research Design

This qualitative study employed focus groups of parents of a pre-teen child with CHD (see inclusion criteria below). The researcher facilitated three focus groups, using a script to guide the questions, and then analyzed verbatim transcripts using interpretive phenomenological analysis (IPA; Smith, Jarman, & Osborn, 1999) to construct a model of how CHD impacts parents and their parenting patterns.

Participants. Inclusion criteria were: (1) being the parent (or guardian; referred to here as “parent”) of at least one child ages 2-12 years old living at home with a CHD that required open-heart surgery; (2) being at least five months out from the last traumatic pediatric medical event experienced by parents and/or children (thus placing all participants in Phase Three based on the pediatric medical traumatic stress model); (3) having lived with the child with CHD more than 50% of the child’s life, including the time of the medical traumatic event; and (4) having sufficient fluency in English to understand and to participate in the focus group. The researcher offered to read aloud questionnaires if needed to assist any parents with low literacy or low vision; however, no parents reported needing this assistance. Due to slow recruitment efforts and many children not eligible because of other medical issues, two initial exclusion criteria were dropped: having no other medical conditions that require surgery/hospitalizations, and having no intellectual disability. Also, the child age range was increased from 2-7 years to 2-12 years.

Procedures

Recruitment. After obtaining IRB approval (Appendix F) from the hospital system and the university, the researcher recruited potential participants through a large regional pediatric cardiology clinic and CHD family support organization in the southeastern U.S. The recruitment flyer, which provided basic information about the study and how to contact the researcher, was posted throughout the clinic and by the support organization during their monthly events and on their social media during the recruitment period from fall 2015 to summer 2016. In addition, the researcher attended three events for the support organization, two for families with young children from birth to 6 years of age and one for families with children of all ages, answering questions about the research and collecting contact information forms (see Appendix B, Recruitment Scripts, Recruitment Flyer, Recruitment Interest Form). During these events, it was emphasized that both fathers and mothers were invited to participate. Due to difficulty recruiting fathers for pediatric research, it was unclear if any fathers would attend. Therefore, this was considered in the design of the study, by having mothers and fathers attend back to back sessions, providing childcare, and encouraging mothers with male partners to encourage these fathers to participate. Medical and clerical staff at the cardiology clinic handed out approximately 50 flyers to potential participants during patient appointments. Of the 14 families who expressed an interest, four were recruited through the cardiology clinic, eight from the young children's events, and two from the support organization online postings. The researcher contacted the 14 mothers who expressed interest via telephone to provide further details about the study, to answer any

questions, to determine eligibility, and, if eligible, to invite them and any additional caregivers, for a total of 22 potential participants to attend one of five scheduled focus groups (see Appendix B, Scheduling Scripts, Confirmation Script, Recruitment Interest Form, and Scheduling Form). Of the 14 families contacted, nine met eligibility, four were ineligible for being outside the age range, and one family was not interested in a focus group. When a parent expressed interest in participating, the researcher scheduled him or her to attend a focus group and provided the parent with the address and directions for the appointment. The researcher contacted the families two days and one day prior to the focus group to remind them of their appointment, via their preferred contact method (see Appendix B, Reminder Contact Script). All eligible parents within a family were invited to participate. Of the nine eligible families, eight families participated, including four couples and four additional mothers. All of the fathers were recruited and scheduled by their wives. One eligible family eventually declined due to scheduling conflicts.

Four fathers attended one of two scheduled focus groups and eight mothers attended one of three scheduled focus groups. Due to scheduling issues and limited recruitment, the proposed plan of eight participants per focus group was not achieved. To compensate for smaller group size, an additional two focus groups were conducted beyond the proposed minimum of three groups. Couples did not attend the same group, and men and women were scheduled in separate groups as there is some evidence of differential impact of pediatric medical traumatic stress based on sex (e.g. Katz, 2002; Nelson & Gold, 2012). Due to the sensitive nature of questions about traumatic responses and parenting practices, parents may feel that sharing information with a parenting

partner present may overburden their partner, or they may not care to divulge these experiences with their partner. All participants were either single mothers or married biological parents of the child with CHD. Had any participants included same-sex couples, step-parents, or other family structures that might include two parents of the same sex, parents of the same child would have been scheduled in separate focus groups to provide each parent a confidential forum to voice their opinions.

Participation was voluntary and confidential. The researcher discussed the limits of confidentiality in a focus group format and requested that all participants agree to maintain confidentiality of information shared in the group (see Appendix G).

Data Collection. The researcher conducted five focus groups, with two fathers each in two separate groups, two mothers each in two separate groups and one group with four mothers for a total of 12 participants. Sample size was limited by recruitment, as eight out of nine eligible families participated. However, in phenomenological research, sample sizes of between one and ten individuals are considered sufficient to explain a phenomenon of interest (Starks & Trinidad, 2007). A registered nurse working as a program coordinator in pediatric research with the cardiology clinic was present for four of the five groups, to assist with the consent process.

Each focus group was approximately two hours long, with 30-minutes for initial consent and survey completion, and 90-minutes for the focus group interview; all focus groups took place in a conference room in the cardiology clinic. Childcare was provided for focus group participants onsite by Levine Children's Hospital approved volunteers. Caregivers were asked to provide appropriate snacks for their children. As caregivers

arrived, they were instructed to drop off their children with the childcare staff in an onsite location and to fill out the check-in form (see Appendix C, Childcare Check-In). Parents listed child allergies and medical concerns on the childcare check-in form. The researcher instructed the childcare providers to contact parents during the focus group if any child needed a diaper change, toileting help, or had any behavioral, medical, or emotional issues. During two of the focus groups, mothers were asked to change diapers and to help a child with toileting. This did not affect the incentives caregivers received, and they were free to continue or to discontinue their participation at any time; both times, the parent returned and continued participation.

The researcher welcomed all parents to the group and provided them with a thorough description of the consent form (see Appendix D, Consent Form). All parents consented, and signed the form and began their participation. In addition, parents who wanted to receive a summary of the study findings included their desired method of contact (i.e., e-mail or mail) and checked a box indicating their interest; eight participants requested a summary of the study results, which were sent via their preferred contact method after the dissertation was completed. Next, the researcher explained the reason for collecting demographic and CHD-related information and how this information was used to understand better how CHD affects parents from different backgrounds and with different experiences with CHD. The caregivers completed a brief survey, including demographic information and information about their child's CHD diagnosis and treatment (see Appendix E). Caregivers selected a pseudonym from a list of choices to use on their survey and during the focus group to protect anonymity and to allow for

comments to be attributed to a particular caregiver and survey. Snacks and beverages were provided to participants.

Once participants completed their surveys, the researcher reviewed the purpose of the research project and provided caregivers with a card to write the name they chose for their survey (a pseudonym or their preferred name).

Next, the researcher began asking the focus group questions (see Appendix E). Focus groups were audio-recorded using two separate digital voice recorders. To allow for identification of the participant in the audio-recording, the researcher instructed caregivers to begin by stating their chosen pseudonym each time they spoke and prompted participants to do so as needed. During the focus group, the researcher followed up to confirm understanding and/or to determine agreement and differing opinions from other group members. The researcher encouraged all participants to share their opinions and ensured everyone had an opportunity to speak. At the conclusion of the focus group, the researcher thanked participants for their participation and gave them contact information for the researcher and supervising faculty from UNC Charlotte and Sanger should there be any additional questions or concerns. In addition, participants each received the incentive, a Target gift card worth \$20 to express appreciation for their time and participation. All data were kept confidential, with a participant identification number (ID) given to each participant. The key, linking participants' identifying information with their ID was stored separately from the data.

Variables and Measures

Demographic variables. A 13-item questionnaire, created by the researcher, collected information on caregiver and child characteristics, including parent and child age and racial/ethnic group; child custody arrangements if any; parent marital/relationship status; parent employment status; parent relationship to the child with CHD; household size; age and sex of any siblings; and household income (see Appendix E).

CHD diagnosis and treatment details. A continuation of the above questionnaire collected 20 questions about the families' CHD experiences, including the specific diagnoses, the number and types of medical procedures including open-heart procedures, length and frequency of hospitalizations for the child with CHD over the past year and lifetime, caregiver's contact with the child during hospitalizations. This questionnaire concluded with the following open-ended questions a description of the most traumatic medical event, length of time since this event, the length of time since the last cardiac procedure, any other medical problems, surgeries, hospitalizations, developmental/learning problems, and services received for the child with CHD, and anything else important to know about the family (see Appendix E, Family Background Questionnaire).

Caregiver experience of CHD, pediatric medical traumatic stress and parenting. The researcher facilitated focus groups to determine caregiver experiences of the impact of CHD and pediatric medical traumatic stress on their wellbeing and parenting (see Appendix E, Dissertation Focus Group Interview Script), using a semi-structured

interview including eight broad open-ended questions. The researcher followed the interview script, asking additional questions to clarify and determine convergent and divergent opinions. The researcher included additional questions in later focus groups to clarify the range of experiences within themes as they emerged. Sample questions included: How has CHD affected your life. Some families notice both positive and negative effects; what has been your experience?

Data Analysis

The researcher computed descriptive statistics from the Family Background Questionnaire data for parent and child demographic variables and CHD diagnosis and treatment variables using frequencies, means, ranges, and standard deviations to describe the sample.

Audio-recordings were transcribed verbatim with each comment attributed to the specific caregivers using their ID. Qualitative data were analyzed using interpretative phenomenological analysis (IPA), a recently developed approach (Smith et al., 1999) that is rapidly gaining favor in health psychology. This method is based on phenomenology, hermeneutics, and idiography. Phenomenology is designed to develop an understanding of individuals' experiences in order to clarify the meaning they give to events. This type of analysis is useful for developing policies and procedures (Cresswell & Poth, 2017). Incorporating hermeneutics, IPA further works to understand participants' attempts to understand and make sense of a life-changing health event (Smith, 2011). In an act described as "double hermeneutics, the researcher attempts to make sense from the participants' sense-making through the participants' use of language. Finally, IPA

incorporates idiography by using in-depth analysis of each individual's account to gain a thorough understanding of the unique experience, combined in multi-participant projects, with both convergent and divergent themes that arise.

(1) In what ways has having a child with CHD affect the life of the parent?

To answer this question, as specified in the IPA approach (Smith et al., 1999), a multi-step process was followed. Beginning with the first focus group transcript, first, the author listened to the audio-recording and read through the transcript multiple times to become familiar with the and develop a gestalt sense of the data, listening for the overall meaning of the participants' responses. Second, the author made preliminary notes summarizing, marking associations (e.g., discussions of supporting other parents were linked with vicarious trauma), making initial interpretations, and indicating similarities and differences among participants' experiences, and began to label emerging themes. As fathers were included among the participants, coding included consideration of any potential gender differences. Third, the author searched for connections between emerging themes and subthemes, developing superordinate themes. This was followed by a review of the transcript, combining, adding, and omitting themes based on the data. Fourth, the author developed a master list of themes and subthemes, checking the transcript for verbatim representations of each theme to ensure against researcher bias. Fifth, the author proceeded with each successive focus group transcript and audio recording, using the master list as a guide, adding, combining, and omitting themes to the master list. This was an iterative process, returning after each transcript to earlier transcripts to code any new or modified themes. Both convergent and divergent themes

were included, to explain the range of experience represented within themes. The author created a matrix of each theme, listing the location in the transcript of each person's supporting statements. Finally, the author developed a narrative account, using direct quotes to illustrate the thematic interpretation of the data.

(2) What are parents' experiences of pediatric medical traumatic stress? The researcher coded for specific themes of posttraumatic stress symptoms: avoidance, negative cognitions/affect, intrusive symptoms, and arousal/reactivity, as well as any open codes related to these constructs. Following the analytical steps outlined above, the author developed a range of experiences related to posttraumatic stress symptoms and other trauma-related themes, constructing a thematic interpretation of the data related to pediatric medical traumatic stress.

(3) In what ways has CHD affected the parenting behavior of parents? For question three, parenting patterns from the relational PTSD model, the following parenting variables were coded: withdrawn/unresponsive/unavailable, overprotective/constricting, and enacting/endangering/frightening, as well as any open codes related to these constructs. Following the analytical steps outlined above, the author developed a range of parenting experiences, constructing a thematic interpretation of the data.

(4) What is the relationship between parent pediatric medical traumatic stress and parenting patterns? For the fourth question, the researcher created a matrix of comments made by each participant related to parenting and PTSD symptoms, including any direct associations that participants stated connecting these two constructs. For example, one mother stated that during the anniversary of her son's surgery, she

becomes very overprotective due to intrusive thoughts, physiological arousal, and negative emotions. Following the analytical steps outlined above, the author developed a thematic interpretation of the connections and associations between parenting patterns and PTSD symptoms.

Next, the researcher computed variables for the number of times each participant mentioned each of the three parenting patterns in the relational PTSD model (i.e., overprotective, withdrawn, enacting/endangering/ frightening), along with permissive parenting, a pattern that emerged in the data and the number of times each participant mentioned PTSD symptom clusters (i.e., re-experience, avoiding, arousal, and negative cognition/affect), along with two additional PTSD experiences that emerged in the data, vicarious trauma, and continuous traumatic stress, along with the total number of mentions of all PTSD symptoms. Next, the author computed zero-order bivariate correlations using SPSS version 18 (SPSS Inc.) to assess the relationship between the parentings variables and the PTSD symptoms variables.

Qualitative rigor. Researchers have debated as to the proper steps to take to ensure qualitative rigor (e.g., Henry, 2015), and indeed even the terminology used to describe rigor (Morse, 2015). For the purposes of this study, the terminology and recommendations from Morse will be employed, using the same terms used to describe rigor in quantitative studies: validity and reliability. In interpretive phenomenological analysis, generalizability is not the goal, but rather to explain an experience using a homogenous sample of those most familiar with the experience. To ensure qualitative rigor in this dissertation, the following steps were completed.

Internal validity in qualitative work refers to extent to which the interpretation is an accurate representation of the experience of the participants (Morse, 2015). Internal validity was established through the use of thick descriptions, peer debriefing, interviewer's skills, sample appropriateness, and clarifying research bias. This study collected rich descriptions of the phenomenon of parenting in the context of CHD, including converging and diverging opinions. Verbatim quotes from multiple participants were included to provide evidence to support the interpretations of the researcher. As themes were developed, the research debriefed with a research mentor who specializes in CHD for confirmation on the thematic structure. In addition, peer debriefing was conducted with a fellow graduate student in health psychology with experience in qualitative methods, who was unfamiliar with CHD to receive an "outsider" perspective. The author is clinically trained and has experience conducting numerous focus groups. The selection of the sample for this study was a purposive one, recruiting those with direct experiences of the phenomena under investigation. In addition, the author remained open to unexpected findings, and indeed, did encounter unexpected themes.

Reliability is defined in qualitative research as consistency and repeatability of the results, whether another researcher would find the same results if asking the same questions of the same participants (Morse, 2015). Reliability was ensured through development of the coding system, the use of thick descriptions, and researcher reflexivity throughout the process. After the initial development of the coding system, the codes were discussed with a research mentor who is an expert in CHD and with a fellow graduate student unfamiliar with the CHD literature. Using rich, full descriptions directly

from the participants grounded the interpretations in the data, providing justification and clarification of the themes. Participant overlap on descriptions of experiences increases internal reliability. Further, recognizing researcher bias and debriefing with others during key stages of the study help protect against negative impact of researcher's experiences and beliefs (Jootun et al., 2009).

Reflexivity. In qualitative research, it is important to note the views, beliefs, and experiences of researchers, and how these biases influence the research process (Jootun, McGhee, & Marland, 2009). By maintaining awareness of the subjective nature of qualitative interpretations in light of personal judgments made by researchers, qualitative projects can benefit from increased transparency and reliability (Darawsheh, 2014). Therefore, it is important to note factors that influenced the current research project. As is common in reflexivity statements, the use of first-person pronouns was employed in the following statement.

My training as a health psychology graduate student influenced my thinking and decision-making around this study. This education provided me with an understanding of pediatric medical traumatic stress and the multiple influences on parenting through a biopsychosocial lens. My selection of CHD as a context in which to study pediatric medical traumatic stress was inspired by a personal experience. I have a four-year-old nephew with critical CHD. My sister and her family, including her four older children, lived with us during her pregnancy, prenatal diagnosis and throughout my nephew's first six months of life, providing me with an intimate experience of the impact of CHD on family functioning. Through my experiences with my nephew, I became active in the

local CHD community, meeting and talking with numerous families. I attended a symposium, with a panel of parents of children with CHD that informed my research questions. Many of the parents discussed the themes of PTSD symptoms and the effect on parenting.

Throughout this project, I kept a process journal to document my thoughts, decisions, and experiences. I made comments on how my own experiences with CHD were related to the themes that were emerging and about my surprise at some unexpected themes. In addition, the research assistant who transcribed the audio recordings provided process comments and we had discussions about her experiences with the data. Many of these were about the emerging themes that we saw. In addition, we discussed how touching many of the comments were and how honored we felt to hear these parents' stories.

During data collection, I discussed the emerging themes with the research coordinator through the cardiac center, who attended the majority of the focus groups, refining questions for future focus groups to clarify meaning of experiences described by participants. I listened to the audio recordings prior to facilitating the next set of focus groups, reflecting on my performance facilitating, noting in my process journal any areas where participant meaning was unclear and places where my own assumptions may have led me to misinterpret a statement, and discussing how to both improve my facilitation at the next focus group and how to clarify any themes that emerged in prior groups that were not fully articulated.

After data collection was completed, I began full-time employment as a pediatric psychology resident at a children's hospital, specializing in cardiology. My clinical experiences working closely with families of hospitalized infants with CHD further informed my understanding of parenting in the face of critical illness and influenced my data analysis. As a clinician in training, my clinical experiences with patients and parents with PTSD symptoms related to medical trauma further added to my understanding of these data. Finally, as a parent of four children, I have experiences with parenting that influenced my interpretation of statements made about parenting. My personal experiences with CHD place me in a hybrid position, in between an inside position and an outsider position (Jootun et al., 2009). This was mentioned by some of the participants, one of whom stated, "Oh! This is personal for you!" Another participant stated, "So you really know what this is like." Throughout data analysis and the creation of the narrative, I referred to my process journal to identify my own experiences, thoughts, and assumptions, to guard against bias in the interpretation of the participants' experiences.

Due to these experiences, training, and beliefs, I went into this project with a number of assumptions. I expected to find high rates of PTSD symptoms among the participants as suggested by the pediatric medical traumatic stress model and expected that these symptoms would be related to suboptimal parenting patterns as suggested by the relational PTSD model. Further, I expected to find examples of posttraumatic growth. While facilitating the focus groups, when participants discussed topics related to these assumptions, I asked follow-up questions to clarify meaning and ensure that my

assumptions were not influencing my understanding of the participants' experiences, but grounded in their own words and descriptions. Throughout data analysis, I was aware of how these assumptions might influence my coding of these themes and therefore, continued to check for other possible meanings behind statement that were coded based on these assumptions.

RESULTS

The interpretive phenomenological analyses of the focus group data resulted in five superordinate themes, including needing/receiving support, giving back, positive changes, lasting effects (i.e., pediatric medical traumatic stress), and parenting patterns (i.e., overprotective and permissive parenting). In addition, gender differences were observed within each theme.

Participant Characteristics

Participants included four couples and four mothers with total of eight mothers and four fathers ($n=12$), ranging in age from 24-44 years old ($M=36$, $SD=5.6$). A majority (92%; $n=11$) were White and married (84%; $n=10$), with an average income level of \$2100-\$3349/month. All had at least some college education. Of the eight children with CHD, a majority were male (75%; $n=6$) and White (88%; $n=7$) between 2 and 7 years of age ($M=3.63$; $SD=1.92$) (see Table 1, Appendix A). The eight families had between one and six children ranging in age from 8-months to 20-years old. Nine participants had received a prenatal diagnosis and three had received a postnatal diagnosis. The eight children with CHD had the following heart diagnoses: hypoplastic left heart syndrome (50%; $n=4$), coarctation of the aorta (25%; $n=2$), tricuspid atresia (12.5%; $n=1$), and 12.5% ($n=1$) with multiple cardiac diagnoses (i.e., ventricular septal defect, transposition of the great vessels, total anomalous pulmonary venous return, double outlet right ventricle, and atrial septal defect). They experienced between one and five open heart surgeries ($M=2.0$; $SD=1.41$), between zero and five heart catheterizations

($M=2.6$; $SD=1.70$), and between zero and five additional heart-related procedures ($M=1.1$; $SD=1.7$) (see Table 2, Appendix A). Two (25%) of the children with CHD spent less than seven days in the ICU in their lifetime, 25% ($n=2$) spent from one week to one month, and 50% spent over one month. Parents reported their child's last heart procedure occurred between 5 months and 43 months ago ($M=18.00$; $SD=13.56$). In addition to their cardiac diagnoses, children had a variety of medical and developmental issues including attention deficits ($n=1$, 12.5%), past stroke and current asthma ($n=1$, 12.5%), life-threatening allergies ($n=1$, 12.5%), chronic otitis media ($n=1$, 12.5%), feeding problems ($n=4$, 50%), and developmental delays ($n=2$, 25%), in speech, motor, and learning. The following social support resources were the most endorsed by the 12 participants related to their child's CHD: family/friends (58%, $n=7$), meeting with other CHD parents (75%, $n=9$), Facebook CHD parent support page (67%, $n=8$), attending a local support group (67%, $n=8$), and meeting with a spiritual leader from their faith tradition (42%, $n=5$) (see Table 3, Appendix A). Parents reported that the most upsetting time related to their child's CHD experience occurred 24-84 months ago ($M=38.57$; $SD=20.74$). One parent reported that the scariest time was "every day." The scariest times included unexpected medical complications such as emergent intubation, collapsed lung; waiting for the surgeon to explain the CHD and the surgical repair plan; seeing the child post-operatively attached to so many machines; awaiting the first open-heart surgery; unexpected open heart surgery; and being told by the neonatologist that "the condition was not compatible with life."

(1) In what ways has CHD affected the life of the parent?

Participants discussed a variety of themes related to their overall experience of being the parent of a child with CHD. The superordinate themes that emerged were needing and receiving support, discussed by all 12 (100%) participants, giving back to the CHD community discussed by 58% ($n=7$), positive changes discussed by 83% ($n=10$), lasting effects from traumatic CHD experiences (100%; $n=12$), and overprotective (50%; $n=6$) and permissive (75%; $n=8$), parenting (see Table 4, Appendix A). These themes were each closely related to each of the other themes as discussed below. In addition, gender differences were found across themes (see Figure 1, Appendix A).

Needing and Receiving Support

The most prominent theme among participants was that of needing and receiving support, with all 12 participants discussing a variety of support that was or would be helpful in navigating their CHD experience. This superordinate theme encompassed several subthemes, including parent-to-parent support, faith-based support, and support and education/preparation from the medical team.

Parent-to-parent support. This subtheme focused on the importance of support from other CHD families. It included a range of experiences from immediately after diagnosis through present day, encompassing the lack of needed support, the loss of support, and the connections parents' made with other CHD families. Eight discussed how friends and family don't always understand CHD and are not able to provide the

support they need. Two parents described losing contact with close friends who “don’t get it.” For example, one mother of a young boy with CHD reported the loss of friendships after her prenatal diagnosis:

I’m very closed with most people. I don’t let a lot of people in. And I think that that’s gotten even worse since [our diagnosis], because people do leave, you know? They can’t handle the stress and they can’t handle the thought of your child dying because then it might affect their life. So, a lot of people do leave so it just makes you kind of a little bit more like – [sigh] ok, this is who is going to be here for me and so it makes it harder for friendships.

Integral to the support parents sought was their need to connect with other families who have children with CHD since these families understand and can share their own experiences. Participants discussed both in-person support and online support from other parents of children with CHD. Fathers primarily valued the in-person connection with other families, while mothers sought a combination of online and in-person support. One mother described this as follows:

You kind of get into this club that you never wanted to be in. But you know, on the other hand, you don’t really know what you would do without them either. So, it’s kind of a blessing in disguise, if that makes any sense.

Another mother followed up, describing how online support has been important to her.

It’s a club you don’t ever want to be a part of but you are glad that the club is there when you need them. I have more of a bigger Facebook group, about 25

moms that we message back and forth every couple days, checking in on each other's kids and stuff, which is nice. So, I don't really have a lot of local contacts, so it's kind of neat that you are really close friends with these people you never even met, you know. It's kind of neat.

One father talked about how another father could be an important support during hospitalizations, because he would understand that one might need a break from thinking about CHD:

Sometimes, hey, I just – I don't want to talk about it. Well that person knows, [and could say] “Hey, what about the Panthers? Let's talk about something else.” And if, as you're sitting there talking, [CHD] might be brought up. Yeah it might be just having that person you could talk to...to just disconnect from [CHD] for a little bit. And that person knows WHY you need to get away from it. And that's not a bad thing to get away from your kid's situation but I mean the emotions can tear you down and if it's on you every day you need to get away.

Participants discussed the importance of hospital-based parent support organizations that provided them with frequent contacts with other families. One father who had to travel to another state for his son's surgery discussed the local foundation that matched them with parent support:

Once we got in contact with the [foundation], you know, that's when a bunch of the avenues started opening up for us and moms were reaching out to my wife and me so that was definitely one of the biggest helps – was just having a parent who had gone through it or knew what to expect.

Mothers discussed how online support connected them with many families at once, increasing their ability to get and give support. In addition to feeling supported and encouraged by these contacts, parents reported frequent feelings of vicarious trauma through exposure to numerous infants and children who have “bad outcomes,” such as permanent disability and death

One mother reported that she has not met any other heart parents and feels a strong longing to connect with others who have been through experiences similar to hers. She reported actively seeking this support and described considerable distress from feeling isolated in the face of support from family and coworkers who do not share her experiences.

Included in the theme of seeking support, participants warned other CHD parents “Don't – Google – Anything!” Parents advised new parents to ask other CHD families and their doctors instead. One father commented that “the last thing you want to google is HLHS,” referring to the wealth of frightening and traumatic information that will come up about CHD when searching online. Parents described that the information online is often not current since the field is moving forward so rapidly. Given this warning, most parents said that they or their spouses did spend a good deal of time searching the internet for information, but described the impact this had on their stress level as not being helpful. Two fathers discussed the dangers of Googling information about CHD.

Father One: And I think that [parent-to-parent support] is the best way because I think when we came people told us DO NOT Google anything. [The search results

are] the worst information you can give someone because there's so many things out there and you will. . .

Father Two: *Well you'll lose your mind pretty much.*

Father One: *Yes, and so from experience...if you know someone that's gone through your same situation then it's definitely hands-on, first experience is a lot better. When we were in it my wife...I had to get her off Google several times just because once you read it...now it's in your mind.*

Faith-based support. Parents also described religious and faith-based support, including contact with their church, their pastor, prayer, and turning it over to God. Seven parents reported handling the many ups and downs of having a critically ill child by relying on their faith to provide them with comfort. They described seeking support from their church community, religious leaders, and from their faith in God. One father described it this way.

I'm a religious guy as well. We knew it was in God's hands. That look...if it's meant to be, it's meant to be.

Support from the medical team. All but one of the parents reported feeling supported by members of their child's medical team (n=11; 91.7%). Conflicting attitudes regarding support from their medical team were also reported. Of the 12 parents, three (25%) described solely supportive interactions with the medical team, one (8.3%) described only negative interactions with the medical team, and eight (66.7%) described a combination of positive and negative interactions. Eleven (91.7%) of the participants reported a strong connection to the medical team, including doctors and nurses. They

described having deep faith in their surgeons and cardiologist and an appreciation for the people who saved their child's life. One mother discussed how helpful her care center was in preparing them for her son's hospitalization and surgery:

I do want to say that [the children's hospital] here was awesome about preparing us ahead of time for what to expect, including the nitty gritty of the hospital experience. The advocate took us down all the corridors, all the rooms where he might be, asked permission, and we went into the patient's room of a baby who had had his same open heart surgery for the same heart defect the day before, still had the cavity open, all the tubes and wires and everything so I knew what it was going to look like, so that was helpful.

However, nine (75%) parents also discussed experiences with the medical team that were unsupportive and sometimes upsetting, including insensitive interactions, medical errors, and lack of support at important times. For example, one mother described a distressing interaction with a nurse as follows:

I did have one nurse who in CVICU. [My child's] diaper was dirty and she said, 'well, I'll take care of that when I do my hands-on care,' which was going to be in an hour.' At first, I said, 'I can change it,' and she said, 'Oh no, I'll take care of it.' 'It needs to be changed.' 'Well I'll take care of it.' I finally said, 'He's not sitting in his own feces for an hour with a catheter. This isn't going to happen. I'm his mother. I'm going to change him. If you have a problem, then you should call security.' 'Well we didn't need to go there!' 'Well obviously we did. You are

not going to call security on me because you refused to change my son's diaper for the next hour because. . . you have one patient. This is it!

This same mother recalls a more positive exchange with another nurse who was supporting parents' participation in care through encouragement and education:

I had one nurse who said you can do his oral care, and it was so wonderful to be able to do something, while he's got this vent in his nose, and when they needed me to just swab out his mouth a couple times a day to keep it fresh and prevent bacteria from building up and it was, . . . she said, 'I know he's your baby and you want to do something for your baby,' and I just started crying and I said, 'He IS my baby!' And she said, 'Yes, and we are going to get him in your arms as soon as we can, but of course his chest was open, so here's what you can do.'

One father recalled an unpleasant interaction about his son's prenatal diagnosis that left him feeling unsupported:

It was very awkward how we found out um we went to try to find a heartbeat I guess it's at the 18th week or I can't remember which one again it was, but all of his valves and platelets, I guess the four chambers – and I don't know all the terminology - but they couldn't find everything and so we went from there to one doctor to eventually the doctor told us we might want to think about aborting...which that never crossed our mind and I won't give names and we pretty much didn't like the way his bedside manners were.

Giving Back

Nine parents so valued the many supports they received from the CHD community that they became involved in efforts to give back to the CHD community. This superordinate theme of giving back included the following subthemes: offering support to heart families and medical teams, being “pioneers,” spreading awareness, and raising money. One of the primary ways families have chosen to give back to the CHD community is through volunteering and informally supporting families who are just beginning their journey with CHD.

Supporting other CHD families. Half of the mothers and all of the fathers discussed this theme. More than one mother volunteers at the hospital to meet with newly diagnosed families. Four parents discussed being asked to allow an expecting couple or family of a newborn awaiting surgery to see their infant immediately post-surgery to help them understand what to expect. While these participants talked about what a difficult time it was and how protective they felt about their very small infants, they nonetheless allowed this unfamiliar couple to come into their private experience, in order to give back and to help those who follow.

When [our son] got out of his surgery that night they actually had. . .a set of parents come back that their son was going to surgery the next day and they asked...They asked us can we show – would it be okay if they came. . .and saw what [our son] looks like so they can be prepared tomorrow. I didn't want them to see it but again, we're pioneers. . .We're gonna, you know, we're gonna let you see the ugly. We're gonna let you see what it is. They did and to this day we're

still really good friends you know? Because [the mother] just said “thank you so much for. . .we know what to expect.”

Parents felt a strong connection and responsibility to share their experience and to support others who come after them. One mother volunteers to create memory boxes for families who lose an infant or child to CHD at their local children’s hospital. Her husband described this as “taking a toll on her,” again, highlighting the vicarious trauma that is a natural part of being connected to this supportive community of heart families. Many mothers are active in online support groups for heart parents and feel a strong sense of responsibility to be there for their online friends. Participants struggled with wanting to be there vs. needing to step back sometimes for their own mental wellbeing, particularly when facing numerous vicarious losses. Again, parents reported that the other families were all understanding of this need to step away from the online groups or in-person volunteering as needed and, in fact, encouraged it.

Pioneers. There was a theme of being pioneers, of being part of moving the field forward, and blazing a trail for families yet to come. Since each surgery and each different case helps the medical team better understand how to help these babies. Mothers expressed a feeling of connection with every family who has gone before them and everyone who will follow. One mother discussed the human side of the statistics about CHD.

They’re not just numbers, you know? Like a lot of people talk about [our surgeon’s] success rate and all that kind of stuff and it’s amazing and...when you’re looking for surgeons, you’re looking for that information, um but those

numbers add up, you know? It's like, they're all kids. They're all babies. So, it does build on – you know, every kid kind of leaves a little path for the next one that is coming through. Because I feel like [the medical teams] learn so much, the staff learns so much from every case, you know?

Another mother described how every patient contributes to the collective medical knowledge of the surgeons who work on these babies. These participants described feeling a strong connection with all the hearts families who have come before and those to come. This touching exchange between two mothers illustrates the importance of being a pioneer in a field where there are so many new advances.

Mother One: It's every single child before us was a pioneer so it's our job to carry that forward. You know? It's just – it's the responsibility that comes with being a CHD parent in my opinion.

Mother Two: You want to kind of honor those parents and respect them, and say, "Your child did not die in vain."

Mother One: Exactly. We're going to carry the torch for you from now on.

There was a sense that their own child's experience helps move the field forward, informing the knowledge of the medical teams and the shared knowledge of medical teams around the country. Indeed, several of the children of participants have a unique condition that required the team to develop procedures that have never been attempted before.

The surgeons at [the children's hospital], when my son was born, contacted [many other children's hospitals]. They contacted, like, any and every contact

they had to see if any child had the multitude of conditions that he had and they haven't found any successful cases, so they are basically going to try and do something that hasn't been done before, with him. . . So, we just found out, actually, they called me Friday to schedule a consult with a surgeon at [another children's hospital]. They have the 3-D model printed of his heart for practice, to see what outcomes would be most achievable.

Supporting the medical team. In addition to supporting parents, five of the participants regularly bring gifts and send cards to their medical team, expressing support and gratitude. One father reported having positive associations with the children's hospital as follows:

I just love going. I mean they saved our son's life. We're friends with all the doctors and nurses...I mean as much as you can be. We go to all the reunions and meetings. I mean that's really why I'm here tonight, just because we're trying to get involved. I enjoy being around people – the types of people that saved his life, so we go to our hospital and hang out, get something to eat, visit with people, take presents and gifts...just little dollar store gifts to the floor.

Spreading Awareness. Sharing information about CHD was another theme, particularly among fathers. Interestingly, three of the four fathers have tattoos about CHD as a way of spreading awareness. One father described it this way:

I want to tell everybody I can. That's one of the reasons why I have it tattooed on my arm. If someone asks me I'm like, "This is what happened to my son." You

know and just. . .getting the word out there you know? It's not debilitating- well, it's debilitating. But you know CHD's medicines have progressed so far now. . .

Five participants have been a part of awareness efforts by making media appearances for hospital publicity and by being part of hospital public relations campaigns. One father described his amazement at all the opportunities presented to his family once they started getting involved.

We did TV commercials; we did interviews for the news, for [the children's hospital]. We were on postcards for [fundraising]. I was like, man, wow!

Supporting CHD Research. Three participants discussed raising funds for CHD research and the hospitals. These families have participated in the Heart Walk and other fundraising efforts. They talked about their hopes for medical advances to support their own children and the heart children to follow.

It's just...he has a heart condition and is gonna have a transplant by the time he's 10, 20, or 30, or 40. You just don't know so. . . I hope he lives to be 100 and runs marathons with his artificial heart you know.

This same father talked about frequently checking for medical updates for his son's complex CHD:

At least once a week. "HLHS." "What causes HLHS?" "HLHS advancements." At least once a week that's my Google search.

Positive Changes

Another major theme was of positive changes since the birth of the heart child. This theme included subthemes of feeling a closer connection with spouse and child,

having a greater appreciation for life, and feeling that the experience made the participant a better parent and a better person.

Closer relationships. Four parents reported feeling a closer connection with their spouse and their child through the experience of going through something difficult together. They reported a feeling of connection and intimacy from sharing the scariest moments of their lives together and of supporting each other during this process.

I'd say it's brought us closer because we had to give each other that comfort. I mean we had some tough days. When you sit there and cry with somebody...obviously it brings you closer. So, I don't think it's really affected [our marriage] other than in a positive way. I hate to say that. Obviously, you don't want that to be the reason it brings you closer together but no, I mean I don't think we ever fought or anything like that or argued. The only thing we've argued about is if he's playing football [laughter].

One participant found that it neither strengthened nor deteriorated his marriage. In contrast, a third participant reported that this experience highlighted difficulties in her marriage and led to a marital separation.

When I had my daughter and [my husband] was like a little baby himself, I was like, go. So, I didn't want him around no more. I was like, "This is MY child. I want all my attention on her."

One father described the CHD experience as creating a special bond with his child, seeing their child as their hero.

You know, as an adult if I scratch my finger...put me in the hospital. So, I consider my son my hero. . .at 2 weeks old. He's my hero. I mean he's going through something I could only IMAGINE myself having to go through a surgery. He's just born...just starting life and now he's hooked up to machines, they're already cutting on him and there's a possibility that the worst could happen and so you look at him and like he's a fighter. You know? And so, you look at our children that do that and it's just... it's pretty awesome. You know? And that's why you wanna tell your kid. I wanna tell him when he gets older... you know that's the first, I guess, experience I got of my son. "Hey man, you're my hero!"

Connections with the CHD community. Another positive change was the close connections parents made with other heart parents and the medical team, discussed above under Parent-to-Parent Support and Support from the Medical Team. All parents feel these connections have enriched their lives.

Greater appreciation for life and their child. A third subtheme was having greater appreciation of life and of their child.

You learn to appreciate a little child and everybody, all our friends and family, maybe hug their kids a little more.

A mother described being reminded to appreciate her family more, tying this in with her faith:

I think we have learned, we've always enjoyed our kids but [our heart child] has taught us to enjoy them more, like every little moment. My husband said, 'I don't know how many more moments we are going to get with him, how many more

Christmases, how many more times going fishing'. . . I said to my husband 'You know we talk about how [our heart child] could be gone tomorrow, well any of them could be gone tomorrow.' God shot a warning shot across the bow. We just really need to pay attention to all of them.

Being a better parent/person. Many participants described how they are better parents than they were before having a child with CHD, emphasizing how the experience made them more patient, more appreciative of the time they spend with their child and how they have become more informed parents and better advocates. One mother summed up several of these aspects:

Yeah, I mean I learned so much in the hospital. I mean, the car seat test they make you do, you learn how to properly secure the car seat and things like that that I wouldn't have otherwise known or researched. I mean, in my opinion, it has made me the best mom that I can be. . . I think it's a different mentality when you almost lose your baby especially when you are not expecting it, it makes you want to do everything you can to protect that baby. So like, I would have been one of those moms who plopped the baby seat with the super loose straps and the chest clip at the belly button. . .but because of almost losing him, I educated myself twice as much as I probably would have and things like that, and it made me want to take a more natural parent... approach to parenting. [Big sigh] I feel like it made me a better mom and a better person, I think.

One mother described how her child helped her to be more patient:

I think you also become more patient. . . when they make bad choices. . .because you've spent so much time with them . . . whether it be in the hospital or because they have to have these other special needs. . .that you spend so much one on one time with your child that you develop a patience for it and you figure it out.

Parents' Experience of Pediatric Medical Traumatic Stress

(2) What are parents' experiences of pediatric medical traumatic stress?

Participants described a variety of posttraumatic reactions including the four symptom clusters: intrusive symptoms, avoidance, negative cognitions/affect, and trauma-related arousal/reactivity. While PTSD was not formally measured, during the focus groups, 11 participants described a number of symptoms that fall within the four symptom clusters of PTSD (American Psychiatric Association, 2013). Mothers ranged from zero symptoms to four out of four symptom clusters, while fathers ranged from two to three symptom clusters (see Table 5, Appendix A). No differences were noted in PTSD symptoms between parents who received prenatal diagnosis and parents who received postnatal diagnosis.

Intrusive symptoms. The most common was intrusive symptoms, which was mentioned by nine of the 12 participants (75%). Importantly, parents' reports of trauma appeared to be a gendered experience. While both mothers and fathers reported experiencing a variety of flashbacks, six out of eight mothers described ongoing intrusive experiences triggered by reminders of the trauma, including the anniversary of the heart surgeries, smells from the hospital, and locations. One mother reported experiencing a panic attack when she exited the freeway on the exit for the children's hospital where her

son has surgery. She described her PTSD symptoms of re-experiencing, physical reactivity, and negative cognitions:

Mine started about three months after he was born. . . I was actually on my way back over here for a follow up appointment and I had a full-blown panic attack when I got off the exit, because it was the first time I had been back. It just hit me out of - that's when the Ativan prescription came. Just because - it wasn't like a daily thing. It was very situational. I had an issue with alarm clocks, because I would set my phone to pump every three hours. You know what I mean? I would always sleep through them, and then once I got home, I woke up [snapped fingers]. It was weird, but different things kind of would trigger it at completely random times - Um, yeah, so since, I have high blood pressure. um, I just feel like on edge a lot. I always play out the worst-case scenario.

This same mother also reported significant emotional distress during her family's celebration of the anniversary of her son's surgery two weeks after his birthday each year:

It's Happy Heart Day like two weeks later so it's kind of a similar situation that whole two week period is just bananas but...I'm not really a crier but I'll cry at anything at that time. Um, the worry part is pretty much all the time. Um...but I try to keep it in check.

Another participant recalled a conversation with her own mother, who cares for her son while she works. This helped her recognize the anniversary of her son's surgery as a reminder of the trauma.

It was every year at this same time and I didn't really notice it and last year is when [my mother] finally said, 'This has something to do with his anniversary because every year you're a basket case for two weeks.' I mean I will call her four and five times a day, asking, 'How's he doing?' [Around the anniversary] he has to be with me at all times if I'm not at work. I need to be able to see him, I need to be able to touch him. . . I just need to be right there to make sure that he's okay. I mean it's ridiculous. . . I just can't control it because it's just such a, [pause] I guess it was just such a traumatic time for me that. . . I need that reassurance that he's okay. I will call multiple, multiple, multiple times. . . And I mean I have left work completely...I mean, shaking, cannot control myself crying because I can't get ahold of [my mother] and she had her phone off! I mean, it's not a quick trip, okay? I mean it's a 45-minute trek home you know?

This same mother also reported on the lasting effects of her medical trauma and her use of counseling and medication to manage her symptoms:

I know for myself I don't handle stress in my personal life very well so I've been going to counseling on and off, especially since his open-heart, it's been very traumatic. . . I went to my primary care doctor, and he's the one who said "I think you have [PTSD]. You need to go talk to somebody." . . . And it was just, I was very, very fearful. . . I definitely have posttraumatic stress syndrome. Just being in the ICU alone can do that, not even necessarily the open heart in my opinion . . . Yes, and that's why I'm on Prozac is because it's not supposed to let me wander into "what-if land" and I have Ativan for days that are really bad.

One mother described intentionally exposing herself to reminders of the trauma as a way of overcoming the panic she experienced when she was near the hospital and the floor where her son had surgery.

So, the day we came back over, when I had the panic attack, I got really angry because I didn't like the feeling that that had that much control over me. . . so I said "Okay, I gotta keep going back over here. . . the more times I walk in those doors the less traumatic it will be and then hopefully, you could turn this into like some kind of like positive thing"

These six mothers described persistent, highly distressing symptoms that are interfering with functioning, including flashbacks, nightmares, intrusive thoughts, and emotional distress and physical reactivity at reminders of the trauma. Three mothers specifically reported a particularly distressing, intrusive image from when their child was intubated on a ventilator. The breathing tube prevents the child from vocalization, so when the child cried, there was no sound. One mother recalls her child awaiting surgery as follows:

They had him intubated the whole time, but he was awake enough to be crying. And so he's only like a year old and he has tears rolling down his face and there's this cry that he can't even really do because he's intubated. And so, I have flashbacks of that a lot. A lot.

Another mother reported:

I only have two flashbacks that are kind of recurring – one was when he was in the CVICU, when they were going to try to take the vent out, he would cry. You

know they would have to like, wean him off or whatever, and they cry but they don't make any noise.

Other flashbacks included cardiac arrest and resuscitation, respiratory therapists thumping the baby on the back to break up the congestion in the lungs, images of their baby connected to numerous tubes and wires “coming out of every orifice,” and all the IVs and medical equipment attached to the child post-operatively. One father described a traumatic imagine of his son and some of the ways he coped with that, alluding to the theme of reframing the past traumatic event based on the positive outcome:

When he had his first open heart surgery you know he came out...and of course his heart was swollen and a lot of his internal organs were swollen so they couldn't actually close his chest at the time. So, him coming out on ECMO and then having 10, 15, 20, however many IVs pumping in him and of course the ECMO, the heart-lung bypass machine in there. Of course, that's upsetting but you know it's there to make him better so in a sense it's good I guess but I guess it's all in perspective of how you look at it I guess...have the ability I guess to have a little disconnect with that.

In contrast to mothers' ongoing intrusive symptoms, the two fathers who reported intrusive symptoms described these as rare and mostly in the past. These two fathers specifically described attempts to expose themselves to reminders of the trauma, such as getting a reminder tattooed on their bodies. One father described how he re-reads the family blog about his son's surgery each year as follows.

I still at least once a year probably go back to the blog and just re-read everything. Just to remind myself. And it's just a good, be by myself, emotional kick. . .to get that manly thing out, you know? Just to see and read everything; and I'll be honest, I tear up and everything and I see those pictures of him. Yeah, I mean, who wouldn't? So, no I don't think it's traumatizing but it's definitely good to look back and to remember everything.

Reframing the traumatic events. Three fathers described allowing the positive outcome of surgery (i.e., their child's surviving) to reframe the traumatic event into a positive. Fathers also described events as being initially traumatic but no longer. When asked to talk about traumatic medical experiences, one father described.

I think while you're living it, while you're experiencing it of course it's upsetting and traumatizing I guess in a sense at that point, but once you get past that and you see him running wide open in the hallway... and to know I can put him in a room with 20 other kids and unless he takes his shirt off you wouldn't know he has CHD, without seeing a zipper [chest scar] so I mean...I guess in a sense the only upsetting or traumatizing part of it would be while you're going through it but you know, to see the outcome almost makes it worth it. Glad we did that...I mean it's wonderful because I've seen him hooked up to an ECMO machine where he's on heart-lung bypass and what looks like 100 different medications pumping in him via IV. So, yeah, to see where the machine is keeping him alive to him out-running me [laughter] is amazing.

Negative cognitions and affect. Negative trauma-related thoughts and feelings were reported by a majority of the participants. Indeed, this was the most common trauma symptom, reported 10 of the 12 parents. Six mothers reported catastrophizing about the worst-case scenarios and reported a lack of trust in others to catch any potential signs of worsening health. This resulted in a feeling of being the only keeper of their child's medical information, something that created stress and worry among these mothers. They reported that these thoughts interfered with work, marriage, and their wellbeing. One mother described the impact on her marriage:

You don't get date nights because you only will leave your children with somebody who knows CPR, who's first aid certified, who knows how to give meds, who knows all this stuff. And now that he's a little bit older and he's a little bit more stable, I feel like we can do these things, but we still haven't. I mean we still, you know, because is she gonna remember to give him his medicine right at 8:00? It's just, that's gonna be in the back of my mind the entire time we're on the date night and then I'm gonna end up texting her. So, it's not really gonna be a very good date night for me because I'm gonna be worried that she's gonna forget his meds

Six mothers reported high levels of emotional distress related to observing their child undergo and recover from traumatic medical procedures. One mother reported feeling unprepared for the possibility of experiencing PTSD symptoms, wishing someone had informed her that this could result from her child's traumatic medical events.

You know, nobody ever said anything about the PTSD part. Nobody ever mentioned that. Um, so I think...there's kind of stuff that's not talked about sometimes, which needs to be brought up.

Two fathers discussed feelings of self-blame, feeling that their primary job is to protect their child from harm and “keep them alive,” feeling that this condition might be their fault somehow. These fathers discussed worrying about what they might have done to have caused this:

Father One: Yeah, I know that we met some people that were very young that had heart babies but I mean we were older. I was 38 and my wife was 34 and I felt like that probably contributed to it, maybe. I don't know.

Father Two: If I would have done this different. . .then maybe this wouldn't have happened or I mean...

Father One: Was it too many Pringles? But that's just conjecture . . . You just have all these points and you connect them at random and it's a really unhealthy thing to do.

Avoidance. Avoidance of reminders of the trauma was endorsed by eight out of 12 participants. Examples included fathers' not wanting any more children due to the distress of seeing their wife and child suffer. One father described it this way:

. . . So, it affected, traumatized me to the fact that she had her tubes tied when I said I don't want any more kids. That reason. I didn't want to see my wife suffer anymore. It just, unfortunately, wasn't worth it to me.

One mother reported avoiding in this way:

I do have a picture on my phone that some people ask to see it. I don't let them I don't want any pictures. . . I have one of her on ECMO but I hate showing it to anybody. I don't want to talk about it, I just want her to be fine.

Another mother described avoiding the location in which she received past traumatic medical news about her son as follows:

And then Monday he went in for the cath and within 10 minutes they were calling us into the little room and I don't do little rooms. . . . So, I got dragged in there by my husband. He literally forced me. He had to physically force me to go in there because I just couldn't do it. Um, and that's when we were told he needed heart surgery right away.

Arousal and reactivity. Trauma-related arousal and reactivity was described by three of the twelve participants endorsing it and was the least frequently described trauma symptom out of the four symptom clusters. These three parents described irritability and hypervigilance. One father described always being in “high safety mode.” Another parent described how she and her husband as get highly irritable and argumentative around the anniversary of the surgery. She described needing to work on how to communicate in healthy ways, even when they are both affected by the trauma of their son's medical experiences.

The month or two leading up to it is really hard because [my husband] won't admit that he's scared and it took me a couple years to realize what was going on. But he'd be really snappy and just really, you know, just be a jerk and it finally dawned on me “Ohhhh, you're scared and this is how it's manifesting itself”

Okay. . .I guess we just haven't learned yet, we've only been married [a few] years so we haven't learned I guess how to communicate through stress without wanting to kill each other. And he's a very old school southern man and does not believe in counseling or anything like that so it's kind of like – I mean he believes in counseling and Prozac for me! [laughter]

Additional trauma-related themes. In addition to these symptoms of PTSD, other trauma-related themes emerged. While 11 parents reported some symptoms of trauma related to the hospitalizing and ICU experience, one parent reported that the hospital experience was not the traumatizing part, but the home care afterwards was. Four mothers reported that events other than the cardiac condition were the biggest source of trauma, including feeding issues and not being able to breastfeed. These parents reported that these feeding issues created more ongoing distress than the initial surgery.

The heart stuff is really tough and serious, but really the feeding issues have been most psychologically challenging to me on a daily basis for all of his life.

Sometime that's neglected by the medical staff as being important.

Continuous traumatic stress. One theme that emerged was that of continuous traumatic stress. Three parents reported that while their children are currently stable, most will definitely or possibly need another surgery in the future, including potential heart transplantation. This was a significant source of distress, preventing parents from ever seeing the trauma as something in the past. In addition, CHD continues to be life-threatening and many children with CHD face ongoing health and developmental challenges. One mother mentioned that the scariest moment for her was not in the past,

but ongoing, as she fears for future complications related to her son's single ventricle condition. She brought up the question from the Family Background Questionnaire that asked about the most upsetting time related to CHD, describing her answer as follows:

Every day! Every day, every cardiology check-up, every time he coughs, every time he inhales in the middle of the night longer than normal . . . every day, watching him do everything.

One mother described how her son was scheduled for surgery each year when her family travels out of state for his annual cardiology care, in case the medical studies indicate the need for surgery. She talked about how difficult it is awaiting word each year about a possible immediate surgery. She discussed the strengthening bond between her and her son made these appointments more difficult, stating:

I've noticed that the older [my son] gets and the more we fall in love with this kid and the more we just love his personality and you know it's this kid and you just love him to death, the harder...like when we go to [the children's hospital] every year they schedule his open heart surgery after his cath because it's better that he be on the books and not need it than him go up there and need it [but not be able to schedule it]. So, every year we're having to prepare ourselves for open heart surgery. And so, like the month or two leading up to it is really hard.

Seeking medical reassurance. Seven (87.5%) of mothers, compared to one (25%) of fathers endorsed this desire to seek reassurance from their children's pediatrician and cardiologist. As the children become more stable, cardiologists begin to space out the

visits farther and farther apart. These mothers reported wanting more frequent visits to the cardiologist for reassurance and to detect any potential development problems.

In contrast, three of the four fathers reported feeling relieved when the visits began to be farther apart, indicating that this means their child is doing better. One father described his opinion of medical appointments with this son:

Yeah, I've seen my son lay open on the table. Going in for an echocardiogram is about the biggest thing that we do, just an ultrasound of the heart. So, I mean you know... it's just another doctor's appointment really. We have our periodic checks here where they'll do an echo and look at his heart and if they see the numbers or pressures going up in his heart from the stenosis. We might go to [the children's hospital] or have a cath done here where they'll put the probe in there and get real time measurements. Them sticking a little probe in his heart is like me going for a physical. It's just another check-up.

Another father described the difference between him and his wife related to the appointments:

After surgery, we had to go back - I think it was every six months - and then they moved it to a year and then it's...I think it's 18 months now. Speaking for my wife, I think we were scheduled out a year when he was 2-years-old, and she called and said, "Can we do it at eight months?" You know, so she... she wanted to have it a lot sooner. She was like "Man I don't know if I want to go a year." And so now we're out to, I think, 18 months and so it's just going to be interesting to see how she does. She wants that assurance of that echo[cardiogram] saying everything is

good. And yeah, I mean I do too but do I anticipate those appointments or anything? No.

Vicarious trauma. Another common theme was that of vicarious trauma. Parents reported experiencing vicarious trauma related to their time in the hospital with their child, seeing families experience loss and very distressing medical experiences. Mothers reported seeing other children suffering who did not have a parent there to comfort them. One mother described how this was sometime more distressing than her own child's medical experiences:

And then just being up here, which I'm sure you've seen...you walk by these rooms where they have nobody. You know we were on progressive care five nights and I didn't see one adult in this child's room other than a nurse or a doctor. And that's heart breaking. That haunts me almost more sometimes than...

Another mother described wanting to help comfort other children in the ICU. She asked a nurse:

"Can I go in there?" And you're not allowed to. You're not allowed to go in and comfort that child. You're not allowed to go and sit with that child because it's not your child, which is extremely hard. And I would sneak over. We share rooms and I would sneak over and give them their pacifier back – Without them knowing. Give them a little pat on the head you know? [laughter]

Four mothers discussed the mixed experience of connecting with other parents. While identified as a strong source of support, contact with other heart families, particularly with online support, was also a significant source of vicarious trauma.

Connecting with a large group of other heart families increases the likelihood of experiencing vicarious trauma through the loss of friends' children. In addition, one mother described how some other heart mothers “overshared,” creating vicarious trauma.

One mother described the internal struggle between providing support for her friends online and self-care when there were several children who passed away in her online support group within a short period of time, highlighting the personal nature of the loss.

You have to have a balance, sometimes you have to step back away from the club sometimes because you can't fully be ensconced all the time. Because you will lose your mind and if it's a bad month, you've lost three kids. Holy crap, you just can't, you know? . . . You can't constantly be surrounded by that. . . I think that that leads to stress, a lot of stress too for us because we want to be supportive of our friends in this club but at the same time, like sometimes I'll email my friends and be like 'I have to check out for a little bit' you know, 'if there's something major text me but, you know, I just need a week to regroup.'

This same mother described her conflicting needs to provide support for this community and to protect herself from frequent vicarious trauma from hearing others' tragic stories. She experiences guilt when she can't be there to support families she has come to know well, especially during a time of grief and loss. She talked about her commitment to supporting her online friends, due to the tremendous help she receives from these friends.

I guess one of my gifts is I just like to encourage people because I know how good that feels to be encouraged as a parent and so I like, you know, I don't take steps back very often because I really do like to encourage other parents even if it's just a 'hey, here's a virtual hug, I hope you have a good day,' you know, and so, I think you just have to take breaks sometimes, and I think even when you know your friends are having a bad day, if you just send a quick like 'hey' that makes ME feel better, so it's not too mind-boggling or whatever.

The Effect of CHD on Parenting Patterns

(3) In what ways has CHD affected the parenting patterns of parents with a child who has undergone open-heart surgery? Parents reported a range of parenting experiences with their children with CHD, including permissive parenting, overprotective parenting, balancing the need to protect with the need for their child to “be a normal kid,” and parenting of siblings.

Permissive parenting. The most common theme was being more permissive, with regards to discipline with their child with CHD. Seven mothers specifically described difficulty setting limits.

He gets away with a lot of stuff. He's really cute. He's got the little elf ears. He's real happy most of the time, so it's just hard to . . . I say “no” less to him [than to my other children].

One father also reported being more permissive with his heart child. While he does use physical discipline, he reported that it is more difficult for him emotionally than it is with his other children:

We try talking to them first and if that doesn't work then we start. . start taking electronics or toys or what-not, outside time, television, computer, anything. I mean and then we try to NOT resolve to spanking but I mean sometimes it does end up going to there. I try not to do it with any of them. But I mean if it gets to the point where you have to – I mean I still do it but it hurts me more doing it to [my child with CHD] than it does the other two. . .She gets away with murder.

Of the four parents who did not report permissive parenting practices, they appeared to use an authoritative parenting style and purposely worked to be consistent in their parenting approach. These parents described working together with their partner to apply discipline in a structured and non-reactive manner.

Gender differences in parenting. Four mothers (50%) and all ($n=4$) of the fathers described gender differences in parenting between them and their partners, with the typical theme of fathers being harsher and mothers being more permissive. Three fathers (75%) further described intergenerational parenting differences, specifically that their own fathers were much more harsh and physical in their discipline than they themselves are, and that their wives disagree with a harsh, punitive parenting approach. Four participants comprising two couple each discussed, in their separate focus groups, that this this as an ongoing marital disagreement. One mother described it as a strength in their relationship, with her partner helping out with discipline when it is difficult for her. Another mother described a contrasting experience, with her spouse being more patient than her in discipline.

Overprotective parenting. Another common theme was that of overprotective parenting. Four mothers reported overprotective parenting practices. This will be further discussed in the following section on the relationship between pediatric medical traumatic stress and parenting.

Letting them “be a normal kid.” While half of the fathers ($n=2$) and mothers ($n=4$) reported overprotective parenting behaviors, mothers were primarily focused on preventing harm, pain, and illness. In contrast, fathers appeared to struggle more with feeling that it is their job to protect their children and “keep them alive,” but also wanting to encourage their children to push the limits and explore. All fathers ($n=4$) discussed the need to balance protection with allowing their child to “be a normal kid.” This was a universal theme for the fathers, but not mentioned by the mothers.

I do realize you have to let them be normal too. You don't want to burden them with...don't want them to think that they're special in a bad way, you know what I mean?

Another father described the difference between him and his wife on this matter as follows:

I don't know maybe it's different from cardiologist to cardiologist but [our son's cardiologist] told us, [because] my wife's – you know...being a helicopter parent – I don't want to keep saying that because I think her ears are burning right now. “Let him do whatever he wants to do and don't use this as a crutch in any way. He's going to tell you if he's tired or not. You'll see it. So just let him be a kid. Let him run around, wear himself out, do whatever.”

One father described how he works to balance his fears for his son with wanting his son to be “a normal kid.” He uses his faith in God to manage these conflicting goals, by allowing his son to explore and do typical child activities even in the face of his own fears.

So, we just had to realize, look! He’s won. He’s got to live his life. He’s gotta jump off the couch and see what happens. He’s gotta run down the hallway as fast as he can...He’s gotta be a child. He’s got to be a little boy and so I guess that’s the first year. I wouldn’t say it’s traumatizing but...you just want to watch what he does and make sure everything – you know that he’s okay. Once you get over that [pause] he’s jumping off the couch, over the couch, beating his sister up. I mean you know...he’s scaring us now with the things he does. He’s just a wild little three-year-old, and so I guess you just have to first get over that, “Is he okay to do that?” But he’s a normal kid. You just gotta realize that.

Other suboptimal parenting patterns. One mother reported frequently crying in front of her daughter, due to high levels of trauma-related distress. This was considered an example of enacting/frightening/endangering parenting pattern. This was the only example of this pattern among this sample. There were no comments related to withdrawn parenting patterns.

Relationship between PTSD Symptoms and Parenting Patterns

(4) What is the relationship between parent pediatric medical traumatic stress and parenting patterns? The dominant themes that emerged at the intersection of

parenting and PTSD symptoms were overprotection and permissive parenting related to self-reported PTSD symptoms.

Associations between permissive parenting and PTSD symptoms. Parents ($n=5$) reported a variety of permissive parenting practices related to self-reported PTSD symptoms. These included “babying,” or doing for the child what they could do for themselves, letting them get away with behaviors of which the parent does not approve, and giving different consequences than siblings. These were related to fears of mortality, negative emotions, re-experiencing, particularly flashbacks, and vicarious trauma.

However, a variety of permissive parenting practices emerged that seem unrelated to PTSD symptoms. Two mothers with few self-reported PTSD symptoms reported permissive parenting, one related to difficulty setting limits and one related to feeding issues. Specifically:

I have a low tolerance for his crying, and I don't know if it's so much because of his heart issues and his health scares or because of his eating and vomiting problem. He cries himself into vomiting and I can't stand cleaning it up. I'd rather just hold him. It's tough to say. He's definitely been babied but we do have expectations for him just like the other children, and he has limits like they do, and we'll see how this goes.

Associations between overprotective parenting and PTSD symptoms. The six parents who reported high levels of overprotective behavior attributed this overprotection to vicarious trauma, negative cognitions and affect, intrusive thoughts, especially flashbacks and reminders of the trauma, and physiological arousal, as illustrated in the

Well that's how I am, I had the baby monitors the regular ones and the video ones. I can't even see if she's breathing, so she's in my bed. Actually, she's on the couch in my room now. . .but she's right beside me. "[child,] are you okay?" all the time. She coughs a lot. She's always right around me.

Another mother captured the interplay between fears of mortality and constant monitoring:

I had to hear that, probably 50 times from our cardiologist, that he could cry and he could get blotchy. and that's fine, and if he cries too much, he may pass out and then his breathing will return to normal. . . I want him where I can reach over and feel him breathing. and feel his heart. and count the beats . . . He is gonna be the teen-age son that wakes up and is terrified because his mom is leaning over him. "Sorry, honey, just making sure you are breathing," you know? I'm gonna have to work on that because that's, you know - I hope that he makes it long enough so that that's a struggle I have to work on.

Three parents reported feeling frightened to allow their child to do activities even after it was cleared by their cardiologist. One father reported his involvement with his daughter's sports:

With her it was great because I was actually her coach so I could keep an eye on her from the sidelines and see if her demeanor or she started breathing heavy or she started getting woozy or anything like that I'd be able to see her...I was able to go up and down the field with them and up and down the court with them so it wasn't like I was looking from the sidelines as a spectator trying to be able to see

her across the field. I was on one side and her mother was on the other side to be able to keep an eye on her so...it wasn't bad. At first it was a little scary and then when she took off with it and just ran with it...I mean I wasn't going to stop her.

One mother talked about the difficulty balancing her fears and worries with wanting to allow her son to run and play.

So, that was kind of scary at first, when he really started getting active, you know, and they just run and run and run, and he'll come to me and his hair is soaking wet, or if he runs and he's out of breath. You know and my husband is like, "He's two...this is what they do." And I just keep trying to remind myself – like, I think it's [our cardiologist] that told me, "Kids are so much better at self-regulating than adults are."

One father described his primary role as protector. He discussed his fears of illness for his son leading to overprotection:

I feel my job is to protect him. If something had happened to me and someone had come to me later and said, "Well you would have been okay had your mom or dad not let you do x..." and that was just some silly childhood adventure that I barely remember anyway. You know what I mean? Like we've kept our son out of play groups in the winter time because if he gets the flu...It's A LOT worse than if a healthy kid...And so if that led to something very bad happening I don't want to be like, "Oh if we just hadn't let him go to that playgroup." How important is the playgroup? Like it's really not that important. My job is to protect him.

Another mother reported that despite her daughter's cardiologist's clearing her for PE and other activities, she and her children's teachers are still reluctant to allow her daughter to fully participate:

I'll talk to [her cardiologist] and be like, "Is it okay for her to go to school?" And he's like, "Yeah." In PE, the instructor is terrified for her to do anything. I'm terrified for her to do anything, you know? He put no restrictions on her and everyone is freaking out.

This same mother also frequently struggles with her urge to overprotect and her strong negative emotions related to thoughts of anything bad happening to her child. Family members encourage this mother to allow her daughter to engage in more typical childhood experiences:

Like I said, I cry all the time, and they just think she's normal, and my dad and mom are like, "Well, just let her run! Let her be!" And I'm like, "You can't just let her do all this stuff." You know? She could easily...[her cousin] is hanging over the rail on the cruise ship and I'm like "I don't want [my daughter] looking over, she might fall in!" And she can't swim! And I just cry a lot.

Associations between other parenting patterns and PTSD symptoms. The other two parenting patterns included withdrawn parenting and endangering/frightening parenting. There were no examples of withdrawn parenting in this sample. Enacting/endangering/frightening parenting was mentioned by one participant. This mother, who also described significant psychological distress (i.e., negative

cognitions/affect) related to her child's condition, reported frequent crying in front of her child, which includes a frightening component.

You listen to the doctors and [you worry] and you just start balling and [my daughter] says, 'Mommy, you cry all the time.' She doesn't understand why, and I don't lead it on, but I'm like, this is my \$20-million baby and that's the only baby I want, really. So, I think that's why I don't want another.

No other comments related to endangering/enacting/frightening parenting practices were reported by these participants.

Correlations between parenting and PTSD symptoms. Zero order correlation were analyzed, looking at the association between the two frequently endorsed parenting patterns (i.e., permissive and overprotective), and PTSD symptoms. Correlations were computed using the number of comments related to each of the PTSD symptom clusters, vicarious trauma, continuous traumatic stress, and total trauma symptom count, with the number of comments about overprotective and permissive parenting. Withdrawn ($n=1$) and enacting/frightening ($n=0$) patterns were not included in correlational analyses due to limited frequency in the sample. Overprotective parenting was strongly correlated with re-experiencing ($r=.75, p<.01$), arousal/reactivity ($r=.72, p<.01$), vicarious trauma ($r=.78, p<.01$) and total number of mentions of PTSD symptoms ($r=.92, p<.001$). Permissive parenting was not significantly correlated with any trauma symptoms (see Table 6, Appendix A).

DISCUSSION

This study, guided by the pediatric medical traumatic stress model (Kazak et al., 2007) and the relational PTSD model (Scheeringa & Zeanah, 2001), explored the experiences of parents of children with critical CHD who had open-heart surgery during infancy. Parents frequently experience symptoms of posttraumatic stress disorder (PTSD) related to traumatic medical events their child experiences. These PTSD symptoms have been found to be a risk factor for child adjustment. The relational PTSD model proposed three suboptimal parenting patterns that may explain this association. The current study explored the experience of parents whose child had open heart surgery during infancy, examining parents' experiences of CHD, PTSD symptoms, and their parenting practices.

The Impact of CHD on Parents

(1) In what ways has CHD affected the life of the parent? The first research question sought to explore the parents' experience of congenital heart disease (CHD). Twelve parents, including four fathers and eight mothers, comprising four couples and four additional mothers, reported a variety of experiences that encompassed the following themes in addition to themes related to PTSD symptoms and parenting, which will be discussed in research questions two through four below: needing and receiving support, giving back, and positive changes.

Needing and receiving support. It was clear that the experience of CHD overtaxed the resources of these families, requiring them to seek additional supports beyond what they brought to this new experience. These additional supports were primarily through other parents of children with CHD, their faith communities, the

medical team, and professional mental health providers. The most common form of support was from the medical team and included emotional support, encouragement, and education/preparation. However, in addition to positive experiences with the medical teams, parents also and times when support was needed and not received. In addition, parents described actions from the medical team that were specifically unsupportive, including insensitive comments, medical errors, and not providing education and support when desired by the parents. Given the frightening and traumatic nature of many of the hospital-based experiences described by participants, the medical team is well positioned to be a significant source of support, information, and preparation for these families. Proper training for the medical team regarding psychosocial care may increase these positive interactions and reduce the negative experiences of CHD families.

Support from other parents was another common theme. Parents valued this support specifically because they felt that no one else was able to understand their experiences and their needs like someone who has been through it. Parent-to-parent support was highly valued by the parents in this sample; however, the connections with other CHD families led to increased risk of vicarious trauma exposure, through parents' "oversharing", hearing about children with negative outcomes, including medical and developmental complications and death. This was especially common among parents who accessed online support. Although this support came with this risk for vicarious trauma, parents described parent to parent support as one of the most helpful resources. Families with limited resources may not have easy access to the internet, reducing the extent to which they can benefit from online support. In addition, low literacy, and

limited English proficiency may significantly limit parents' ability to access online support, creating barriers that may negatively affect their adjustment and furthering health disparities in these low-resourced populations.

Giving back. The parents in this sample reported feeling grateful for the supports they received, leading them to want to give back to the CHD community. Subthemes included offering support to heart families and medical teams, being “pioneers” in a field with rapidly improving procedures and technologies, spreading awareness, and raising money. These activities provided meaning to these families. The experience of CHD changed these families and created unique experiences that drove them to want to contribute by improving the lives of other CHD families and the medical teams that help children with CHD.

Positive changes. Parents reported a variety of benefits resulting from their CHD experiences, including the connections made with other CHD families and the medical teams, feeling a closer connection with spouse and child, having a greater appreciation for life, and feeling that the experience made the participant a better parent and a better person.

Many of these changes corresponded to key categories in the posttraumatic growth literature. Posttraumatic growth is defined as positive changes reported after struggling with traumatic or highly stressful life events (Tedeschi & Calhoun 2004). The posttraumatic growth model suggests five domains of posttraumatic growth, including closer relationship with others, increased sense of personal strength, new pathways and possibilities in life, greater appreciation for life with new priorities, and spiritual

development. Parents in the current study discussed experiences that fall under two of these domains: changing priorities and a greater appreciation for life, and improved closeness in their relationships. Most parents discussed wanting to give back and contribute to the CHD community. One father specifically discussed having a greater appreciation for his child and how his son's experience will hopefully inspire others to hold their children close. Several parents described feeling that going through the traumatic medical experiences together with their spouses brought them close as a couple.

Gender differences. The data revealed that parenting a child with CHD is a gendered experience, with mothers and fathers discussing different ranges of experience on many themes. Fathers reported balancing their desire to protect their child with their desire to encourage their child's ability to "be a normal kid." Mothers, in contrast, weighed in more strongly on wanting to protect. Indeed, married partners frequently mentioned this as a source of marital conflict.

Another gender difference emerged in parent-to-parent supports. Mothers accessed both in-person and online social media supports, whereas fathers frequently preferred in-person supports. Many mothers were highly involved with a close group of online mothers experiencing CHD. As discussed above, online support was a particular risk for vicarious trauma exposures, as it increased the likelihood of knowing a family experiencing a negative outcome. In addition, it may be that parents of a child with CHD who is experiencing higher medical risk and complications may be more likely to access

online support for a variety of reasons including challenges of meeting with others face to face when managing significant medical challenges and hospital admissions.

A third gender difference was that fathers reported needing a break from talking and thinking about CHD during the intense hospitalization period, preferring support from another father instead of from a professional, feeling that the father would understand this need to step back from the intensity of the situation. Mothers were largely interested in direct professional psychosocial support both during their child's admission and following discharge, in addition to frequent support from other parents.

In the pediatric literature, fathers' voices have been largely missing. In a recent review of parents' experiences with preterm and very low birthweight infants, the vast majority of studies assessed maternal experience; fathers were rarely included (Treyvaud, 2014). In a pediatric palliative care study reviewing parental experience, the authors concluded that "parental experience" generally mean maternal experience, with over 75% of participating parents being mothers (MacDonald, Chilibeck, Affleck, & Cadell, 2010). Father clearly play a variety of important roles in the lives of infants with CHD, from supporting their wives to caring for older children at home, yet are largely overlooked in the literature. Understanding fathers' unique experiences can help to inform family-centered care. In the current study, fathers were primarily recruited by their wives who also participated. This may be one recruitment strategy that would facilitate increased participation of fathers in pediatric research.

Parents' Experience of Pediatric Medical Traumatic Stress

(2) What are parents' experiences of pediatric medical traumatic stress?

Almost all participants describing some symptoms of PTSD. The most common self-reported PTSD symptoms were re-experiencing and negative affective/cognitions. As suggested by the pediatric medical traumatic stress model, not all parents reported PTSD symptoms. One parent, reporting high levels of support and effective coping, had relatively few past and current PTSD symptoms. However, the majority reported significant PTSD symptoms.

In addition, gender differences emerged. A sizeable majority of mothers reporting many current PTSD symptoms and high levels of distress, while fathers reported minimal current and some past PTSD symptoms that have resolved, seemingly related to their child's current positive reports from the cardiologists. Those fathers who did endorse PTSD symptoms reported negative cognitions involving self-blame. These thoughts and beliefs centered around possible actions on the fathers' part that might explain their child's CHD. The explanatory model of illness describes how individuals develop thoughts, beliefs, and personal meaning ascribed to an illness (Kleinman, Eisenberg, & Good, (1978). Fathers in the current study appeared to be seeking a sense of control over an uncontrollable situation by attributing self-blame.

In addition, fathers reframed traumatic events as positive, based on the outcome, stating that events were traumatic at the time but the surgeries were successful at saving the child's life so it was "a positive thing." Mothers, in contrast, largely continue to view the medical events as traumatic and continue to report high levels of distress. While the

children in the current study were all much older, one study found no difference in distress between mothers and fathers of 6-month-old babies with CHD (Brosig, Whitstone, Frommelt, Frisbee, & Leuthner, 2007). The fathers in the current study did not discuss prior PTSD symptoms and prior distress that has partially resolved, so it is unclear if this sample of fathers would have reported distress similar to mothers when their children were 6 months of age. In addition, distress was reported qualitatively in the current study; therefore, it is unclear if parents in this study would differ on quantitative measures of distress. In a study of parents of children with type 1 diabetes, mothers reported more distress than fathers overall and more disease burden (Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2011), similar to the findings of the current study, in which mothers reported higher levels of ongoing PTSD symptoms than did fathers. Similarly, among parents of children with spina bifida, another condition with potential for ongoing traumatic parental experiences, mothers had higher levels of distress than did fathers (Vermaes et al., 2008). Further, the more critical the child's condition, the slower the PTSD symptoms were to reduce over the first several years after diagnosis.

Mothers reported vicarious trauma exposure through their connections with other CHD parents and through their experiences in the cardiac ICU. In addition, parents talked about the theme of continuous traumatic stress. While the traditional conceptualization of PTSD is that the trauma is in the past, researchers are beginning to examine ongoing traumatic experiences, particularly in the context of war, using the term continuous traumatic stress to describe these experiences (Eagle & Kaminer, 2013). This

seems to most closely capture the experiences of ongoing traumatic experiences without a resolution reported by the participants in the current study.

The Effect of CHD on Parenting Patterns

(3) In what ways has CHD affected the parenting patterns of parents with a child who has undergone open-heart surgery? Parents reported that CHD has affected their parenting, creating overprotective and permissive parenting patterns. In their discussions of overprotective parenting, parents reported excessive monitoring and restricting their children's freedom with the primary goal of reducing risk for potential illness and injury. Parents indicated that they persisted in this overprotection even when the activity was cleared by the cardiologist. Some examples included watching their children sleep, not leaving the house except for appointments, and calling their child care providers numerous times daily to ask for updates on their children's condition. In addition, parents reported significant permissive parenting, giving fewer limits and employing discipline less than they would prefer, or feeling bad about disciplining their child with CHD. Consistent with these findings, permissive parenting practices are reported in the literature among parents of children with cancer (Dunn, 2012) and CHD (Brosig et al., 2007). In addition, fathers and mothers discussed gender differences in parenting, with the general theme of fathers being "too harsh" and mothers being "too soft." Indeed, mothers reported permissive parenting at higher rates than did fathers. These differences have also been identified in parents of preschool children without serious medical conditions (Winsler, Madigan, & Aquilino, 2005), suggesting that these

differences found in the current study are not specific to parents of children with life-threatening medical conditions.

Relationship between PTSD Symptoms and Parenting Patterns

(4) What is the relationship between parent pediatric medical traumatic stress and parenting patterns? The relational PTSD model that suggests that parental PTSD symptoms influence their patterns in predictable ways. The one parenting pattern in the relational PTSD model observed in this sample was overprotective parenting. Parents who discussed many PTSD symptoms and expressed high levels of trauma-related distress reported high overprotective parenting behaviors, supporting the relational PTSD model in part. In their narratives, parents often specifically linked their overprotective behavior with their child's traumatic medical experiences. It is unclear, however, if the parents in the current study are reporting more overprotective parenting than would parents of children without medical conditions. Overprotective parenting practices create risks for child adjustment. Research has documented negative child outcomes related to overprotective parenting among parents of children with a variety of medical conditions (e.g., Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010), making it an important clinical consideration.

The relational PTSD model includes withdrawn and endangering/frightening parenting patterns in addition to overprotection; however, there were no examples of withdrawn parenting style in this sample. It is possible that parents with a more withdrawn parenting pattern may be less likely to participate in a study about parenting and CHD. Only one mother, out of the 12 parents in this study, described

endangering/frightening parenting pattern; she frequently cried in front of her child due to high levels of negative cognitions and affect. It is possible that, in medical-related trauma, overprotection is the dominant pattern that emerges in the context of parental PTSD. Endangering/frightening parenting parent may indeed be more common among parents who have PTSD from interpersonal violence or combat, as this sometimes presents as re-enacting the violence (Scheeringa & Zeanah, 2001). Further research using larger, more representational samples with quantitative measures of both PTSD symptoms and parenting patterns is needed to clarify this relationship.

Permissive parenting was a parenting pattern seen in these data that was not addressed in the relational PTSD model. This may be unique to medical experiences that involve ongoing medical risk and high levels of pain and distress in the child. While parents in this study discussed a link between their traumatic experiences with their child's heart surgery and their permissive parenting patterns, some parents who were not reporting PTSD symptoms also discussed permissive parenting patterns. Further, it is not clear if the level of permissive parenting is beyond that seen among parents of children without medical problems.

As there were no examples of withdrawn parenting and only one participant with enacting/endangering/frightening, these patterns were not included in the correlational analyses. Permissive parenting, while not included in the relational PTSD model, was included in the correlational matrix, as it was a common theme among these participants and has been found to be a pattern that develops in parents of children with life-threatening medical conditions (e.g., Brosig et al., 2007). Also, the trauma themes of

vicarious trauma and continuous traumatic stress were added. The number of comments about overprotective parenting was, indeed, strongly correlated with total number of comments about PTSD symptoms and also with re-experiencing symptoms, and vicarious trauma exposure. In a meta-analysis, overprotective parenting was more common in parents of children with chronic illness than in parents with healthy children (Pinquart, 2013). The current study suggests that parental PTSD may be an important factor driving overprotective parenting.

Permissive parenting, however, was not correlated with any of the trauma themes, suggesting that something other than PTSD symptoms, such as possibly perceived child vulnerability, may be driving the permissive parenting among parents of children with CHD. It may be that having a child with CHD regardless of the parental PTSD symptom is associated with permissive parenting, as has been demonstrated in the literature. Another possibility is that in this fairly homogenous sample, permissive parenting was more common than would be found in a more heterogeneous sample of parents of children with CHD.

Limitations

This study has some limitations that are important to discuss. First, this qualitative study included a fairly homogenous sample of mostly White, married, college educated families with moderate to high income. The goal of this study was to explore the experiences of parents and the researcher accepted all eligible parents who expressed interest. The findings of this qualitative study were not intended to generalize to all parents of CHD; however, caution should be used when interpreting these results as a

more representative sample of CHD parents may have very different experiences. Psychosocial factors, including single parenthood, cultural and racial backgrounds, income, and education are known to influence parenting practices (e.g., Repetti, Taylor, & Seeman, 2002) and adjustment to stressors and traumatic events (e.g., Ungar, Ghazinour, & Rochter, 2013). A more diverse, representative sample would likely have resulted in different themes and relationships between themes than did the current sample. However, interpretive phenomenological analysis is often conducted with homogenous samples for the express purpose of understanding the divergent and convergent experiences of a group based on shared characteristics.

Second, the sample size was small, with a total of twelve parents, including eight mothers and four fathers. In qualitative research, a sample size of twelve is sufficient to gain an in-depth understanding of the experience of the participants (Starks & Trinidad, 2007). However, to gain a broader understanding of both mothers' and fathers' experiences with CHD, PTSD, and parenting, larger samples are needed. This study highlights important areas for further exploration through the in-depth analysis of the experience of a homogeneous group of parents, including the types of traumatic symptoms and experiences parents report and the relationship between these and their parenting practices.

Third, these data were analyzed by a single coder. The process of double hermeneutics was employed in the analyses; therefore, this researcher's own bias and experiences have factored into the decision-making process during data analysis and contributed to the interpretation of the results and conclusions. To guard against any

negative impact this could create, the researcher discussed the coding process with colleagues knowledgeable about qualitative research and CHD. Lastly, correlational analyses were conducted. Nonetheless, given the small sample size, these results must be viewed with caution. Counting the number of comments made by a participant about a phenomenon does not equal the strength of that experience. Quantitative analyses with robust measures of parental PTSD and parenting patterns are needed to clarify the relationship between parenting patterns and parental PTSD.

Despite these limitations, this study is an important step toward better understanding the experiences of parents of children with CHD and the relationship between PTSD and parenting patterns among this sample. Given the limited research on these relationships, this study contributes to the literature by identifying some areas for future research, including the potential impact of vicarious medical trauma on parenting.

Clinical Implications and Conclusions

Several important clinical implications emerged from this research. First, psychosocial support from professionals and from other parents may lessen the risk for PTSD symptoms among parents of children with CHD. Parents in this study reported significant emotional distress related to traumatic events during hospitalizations with their child with CHD. However, support from other CHD parents, which was highly valued by the parents in this study, comes with additional risk for vicarious trauma. Some other parents “overshared” by showing upsetting post-operative photos or telling of highly distressing medical experiences. Proper training for parent-to-parent volunteers can lessen the risks of “oversharing” and increase the benefit that parents receive from

such supports. Vicarious trauma also occurred when other CHD parents in the families' support system lost children to CHD. Parents in this sample had to balance the benefits of this support with self-care, when they needed to take a step back from supportive others due to vicarious loss. It is important to discuss with parents both the benefits and the potential risks when recommending online support for CHD parents.

Furthermore, several mothers reported wanting professional support focused on their needs during hospitalizations. This support, coupled with the development and implementation of interventions designed to reduce the risk of PTSD, would likely improve the functioning and wellbeing of parents of children with CHD.

Parents may need gender specific types of support. Mothers reported they would welcome psychosocial support from a professional during their child's hospitalizations. In contrast, fathers reported that they did not want an unfamiliar professional to ask them about their feelings and experiences, but preferred support from other parents, particularly fathers, who have been through similar situations. This support may not include asking them directly about how they are feeling. Fathers discussed the importance of getting a break from the intensity of emotional discussions they have with their wives about their child's heart condition. They felt that another father of a child with CHD would be able to relate to this need. This highlights the importance of including fathers in parent-to-parent match programs and the gender-specific training of such peer volunteers to be sensitive to the needs of the parents whom they are supporting.

Second, parents may benefit from support specifically during the most potentially traumatic experiences, including during times of diagnosis, seeing their child

immediately post-op, during mechanical ventilation seeing the child is awake and crying, during time in ICU with numerous potential traumatic events and high risk of vicarious trauma, and during significant changes in medical status. According to the pediatric medical traumatic stress model, the goal of intervention during the potentially traumatic medical event is to help reframe the event for the family to prevent PTSD symptoms (Kazak et al., 2006). Through providing professional and parent-to-parent support during the most difficult and potentially traumatic events, risk for PTSD may be reduced.

Third, practitioners should be aware of the positive changes many parents report, even when still currently facing high levels of trauma-related distress. While parents in this sample reported varying levels of distress, they also reported posttraumatic growth, or positive changes resulting from their CHD experiences. Posttraumatic growth has been linked with positive adjustment following a number of different traumatic experiences (e.g., Wang et al., 2017). In fact, clinicians can facilitate posttraumatic growth among people struggling with life-changing events through a variety of strategies (Calhoun & Tedeschi, 2013).

Fourth, care centers and others working with CHD families should be aware of the benefit parents feel from giving back to the CHD community. Linking parents with organizations and opportunities to give back to the CHD community may help parents feel sense of connection and of contribution, and may assist parents with adjusting to CHD.

Finally, screening of parents for PTSD symptoms during cardiology outpatient follow up will allow practitioners to connect families with needed professional resources

earlier, thus mitigating the risk for long term PTSD symptoms and their sequelae. Parental PTSD is associated with numerous negative parent and child outcomes. In the current study, parental PTSD symptoms were associated with overprotective parenting. Overprotective parenting is defined as excessive parenting that is inappropriate for the child's chronological age and is related to child illness and parent perception of child vulnerability (Thomasgard & Metz, 1997). It is associated with several important negative psychological outcomes for children, including anxiety, depression, and increased risk of child PTSD (Tillery, Long, & Phipps, 2014), further increasing risk for child maladaptation. Through screening efforts, resources and referrals can be provided to parents to reduce the risk of parental PTSD symptoms and the subsequent risk for child adaptation.

Future Directions

The current study supports the need to consider parents' wellbeing following infant open heart surgery and to develop policies and practices to reduce the risk for parental PTSD symptoms. Important information about the relationship between pediatric medical traumatic stress and parenting patterns emerged, indicating that parental PTSD symptoms are related to overprotective parenting in this sample. In addition, permissive parenting parents were found to be common in this sample, but not specific to parents reporting PTSD symptoms. Further mixed-method research is needed to explore the relationship between PTSD symptoms and parenting patterns among a large, diverse, representative sample of parents of children with critical CHD. Future research should

focus on using mixed methods to assess factors related to parental PTSD, including pre-existing psychosocial factors, and how parental PTSD relates to parenting.

Studies comparing CHD parents with parents of children without medical issues should be conducted to determine if CHD leads to more PTSD symptoms and overprotective parenting than is seen in parents who do not experience medical trauma. This line of research can lead to the development, implementation, and dissemination of interventions designed to reduce long term risks from pediatric medical traumatic stress in this high-risk population.

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APPENDIX A: Tables and Figures

Table 1
Demographics for Participants and their Children with CHD

	n(%)
Parent Demographics (N=12)	
Age in Years – M(SD)	36.00(5.62)
Sex (female)	8(66.7)
Race	
Black/African American	1(8.3)
Non-Hispanic White	11(91.7)
Relationship Status	
Married	10(83.3)
Never Married	1(8.3)
Divorced	1(8.3)
Educational Level	
Some College	4(33.3)
Bachelor’s Degree	8(66.7)
Household Monthly Income	
\$1,250-2,099	2(16.7)
\$2,100-3,349	3(25)
#3,350 and over	7(58.3)
Child Demographics (N=8)	
Age in Years – M(SD)	3.83(1.85)
Sex (female)	
Race	
Non-Hispanic White	7(87.5)
Biracial	1(12.5)

Note. Parent age range=24-44. Child age range=2-7. SD=standard deviation.

Table 2
 Number of Child Medical Experiences Reported by Participants

	Mean(SD)	Range
Open Heart Surgery	1.83(1.27)	1-5
Heart Catheterization	2.1(1.79)	0-5
Other Heart Surgery	0.83(1.47)	0-5
Hospitalized – Past Year	0.83(1.75)	0-5
Hospitalized- Lifetime*	5.75(6.80)	1-20

Note. N=12. *N=8 due to missing data. 4 parents indicated zero prior hospitalizations and zero heart catheterizations, which is inaccurate as all children had at least one hospitalization for open heart surgery.

Table 3
 Number of Participants Accessing CHD Resources

Resource	n(%)
Facebook Group	8(66.7)
Other Online Support	5(41.7)
Individual Counseling	1(8.3)
Group/Family Counseling	2(16.7)
Religious Leader	5(41.7)
CHD Parents - Informally	9(75)
Local Parent Support Group	8(66.7)
Family/Friends	7(58.3)

Note. *N*=12

Table 4
Qualitative Themes

Theme and Subtheme	n(%) Mothers	n(%) Fathers	n(%) Total
Needing/Receiving Support	8(100)	4(100)	12(100)
- Parent to Parent	5(62.5)	3(75)	8(66.7)
- Faith-based	4(50)	3(75)	7(58.3)
-Medical team	8(100)	4(100)	12(100)
- Mental health professional	3(37.5)	0(0)	3(25)
Giving Back to the CHD Community	5(62.5)	4(100)	9(75)
- Supporting CHD families	4(50)	4(100)	8(66.7)
- Supporting medical team	2(25)	3(75)	5(41.7)
- Spreading awareness	2(25)	3(75)	5(41.7)
- Fundraising	2(25)	1(25)	3(25)
- Being “pioneers”	4(50)	0(0)	4(33.3)
Benefit-Finding	6(75)	4(100)	10(83.3)
- Closer relationship	2(25)	3(75)	5(41.7)
- Greater appreciation for life	5(62.5)	3(75)	8(66.7)
- Being a better person	2(25)	1(25)	3(25)
- Connecting with CHD community	8(100)	4(100)	12(100)
Lasting Effects	8(100)	4(100)	12(100)
- Intrusive	6(75)	3(75)	9(75)
- Negative cognition/affect	6(75)	4(100)	10(83.3)
- Mortality cog/affect	6(75)	2(50)	8(66.7)
- Avoidance	5(62.5)	3(75)	8(66.7)
- Arousal/reactivity	2(25)	1(25)	3(25)
- Vicarious trauma	4(50)	0(0)	4(33.3)
- Continuous traumatic stress	2(25)	1(25)	3(25)
- Trauma related to feeding difficulties	4(50)	0(0)	4(33.3)
- Reframing the trauma based on positive outcome	0(0)	3(75)	3(25)
- Resolved prior trauma symptoms	0(0)	3(75)	3(25)
Parenting	8(100)	4(100)	12(100)
- Overprotective	4(50)	2(50)	6(50)
- Withdrawn	0(0)	0(0)	0(0)
-Enacting/endangering/ frightening	1(12.5)	0(0)	1(8.3)
- Permissive	7(87.5)	1(25)	8(66.7)

- Let them be a “normal kid”	3(37.5)	4(100)	7(58.3)
Additional Themes			
- Dad vs. Moms	4(50)	4(100)	8(66.7)
- Sibling Concerns	5(62.5)	2(50)	7(58.3)

Note. N=12

Table 5
Self-Reported Parental PTSD Symptoms

No. of PTSD Symptom Clusters	n(%)
0	1(8.3)
1	1(8.3)
2	5(41.7)
3	3(25)
4	2(16.7)

Note. N=12. 4 symptom clusters of PTSD

Table 6
 Correlations Among Parental PTSD Symptoms and Parenting Patterns

Symptoms	Permissive Parenting	Overprotective Parenting
Intrusive	.06	.75**
Negative Cog/Affect	.14	.42
Avoidance	.14	.26
Arousal/Reactivity	-.17	.72**
Vicarious Trauma	.00	.78**
Continuous Traumatic Stress	.12	.52
Total Symptoms	.14	.92***

Note. N=12. * $p < .05$, ** $p < .01$, *** $p < .001$

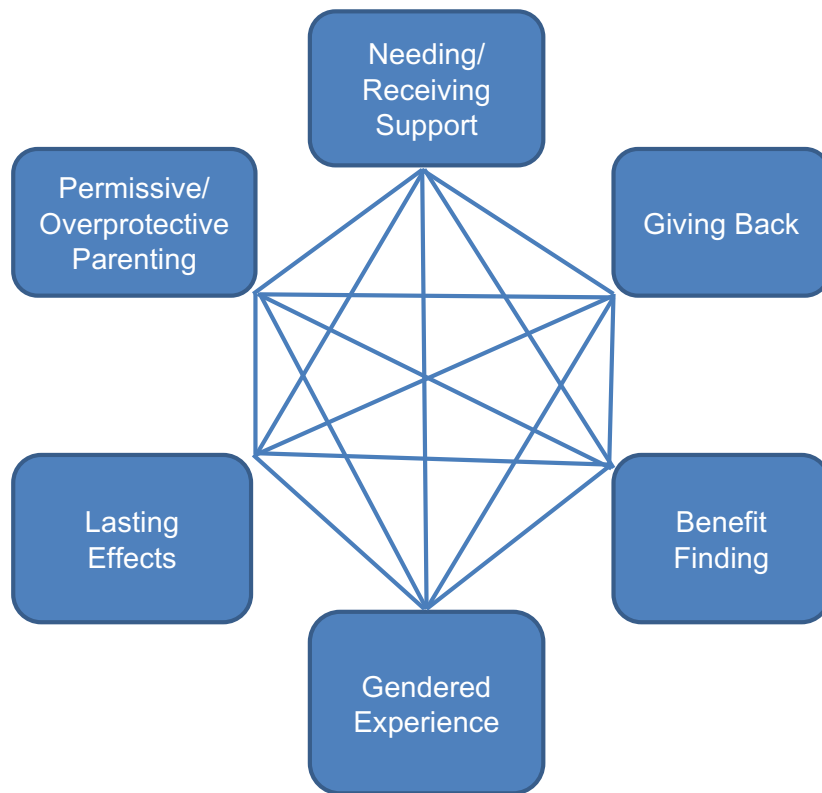


Figure 1. Superordinate Themes

Recruitment Interest Form

INTEREST FORM

The Impact of CHD on Parent Wellbeing

Dr. Herlong and Linda McWhorter (doctoral candidate at UNC Charlotte) are doing a research study to understand your experiences as the parent of a child with CHD. You can be a part of a 2-hour focus group with other parents. **Child care and parking will be free.** You will get a **\$20 Target Gift Card** and a **helpful parent information packet.**

If you are interested in hearing more about this study, **please fill out the information below** so that a researcher may contact you.

If you have any questions, please feel free to contact:

- Linda McWhorter, Doctoral Student, Clinical Health Psychology; (704) 493-4236 (lmcwhor1@uncc.edu)
- Or Linda's advisor, Dr. Sharon Portwood, Professor, Public Health Department; (704)687-7916 (sgportwo@uncc.edu)
- Or Dr. Herlong, Cardiologist, Sanger Heart and Vascular Institute, Department of Cardiology; (704)381-3945; Blythe Boulevard, Suite 200-D, Charlotte, NC 28203.

This study is part of the doctoral research of Linda McWhorter, M.A., Health Psychology Ph.D. Program, UNC Charlotte. This research has been approved by the Institution Review Boards of Carolinas Healthcare System and UNC Charlotte.

Please return this form to a staff member.

Yes, I am interested in this study. Please contact me.

Name: _____ **Date:**

Phone number:

May we contact you by text message? Yes No

Alternate Phone Number:

E-mail Address (please print neatly):

Recruitment Flyer:

Help medical providers
understand your experiences
as a parent of a child with CHD.

Attention Heart Parents!

- ü Did your child have **open heart** surgery **before age 1 year**?
- ü Is your child between the ages of **2 yrs and 8 yrs old**?
- ü Was the **last** heart procedure/hospitalization **over 5 months** ago?
*(To be eligible, your child **cannot** have an **unrelated medical condition** that requires hospitalizations or an **intellectual disability**.)*

Be a part of important research on the impact of CHD on parent wellbeing.

Join other heart parents in a **2-hour focus group** to describe your experiences as a parent of a child with CHD. All focus groups will meet at **Sanger Heart and Vascular Institute, Pediatric Cardiology, or Levine**.

Childcare and parking provided free of charge.

Participants will receive a \$20 Target gift care for attending.

(You will have the option of a 1 hour individual interview at a later time.)

Participation in the study is **voluntary** and **confidential**.

Take a picture of this flyer with your phone!

If you are interested in participating, please contact **Linda McWhorter**.

- BY PHONE: 704/493-4236, call (leave message) or text; OR
- BY EMAIL: lmcwhor1@uncc.edu, OR
- BY Completing an **Interest Form** available at the Pediatric Cardiology office.

This study is part of the graduate research of Linda McWhorter, Doctoral Candidate at UNC Charlotte in collaboration with Dr. Rene Herlong with Sanger Heart and Vascular Institute.

RECRUITMENT SCRIPT
The Impact of CHD on Parents' Wellbeing

Hello, My name is Linda McWhorter and I am working with Dr. Herlong on a research project. We want to talk with parents about their experiences with a child with a heart condition.

Do you have a few minutes for me to explain more details about the study to you?

If yes, continue with the script, if no: **“Would you like me to call you at a convenient time?”**

If yes, “Please fill out this interest form and I will call you with more information.”

Then skip to ***Call Back Closing***.

If no, skip to ***Closing***.

This study will ask parents about how the experience of your child having open heart surgery.

First of all, I want to find out if you are eligible to participate.

What is your relationship to the child with CHD?

If primary caregiver, continue with the script, if not, skip to ***Ineligible Closing Comments***.

Are you 18 years old or older?

If yes, continue with the script, if no, skip to ***Ineligible Closing Comments***.

Did you child have open heart surgery before turning 1 yr old?

If yes, continue with the script, if no, skip to *Ineligible Closing Comments*.

How old is your child with CHD?

If 2 years 0 months through 7 years and 11 months, continue with the script, if no, skip to *Ineligible Closing Comments*.

When was your child's last surgery or procedure?

If 5 months or more ago, continue with script. If less than 5 months ago, skip to *Ineligible Closing Comments*.

Have you lived with your child with CHD at least 50% of the child's life, including the time of their open heart surgery?

If yes, continue with the script, if no, skip to *Ineligible Closing Comments*.

Does your child with CHD have an intellectual disability ore mental retardation?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Does your child with CHD have another medical condition that requires long or frequent hospital stays?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Do you read and speak English well enough to complete a questionnaire and talk to the researcher?

If no, continue with the script, if yes, skip to Ineligible *Closing Comments*.

Do you have any difficulty speaking or reading in English?

If no, continue with the script, if yes, skip to Ineligible *Closing Comments*.

Okay, it appears you are eligible to participate. Let me tell you a little more about this study.

If you agree to participate, you will attend one focus group meeting lasting 2 hours. You will receive a \$20 Target Gift Card, free child care, free parking, and refreshments. You will fill out a questionnaire about your family, some of your experiences, and about your child's CHD. You and up to 7 other parents will be in a focus group led by [me/Linda McWhorter]. [She/I] will ask you all to talk about your experiences and emotions related to your child's open heart surgery, about your experiences as a parent of a child with CHD, and about your parenting practices.

The focus group meetings will be at either the Sanger Heart and Vascular Institute, Pediatric Cardiology Clinic or Levine Children's Hospital.

Childcare and parking are provided free of charge. You will also receive a \$20 Target gift card and a packet of information and resources for parents, to show our appreciation for your time and participation.

There are minimal risks to participants in this study.

All information will be confidential and all parents will be asked to sign an agreement to not share anything heard during the focus group.

A potential risk is that talking about these experiences may cause you distress. The researcher will provide all participants with a list of mental health and support resources you can use if you want to talk with someone after the group. You may also discontinue your participation at any time.

A potential benefit of participation in this study is that you might feel relief in talking about some of these emotions and experiences. Also this research will help medical providers to improve the experiences for families with a child with CHD.

Participation in this study is voluntary. You will not be treated differently by Sanger, Levine, or Camp LUCK if you do or do not participate.

**Are you interested in participating in the study? YES No
Is there another parent in the home who might [also] like to participate?**

If yes they want to participate, continue, if no, and no other parent, skip to *Not Interested Closing Comments*.

If they say No but another parent, ask, “**Can you provide me that parent’s contact information?**” then skip to *Closing*.

Would you like to go ahead and schedule the focus group now or would you prefer me to call you back?

If yes, continue. If no, give information form and arrange a time to call back.

Ok, we are scheduling mothers and fathers to attend separate groups, and these groups meet back to back. We will provide snacks. Free childcare is available for each focus group. We have hospital staff and approved volunteers providing child care.

There is a group for mothers scheduled a [date, time, location] and a group for fathers schedule at [date, time, location]. Would this time work?

Offer other times as needed. If they can't attend any scheduled groups, say, **"Please give me some times that would work for your schedule and I will let you know if a group gets scheduled at that time."**

__ (availability). Then skip to *Awaiting Scheduling Closing*

If scheduled, continue with script.

Will you need childcare?

If not, skip to next statement. If yes, continue:

For how many children? _____

What are their ages? _____

Please bring snacks and, if needed, diapers for your child/children. And please plan on arriving at [15-20 min early] so you can sign your child/ren into the childcare room.

How would you like to receive a reminder about this appointment?

Text? Phone call? E-mail?

Can you confirm your contact information please? _____ [contact for reminder]

_____ email or text-----

Okay. You are scheduled for 2 hour meeting with several other parents at [location] on [day/date] from [time frame a.m/pm]. Park in the usual patient parking area. We will validate parking for you and will send you a couple reminders before the meeting. [Linda McWhorter/I] will meet you there. [My name is Linda McWhorter.]

Please remember to bring a snack for your child/ren and if needed, diapers.

Do you have any questions?

Answer any questions or offer to get back with the answer.

If they ask for telephone reminder: continue. If not, skip to next statement

Let me give you [Linda's/my] contact information in case you need to reschedule or cancel your appointment for the study, you can reach [Linda/me] at (704) 493-4236, or by e-mail at lmcwhor1@uncc.edu.

I will send you a confirmation e-mail or text shortly, with your appointment time and contact information in case you have further questions.

Also, we will send you a couple reminders before your appointment. Please let me know if you need to cancel or reschedule so another parent can attend in that spot.

We appreciate you help.

Good bye.

End.

CALL BACK FOR SPOUSE/PARTNER

I will call back to try and reach the other parent/mother/ father later.
Thank you. Good bye.

AWAITING SCHEDULING CLOSING

Okay. Thank you for your interest. I will let you know when we get something scheduled that works with your times. If you have any questions for me, you may reach me at (704) 493-4236.

CALL BACK CLOSING COMMENTS

Okay. I will call you back to discuss it at a more convenient time. Thank you. Good bye.

INELIGIBLE CLOSING COMMENTS

It appears you are not eligible to participate in this study. We will keep you in mind for additional studies of CHD parents. Thank you for your time.
Good bye.

NOT INTERESTED CLOSING COMMENTS

Okay. Thank you for your time. Good bye.

Recruitment Script - Telephone

RECRUITMENT SCRIPT

The Impact of CHD on Parents' Wellbeing

(To follow up with Interest Forms)

Hello, I am calling from Sanger Heart and Vascular Institute, pediatric cardiology/Camp LUCK. May I please speak with (First and Last Name OR the parent of [patient's first and last name])?

My name is Linda McWhorter and I am working with Dr. Herlong on a research project. We want to know what your child's medical experiences were like for you.

You filled out an interest form for this study.

Do you have a few minutes for me to explain more details about the study to you?

If yes, continue with the script, if no: "When would be a good time to call you back?"

Then skip to **Call Back Closing**).

This study will ask parents about how your experiences having a child with CHD.

First of all, I want to find out if you are eligible to participate.

What is your relationship to the child with CHD?

If primary caregiver, continue with the script, if not, skip to *Ineligible Closing Comments*.

Are you 18 years old or older?

If yes, continue with the script, if no, skip to *Ineligible Closing Comments*.

Did your child have open heart surgery before turning 1 year old?

If yes, continue with the script, if no, skip to *Ineligible Closing Comments*.

How old is your child with CHD?

If 2 years through 7 years and 11 months, continue with the script, if no, skip to *Ineligible Closing Comments*.

When was your child's last surgery or procedure?

If 5 months or more ago, continue with script. If less than 5 months ago, skip to *Ineligible Closing Comments*.

Have you lived with your child with CHD at least 50% of the child's life, including the time of their open heart surgery?

If yes, continue with the script, if no, skip to *Ineligible Closing Comments*.

Does your child with CHD have an intellectual disability or mental retardation?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Does your child with CHD have another medical condition that requires long or frequent hospital stays?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Do you read and speak English well enough to complete a questionnaire and talk to the researcher?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Do you have any difficulty speaking or reading in English?

If no, continue with the script, if yes, skip to *Ineligible Closing Comments*.

Okay, it appears you are eligible to participate. Let me tell you a little more about this study.

If you agree to participate, you will attend one focus group meeting lasting 2 hours.

You will fill out a questionnaire about your family, some of your experiences, and about your child's CHD. You and up to 7 other parents will be in a focus group led by me. I will ask you all to talk about your experiences and emotions related to your child's open heart surgery, about your experiences as a parent of a child with CHD, and about your parenting practices.

The focus group meetings will be at either the Children's Specialty Clinic or Levine Children's Hospital.

Childcare and parking are provided free of charge. You will also receive a \$20 Target gift card and a packet of information and resources for parents, to show our appreciation for your time and participation.

There are minimal risks to participants in this study.

All information will be confidential and all parents will be asked to sign an agreement to not share anything heard during the focus group.

A potential risk is that talking about these experiences may cause you distress. The researcher will provide all participants with a list of mental health and support resources you can use if you want to talk with someone after the group. You may also discontinue your participation at any time.

A potential benefit of participation in this study is that you might feel relief in talking about some of these emotions and experiences. Also this research will help medical providers to improve the experiences for families with a child with CHD.

Participation in this study is voluntary. You will not be treated differently by Sanger or Levine if you do or do not participate.

**Are you interested in participating in the study? YES No
Is there another parent in the home who might [also] like to participate?**

If yes they want to participate, continue, if no, and no other parent, skip to *Not Interested Closing Comments*.

If they say No but another parent, ask, **“Can I speak with that other parent? Can you provide me their contact information?”** then either close or skip to beginning of script with this parent.

Ok, we are scheduling mothers and fathers to attend separate groups, and these groups meet back to back. We will provide snacks. Free childcare is available for each focus group. We have professionals and graduate students in charge of child care.

There is a group for mothers scheduled a [date, time, location] and a group for fathers schedule at [date, time, location]. Would this time work?

Offer other times as needed. If they can't attend any scheduled groups, say, **“Please give me some times that would work for your schedule and I will let you know if a group gets scheduled at that time.”**

(availability). Then skip to *Awaiting Scheduling Closing*

If scheduled, continue with script.

Will you need childcare?

If not, skip to next statement. If yes, continue:

For how many children? _____

What are their ages? _____

Please bring snacks and, if needed, diapers for your child/children. And please plan on arriving at [15-20 min early] so you can sign your child/ren into the childcare room.

How would you like to receive a reminder about this appointment? Text?

Phone call? E-mail?

Can you confirm your contact information please? _____[contact for reminder]

_____email or text-----

Okay. You are scheduled for 2 hour meeting with several other parents at [location] on [day/date] from [time frame a.m/pm]. Park in the usual patient parking area. We will validate parking for you and will send you a couple reminders before the meeting. I will meet you there. My name is Linda McWhorter.

Please remember to bring a snack for your child/ren and if needed diapers.

Do you have any questions?

Answer any questions or offer to get back with the answer.

If they ask for telephone reminder: continue. If not, skip to next statement

Do you have something to write with? Does my phone number show up on your phone? nlf you need to reschedule or cancel your appointment for the study, you can reach me at (704) 493-4236, or by e-mail at lmcwhor1@uncc.edu.

I will send you a confirmation e-mail or text shortly, with your appointment time and my contact information in case you need to get in touch with me.

Also, I will send you a couple reminders before your appointment. Please let me know if you need to cancel or reschedule so another parent can attend in that spot.

We appreciate you help.
Good bye.
End.

CALL BACK FOR SPOUSE/PARTNER

I will call back to try and reach the other parent/mother/ father later. Thank you.
Good bye.

AWAITING SCHEDULING CLOSING

Okay. Thank you for your interest. I will let you know when we get something scheduled that works with your times. If you have any questions for me, you may reach me at (704) 493-4236.

CALL BACK CLOSING COMMENTS

Okay. I will call you back to discuss it at a more convenient time. Thank you.
Good bye.

INELIGIBLE CLOSING COMMENTS

It appears you are not eligible to participate in this study. We will keep you in mind for additional studies of CHD parents. Thank you for your time. Good bye.

NOT INTERESTED CLOSING COMMENTS

Okay. Thank you for your time. Good bye.

Scheduling Form:

Focus Group Schedule Form

Date/Time: _____ Location:

Participants: Mothers Fathers

Parent Name	Child care?	Child Age	Phone	Email	Reminders Sent - Dates
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					

Confirmation Script:

FOCUS GROUP CONFIRMATION SCRIPT
The Impact of CHD on Parents' Wellbeing

TELEPHONE CONFIRMATION:

Hello, My name is Linda McWhorter. May I please speak with [Parent Name]?

I am calling to confirm you that you are schedule to participate in our focus group research with other parents of kids with CHD on [DATE, DAY, TIME span (including extra time for childcare drop off), LOCATION including exact address]. Do you know how to get there? You will park in patient parking. We will validate parking for you.

I wanted to confirm that: [choose correct statement]

-you will be bringing [#] child/children age(s) [age/ages]. Is this correct? _____ Please remember to bring a drink and a snack for your child/ren, and diapers if needed.

-you will NOT be bringing children with you and will not need childcare. Is this correct?

The group will last approximately 2 hours. Please arrive at [state exact time 15-20 min early] to sign in your child(ren) in the childcare room.

Do you have any questions?

Answer any questions or offer to get back with the answer.

Please be on time. I will see you there.

If you are unable to make it, please let me know by text, call or email. Do you have my phone number and e-mail?

Thank you. I look forward to meeting you! Good bye.

EMAIL REMINDER:

Hello, My name is Linda McWhorter.

This is to confirm that you that you are scheduled to participate in our focus group research with other parents of kids with CHD on [DATE, DAY, TIME span (include early arrival for childcare drop off), LOCATION + address].

You will park in patient parking. We will validate parking for you.

I wanted to confirm that: [choose correct statement]

-you will be bringing [#] child/children age(s) [age/ages].

Please remember to bring a drink and a snack for your child/ren, and diapers if needed.

Please arrive 15 to 20 minutes early to sign in your child(ren) in the childcare room. [include if using child care only]

-you will NOT be bringing children with you and will not need childcare.

If this is NOT correct, please reply immediately with the correct information.

The group will last approximately 2 hours.

If you have any questions, please call, text, or email me: lmcwhor1@uncc.edu (704) 493-4236

Answer any questions or offer to get back with the answer.

If you are unable to make it, please let me know by text, call or email.

Please arrive on time.

I will see you there.

Thank you. I look forward to meeting you! Good bye.

TEXT REMINDER:

From Linda with Sanger: Confirmation – Focus group appointment [day, date, time span (including arrival early for child care!), location, address]. You are [not

bringing/are bring # children for childcare]. Remember a snack and diapers for your child/children. Text/call with any questions or to cancel. See you there!

Reminder Contact Script:

FOCUS GROUP REMINDER SCRIPT
The Impact of CHD on Parents' Wellbeing

TELEPHONE REMINDER:

Hello, My name is Linda McWhorter. May I please speak with [Parent Name]?

I am calling to remind you of your focus group research appointment on [DATE, DAY, TIME span (including extra time for childcare drop off), LOCATION including exact address].

The group will last approximately 2 hours.

Please arrive at [exact time 15 to 20 minutes early] to sign in your child(ren) in the childcare room.

We ask that you please be on time. If you are unable to make it, please let me know by text, call or email.

Thank you. I look forward to meeting you! Good bye.

EMAIL REMINDER:

Hello, My name is Linda McWhorter.

This is reminder that you of your focus group research appointment on [DATE, DAY, TIME span (include early arrival for childcare drop off), LOCATION + address].

The group will last approximately 2 hours.

Please arrive at [exact time 15 to 20 minutes early] to sign in your child(ren) in the childcare room.

We ask that you please be on time. If you are unable to make it, please let me know by text, call or email.

Thank you. I look forward to meeting you! Good bye.

TEXT REMINDER:

From Linda with Sanger: Reminder – Focus group appointment REMINDER [day, date, time span (including arrival early for child care!), location, address]. Text/call with any questions or to cancel. Please be on time!

Child Care Information Sheet

Child's Name: _____

Parent/Guardian's Name: _____

Parent/Child Wrist Band #: _____

Child's Age: _____

Emergency Contact: _____

Any special needs or medical condition we need to know about?

Is this child independent with toileting?

If no, what help do they need?

Child is allergic to:

You will be contacted if your child is continually crying and cannot be consoled by childcare volunteers.

CAROLINAS HEALTHCARE SYSTEM

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

A Broken Heart: The Impact of Pediatric Open Heart Surgery On Parents' Wellbeing and Parenting

INTRODUCTION

Dr. Rene Herlong and his associates are asking you to participate in this research study to explore the experiences of being the parent of a child born with congenital heart disease (CHD). This study will take place at, Sanger Heart and Vascular Institute, Pediatric Cardiology Clinic, and Levine Children's Hospital with Carolinas HealthCare System (CHS). You are being asked to take part because:

- You are the parent or legal guardian of a child ages 2-12 years old who has had open-heart surgery because of a CHD.
- The last heart procedure your child had was at least 5 months ago
- You lived with your heart child for at least 50% of the child's life, including the time of their open heart surgery/surgeries.
- You speak and read English well enough to participate in the focus group and complete the questionnaires.

The purpose of this study is to determine how open heart surgery has affected parents. We want to know what types of stress you experienced related to CHD, how your child's open heart surgery affected you, and what are your strengths and challenges as a parent. This will help researchers to make medical experiences better for parents and children.

You will be one of approximately 25 people involved in this research project at CHS, and your participation in the focus group will last for 2 hours, with the opportunity for an additional one hour individual interview that is optional, for a maximum total of 3 hours.

Dr. Herlong is working with Linda McWhorter, doctoral candidate in the Health Psychology Ph.D. program (Clinical Track) at the University of North Carolina at Charlotte. This study is for her dissertation. She is supervised by Dr. Sharon Portwood, professor in the Public Health Department at the University of North Carolina at Charlotte.

HOW THE STUDY WORKS

If you agree to be in the study, you will come to a 2-hour focus group with other parents of children with CHD. You will complete a questionnaire about your family and about

your child's cardiac condition and experiences. We will ask you questions about your experiences as the parent of a heart child. We will ask about your emotions, and about your parenting style. You will choose a pseudonym, or a fake name to use for the focus group and the written questionnaire for your privacy. The focus group will be audio-recorded. A research assistant will take notes during the focus group, using the name you choose.

The focus group will be 2-hours long. You might be asked to participate in an individual interview in the future. This interview will occur at a CHS facilitate or over the telephone, and will be 60 minutes long. This can help the researchers answer any questions they have after the focus group. You can choose if you want an individual interview. We will not contact you after the focus group unless you give us permission. You will not be treated any differently if you choose to have an individual interview or not.

Please write your **initials** next to an option below:

_____ I **do not** want to be contacted about an individual interview.

_____ If the researchers have questions, **they may** contact me for an individual interview.

_____ I **would like** to schedule an individual interview.

How do you want to be contacted?

(**Initial** one) _____ Text _____ Telephone _____ E-mail

(Please list telephone number or e-mail address)

Also, if you want to know the results of the focus groups, the researchers can send you a summary of their findings. This will be available in summer or fall of 2016.
(Please **Initial** to get a COPY)

(initial)_____ I want a copy of the results e-mailed to me.

E-mail address: _____

(initial)_____ I want a copy of the results mailed to me.

Mailing address:

RISKS

There are minimal (small) risks to participation in this study.

The researchers will ask you questions about your emotions and posttraumatic stress. It can be hard to talk about traumatic events related to your child and how they affect you. This might bring up unpleasant feeling. You may discontinue your participation at any time if you become distressed. The research will provide you with a list of mental health resources you can use should you want to talk further with a therapist or counselor about your experiences.

EXCLUSION CRITERIA

- You are not the parent or legal guardian of a child ages 2-12 years old who has had open-heart surgery during the first year of life because of CHD.
- The last heart procedure your child had was less than 5 months ago
- You live with your heart child for less 50% of the child's life, or did not live with your child during the time of their open heart surgery/surgeries.
- You do not speak and read English well enough to participate in the focus group and complete the questionnaires.

BENEFITS

This study may or may not benefit you directly. The information gained from your case may benefit other families of children with CHD.

ALTERNATIVE PROCEDURE/TREATMENT

You do not have to take part in this study. If you choose to not participate in this study, your child's care at Carolinas HealthCare System will not be affected. Choosing not to participate in this study will not affect your relationship with Dr. Herlong and his associates.

ADDITIONAL COST

There are no costs to you in participating in this study. Childcare is offered free of charge. Participants are asked to bring appropriate snacks for their child(ren). Researchers will validate parking tickets, so parking will be free.

COMPENSATION

There is no cost to you for participating in this focus group. Childcare will be provided free of charge. At the end of the focus group, we will give you a \$20 Target gift card and a packet of helpful information. This is to compensate you for your time and show our appreciation for you participating in this focus group research.

WITHDRAWAL

Your participation in this study is completely voluntary. You should feel under no pressure to be in the study. If you decide not to be in the study that will not in any way harm your relations with your doctors or with Carolinas HealthCare System. You are free to stop being in the study if you change your mind after entering it. This would not harm your relations with your doctors or Carolinas HealthCare System.

Should you have to end participation early due to your child's wellbeing, you will still receive the \$20 Target Gift Card and the Packet of Information, as if you had completed the study.

CONFIDENTIALITY:

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a patient. Your record for this study may, however, be reviewed and/or photocopied by faculty and doctoral students at UNC Charlotte and Carolinas HealthCare System. To that extent, confidentiality is not absolute.

Your name and identifying information will not be on your questionnaire, the audio-recording, or the researchers' notes. You will select another name to use during on the questionnaire and focus group. Once the questionnaire and the audio-recording are entered into the computer, you will be given a participant number instead of your pseudonym. No identifying information will be kept with your study responses. Your information will remain confidential to the extent possible and will only be disclosed with your permission or as required by law. Your child's medical team will not have access to your comments linked to any identifying information. Questionnaires and audio-recordings will be transported safely to UNC Charlotte and kept in a locked office. Study information will be analyzed on a password-secured computer, and in a secure campus network.

All presentations (oral and written) of the questionnaire and focus group information will be shared without identifying information. Your name, the specifics of your family, and your identity will not be shared. No one will be able to tell you were a part of the focus group from any presentation of the results.

To help protect participants' confidentiality, other participants will only be shown your pseudonym. However, it is possible that you may know other participants in the focus

group. The researchers cannot guarantee that other participants in the group will keep all information confidential. However, the researchers will ask all parents to sign a confidentiality agreement saying they will not repeat anything they hear in the focus group.

AUTHORIZATION:

If you wish to take part in this focus group study, you will be asked to sign this consent form. It allows the study investigator to collect, process any relevant personal health information collected from you during the study. These are activities routinely carried out during focus group studies.

You have been told that personal information about you (including sensitive personal health information, such as your medical history and your racial/ethnic origin if relevant to the study) will be reviewed, collected on a computer database, stored in electronic or manual files, audited, and/or otherwise processed by:

the study investigator, and research staff, Dr. Rene Herlong (Levine Children's Hospital, Sanger Heart and Vascular Institute, 1001 Blythe Blvd. Charlotte, NC 28203), Linda McWhorter (Health Psychology Ph.D. Program, UNC Charlotte, 9201 University Blvd., Charlotte, NC 28223), and UNC Charlotte supervising faculty and doctoral student research assistants.

Carolinas HealthCare System employees,
other persons or agencies as required by law or allowed by federal regulations.

You have been told that your personal data are being collected and processed to:

check your suitability to take part in the study,
provide contact information for recruitment.

You have the right to inspect your research record, which will be unavailable until the conclusion of the study. Please speak with the study doctor if you desire to access your record.

You have been told whenever your personal information is processed; it will be kept confidential and secure, to the best of our ability. It will be used only for the purpose for which it was collected.

This Authorization does not have an expiration date. You have been told that the study investigator and sponsor will keep your personal information until the study has been concluded and all materials analyzed. After that point, your signed consent form will be kept, separate from the study materials, for up to 6 years. Other study data with no identifying information will be kept indefinitely. If you do not withdraw this Authorization in writing, it will remain in effect indefinitely. If you wish to revoke

authorization to use your personal information, you will notify the study doctor, Dr. Rene Herlong, in writing. Some of the data obtained from your record prior to your revocation may still be used if considered necessary for the study. Requests for withdrawal may be sent to the following address:

**Dr. Rene Herlong
Levine Children's Hospital
Sanger Heart and Vascular Institute
Blythe Boulevard, Suite 200-D
Charlotte, NC 28203
704-381-3945**

FINANCIAL INTEREST OF INVESTIGATOR

Researchers do not have any financial interest in this study.

QUESTIONS

The researchers doing the study at Carolinas HealthCare System are Dr. Rene Herlong along with Linda McWhorter, M.A., clinical psychology doctoral candidate in the Health Psychology PhD Program at UNC Charlotte, and her supervising faculty member, Dr. Sharon Portwood, in the Public Health Department at UNC Charlotte. You may ask them any questions you have now. If you have questions later, you may use the contact information below: Linda McWhorter (704) 493-4236; e-mail: lmcwhor1@uncc.edu, Dr. Portwood (704) 687-7916; e-mail: sgportwo@uncc.edu, or Dr. Herlong at:

**Dr. Rene Herlong
Levine Children's Hospital
Sanger Heart and Vascular Institute
Blythe Boulevard, Suite 200-D
Charlotte, NC 28203
704-381-3945**

The researchers want to make sure that you are treated in a fair and respectful manner. If you have questions about how you are treated as a study participant please contact the Institutional Review Board. This board is a group of people who review the research to protect your rights. If you have questions about the conduct of this study or about your rights as a research subject, you may call the chairperson of the Institutional Review Board of Carolinas HealthCare System for information regarding patients' rights in a research study. You can obtain the name and number of this person by calling (704) 355-3158.

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Appendix E: Measures

Dissertation Focus Group Interview Script

1. Please tell us your name you are using for today's focus group and the age of your child or children. Let us know which is your heart child, and their heart diagnosis, and any other medical or developmental diagnoses if you care to share that.
2. How has CHD affected your life?
3. Some families notice both positive and negative effects. What has been your experience?
4. Many medical experiences related to CHD can be upsetting to parents. Sometimes these experiences have long-term effects on parents. Some families describe their life as being divided into "before" and "after" a certain event in their child's life. What effects have you noticed?
 - a. Probe for: Some parents try to avoid reminders of the trauma.
 - b. Sometimes parents feel they are always on their guard.
 - c. Some parents have memories or thoughts of certain medical events that they wish would go away.
5. How has CHD affected your parenting – your relationship with your child, your expectations, discipline, protection, and other care taking responsibilities?
 - a. Probe for:
 - What do you feel you do well?
 - What would you want to change?
 - b. Limits/expectations – age appropriate
 - c. Discipline
 - d. Monitoring
 - e. Protecting
 - f. Closeness, affection.
 - g. Talking about CHD
6. Some parents feel they treat their child with CHD differently than their other children. How does this relate to your family?
7. What else is important for me to know to understand how you, as a parent, have been affected by CHD?
8. What would you like other families who are having a baby with CHD to know?

FAMILY BACKGROUND QUESTIONNAIRE

Page 1

Code NAME: _____

This survey helps us get to know some basic information about your family. Please read and answer every question on the form. All information provided will be treated in strict confidence and will only be used for research on how families are affected by CHD.

PARENT/CAREGIVER INFORMATION

TODAY'S DATE _____

SEX: Male Female

AGE: _____

RACE/ETHNICITY: 1 American Indian/Alaska Native 5 Native Hawaiian/Other
Pacific Islander
(Check all that apply) 2 Asian 6 Hispanic/Latino
3 Black/African American 7 Non-Hispanic White
4 Other _____

RELATIONSHIP STATUS: Married Divorced Separated Widowed Domestic partner
Never Married
(Check one)

YOUR RELATIONSHIP TO HEART CHILD: (ex. biological parent, step-parent, adoptive/foster, grandparent, partner of biological parent)

PARENT/CAREGIVER EDUCATION: 1 Less than 9th grade 4 Some college or vocational training
(CHECK the level that applies) 2 Less than 12th grade 5 College degree or higher
3 GED or high school diploma

TYPE OF WORK YOU DO, IF EMPLOYED:

HOW MUCH MONEY DID YOUR HOUSEHOLD EARN LAST MONTH?

(Circle the level that applies)

\$2099

\$3349

and above

1 Less than \$300

2 \$300-\$599

3 \$600-\$1249

4 \$1250-

5 \$2100-

6 \$3350

HEART CHILD INFORMATION:

(This section is about your child who had open-heart surgery)

WHAT IS THE CUSTODY ARRANGEMENT FOR THIS CHILD? _____

CHILD'S AGE: _____

CHILD'S SEX: Male Female

CHILD'S RACE/ETHNICITY:

Hawaiian/Other Pacific Islander

(Check all that apply)

1 American Indian/Alaska Native

2 Asian

3 Black/African American

4 Other _____

5 Native

6 Hispanic/Latino

7 Non-Hispanic White

AGE OF OTHER CHILDREN (Under 18 yrs) IN THE HOME: Girls: _____ Boys:

CHD INFORMATION: WHAT IS YOUR CHILD'S HEART DIAGNOSIS? (CHECK all that apply)

1 Ventricular septal disease

2 Transposition of the great vessels

3 Tetralogy of Fallot

4 Total anomalous pulmonary venous return

5 Truncus arteriosus

6 Single-ventricle disorder (specify) _____

6 Other heart condition (specify) _____

SURGERIES/PROCEDURES YOUR CHILD HAS HAD: (If you don't know the name or how many, write "don't know")

1 Open heart surgery (how many?) _____

2 Heart catheterization (how many?) _____

3 Other heart procedure (specify) _____ (how many?) _____

NUMBER OF DAYS YOUR CHILD SPENT IN INTENSIVE CARE (PICU, NICU, CVICU, ETC.) IN THE PAST YEAR: (Check one)

None 1-3 days 4-7 days 1-2 weeks 2-4 weeks 1-3 months More than 3 months

SINCE BIRTH: (Check one)

None 1-3 days 4-7 days 1-2 weeks 2-4 weeks 1-3 months More than 3 months

HOW MUCH TIME DID YOU SPEND WITH YOUR CHILD IN INTENSIVE CARE? (please estimate)

None 1 hr/day or less 2-4 hrs/day 3-6 hrs/day 7-9 hrs/day More than 9 hrs/day

NUMBER OF TIMES YOUR CHILD HAS BEEN HOSPITALIZED (NOT including Intensive Care) IN THE PAST YEAR _____

IN HIS/HER LIFETIME _____

HOW MUCH TIME DID YOU SPEND WITH YOUR CHILD IN THE HOSPITAL (NOT including INTENSIVE CARE)?

None 1 hr/day or less 2-4 hrs/day 3-6 hrs/day 7-9 hrs/day More than 9 hrs/day
N/A

WHEN WAS YOUR CHILD'S LAST HEART PROCEDURE?

THINK BACK TO YOUR MOST UPSETTING, SCARY TIME RELATED TO YOUR CHILD'S HEART CONDITION.

BRIEFLY DESCRIBE THAT TIME.

HOW LONG AGO WAS THAT UPSETTING TIME?

HAVE YOU USED ANY OF THESE RESOURCES or SUPPORTS RELATED TO YOUR CHILD'S HEART CONDITION?

(Check all that apply)

1 Online CHD Support group (specify)

2 Facebook page for CHD

3 Individual Counseling or Psychotherapy

4 Group or Family Counseling or Psychotherapy

5 Met with other parents of children with CHD

6 Talked with a pastor, rabbi, or other spiritual leader

7 Attended local groups for CHD families, such as Camp LUCK (specify)

8 Talked with family/friends about my emotions about my child's medical procedures.

9 Other (specify)

Please describe any other medical problems your child experiences: _____

Tell us about any surgeries or hospitalizations related to the other medical problems.

Please describe any developmental or learning problems your child experiences:

What are the diagnoses, if any?

What services, medications, or treatments has your child received for these?

WHAT ELSE IS IMPORTANT TO KNOW ABOUT YOU? (you may use a separate sheet if needed)

APPENDIX F: IRB Approval



UNC CHARLOTTE

Research and Economic Development

Office of Research Compliance

9201 University City Blvd, Charlotte, NC 28223-0001

t/ 704.687.1876 f/ 704.687.0980 <http://research.uncc.edu/compliance-ethics>

Institutional Review Board (IRB) for Research with Human Subjects

Acknowledgement of IRB Authorization Agreement

Protocol #:	15-07-15	
Title:	A Broken Heart: The Impact of Pediatric Open Heart Surgery on Parents' Wellbeing and Parenting	
Designated IRB:	Carolinas HealthCare System	
FWA #:	00000387	
Date:	10/2/2015	
Investigator:	Dr. Rene Herlong, M.D.	Carolinas HealthCare System
Co-investigator:	Ms. Linda McWhorter	Psychology
Co-investigator:	Dr. Sharon Portwood	Public Health Sciences
Co-investigator:	Ms. Jen LaMothe	Carolinas HealthCare System

UNC Charlotte's has obtained sufficient supporting documentation regarding this study to rely on the review and continuing oversight performed by the Designated IRB. UNC Charlotte is assured that the review provided by the Designated IRB meets the human subjects protection requirements of an OHRP-approved FWA.

The Designated IRB will follow OHRP-required procedures for reporting its findings and actions to appropriate officials at UNC Charlotte. The Designated IRB remains responsible for ensuring compliance with its determinations and with the terms of its OHRP-approved Assurance for activities under its purview.

This document must be kept on file at both institutions and provided to OHRP upon request.

Please note that it is the investigator's responsibility to promptly inform the IRB committees of any changes in the proposed research, as well as any unanticipated problems that may arise involving risks to subjects. UNC Charlotte's Amendment and Event Reporting guidelines and forms are available on our web site: <http://research.uncc.edu/compliance-ethics/human-subjects>


Dr. M. Lynn Exum, IRB Chair

10/22/15
Date

The UNIVERSITY of NORTH CAROLINA at CHARLOTTE

An Equal Opportunity/Affirmative Action Employer

Institutional Review Board (IRB) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution A):

Carolinas HealthCare System

OHRP Federalwide Assurance (FWA) #: 00000387

Name of Institution Relying on the Designated IRB (Institution B):

UNC Charlotte

Federalwide Assurance (FWA)#: 00000649 IRB Registration #: 00001466

The Officials signing below agree that **UNC Charlotte** may rely on **Carolinas HealthCare System's** designated IRB for review and continuing oversight of its human subject research described below: (*check one*)

() This agreement applies to all human subjects research covered by Institution B's FWA:

() This agreement is limited to the following specific project(s):

Name of Research Project: **A Broken Heart: The Impact of Pediatric Open Heart Surgery on Parents' Wellbeing and Parenting**

Principal Investigator: **Rene Herlong, M.D.**
Carolinas HealthCare System

Co-Investigators: **Linda McWhorter**
UNC Charlotte

Co-Investigators: **Sharon Portwood, Ph.D.**
UNC Charlotte

Co-Investigators: **Jen LaMothe**
Carolinas HealthCare System

Sponsor/Funding Agency: _____ Award Number, if any: _____

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official Providing IRB Review:



Michael Gibbs, M.D.
Vice President for Research, Carolinas Healthcare System, P.O. Box 32861, Charlotte, NC 28232

Date: 10/2/15

Signature of Signatory Official Relying on Designated IRB:



Robert G. Wilhelm, Ph.D.
Vice Chancellor for Research and Economic Development, UNC Charlotte 9201 University City Blvd., Charlotte, NC 28223-0001; PH: 704-687-1888

Date: 7/27/15



Carolinus HealthCare System

Edward J. Brown III
Chairman

August 3, 2016

Eugene A. Woods, FACHE
President and CEO

Dr. Rene Herlong

PROTOCOL REAPPROVAL - IRB File #: 08-15-04E

The Institutional Review Board of the Carolinas HealthCare System recently reviewed your request for reapproval of the research project:

A Broken Heart: The Impact of Pediatric Open Heart Surgery on Parents' Wellbeing and Parenting

Your research project has been renewed **for a period of one year (August 3, 2016, to August 2, 2017)**. We will contact you in 10 months to schedule an annual update and review of this project. Please report any significant complications resulting from this project to the IRB immediately. Any changes to the research study must be presented to the IRB for approval prior to implementation. The Board determined your study poses minimal risk to subjects and meets criteria for Expedited review under 45 CFR 46.110, Category 6 (Collection of data) and Category 7 (Research on individual or group characteristics).

If we can be of further assistance, please do not hesitate to contact us.

A handwritten signature in cursive script, appearing to read "Michael Runyon".

Michael Runyon, MD
VICE-CHAIR, IRB

MR/sec
Next Renewal Due: August 2017

Note: The IRB complies with the requirements found in Parts 50 and 56 of the 21 Code of Federal Regulations and Part 46 of the 45 Code of Federal Regulations. The Federal-Wide Assurance (FWA) Number is 00000387. The Registration number is IORG 0000740. The Carolinas HealthCare System Institutional Review Board follows the ICH GCP guidelines with regard to the rights of human subjects.

PO Box 32861 • Charlotte, NC 28232-2861

Appendix G: Participant Confidentiality Agreement



Health Psychology Ph.D. Program

**Participant Confidentiality Agreement
Open Heart Surgery Focus Group**

I understand that everything I hear and say at the Open Heart Surgery Focus Group is private and confidential. The names of other participants are also private and confidential. I will not share anything I hear or see at the focus group with anyone under any circumstances. I understand that this means:

- I will not discuss what other parents said or did with my family, friends, or medical staff.
- I will not tell the names of parents I saw at the focus group to family, friends, or medical staff.
- I will not take pictures or record during the focus group.

This will allow all parents to feel comfortable sharing their opinions and experiences. I agree to keep the names and comments of other parents private and confidential. This agreement helps support research to improve the experiences of families of children with CHD.

Participant's Name (Please Print)

Participant's Signature Date

LINDA MCWHORTER
Researcher's Name (Please Print)

Researcher's Signature Date

Appendix H: Gift Card Confirmation Form

Target Gift Card Confirmation

I have received a \$20 Target Gift Card for my participation in the focus group research project with Linda McWhorter.

Card Number:

Participant Name

Participant Signature

Date

Researcher's Signature

Date