EXPERIENCES OF SCHOOL-AGED SIBLINGS OF INDIVIDUALS LIVING WITH COMPLEX CONGENITAL HEART DEFECTS

by

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Although some research has examined the experiences of well-siblings of children with chronic health conditions, more research is needed to specifically explore the lived experiences of school-aged well-siblings of individuals living with complex congenital heart defects. Using family systems theoretical framework, this phenomenological study explored the experiences of well-siblings of individuals living with a complex congenital heart defect. Six well-siblings between the ages of 12 years and 17 years shared their experiences through two in-depth, semi-structured interviews. All participants were younger in age than their sibling living with a CHD. Data saturation was achieved. Interview questions explored the daily lives of the participants, perception of their sense of normalcy, their knowledge of their sibling's heart diagnosis, and their present level of support. Participants also completed questionnaires to gauge their level of health literacy and current symptoms of anxiety (GAD-7) and depression (PHQ-8). Parents of participants completed a demographic questionnaire. Data analysis resulted in three overlapping themes: viewpoint of daily life in the family, understanding of the sibling's heart diagnosis, and the well-child's support champions. Findings suggested parents' differential treatment of well-siblings. Although the participants were younger than the individual with the complex heart defects, results indicated that well-children experienced roles and expectations congruent with an

older sibling, such as increased feelings of responsibility and protectiveness over their sibling living with a heart defect. Sibling rivalry and jealousy were also expressed. Well-children reported their parents as being their primary source of social support, with mothers being the first go-to person for information and support. While participants gained support from close friends, they did not want to share information about their sibling's heart diagnosis with all friends. Notably, participants reported increased worry about adverse health outcomes including the possibility of death of their sibling during the COVID-19 pandemic and followed more restrictions in their social lives to minimize exposures. The results of this study emphasize the importance of including well-children in conversations about their sibling's heart diagnosis, as well as the need for both professional and personal support systems. Implications for practice include an ongoing need for psychoeducational interventions for well-children and involvement of well-siblings with child life specialists. For parents, this study indicates a need for improved communication with and attention towards well-children during their sibling's hospitalizations. Future research should examine the perceptions and experiences of adult siblings and siblings who are older in age than their sibling living with a CHD as well as further examine the experiences of well-siblings during the COVID-19 pandemic and the role of friendships in providing support.

EXPERIENCES OF SCHOOL-AGED SIBLINGS OF INDIVIDUALS LIVING WITH COMPLEX, CONGENITAL HEART DEFECTS

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CHAPTER 1: INTRODUCTION

Siblings of Children with Complex Congenital Heart Defects

When a child is diagnosed with a complex congenital heart defect, the impact across other members of the family is felt deeply. Although there is extensive research being done, a majority of it focuses on the needs of the child with the diagnosis or their parents. Relatively little literature exists exploring the experiences of their well-siblings. In comparison to their peers born into healthy families, well-siblings of children with complex congenital heart defects tend to report a lower quality of life and higher rates of internalizing and externalizing behaviors (Caris et al., 2018; Parker et al., 2020). Well-siblings are often asked to refrain from participation in activities that increase their unwell sibling's exposure to outside infections and have been reported to receive less attention from their parents, leading to feelings of exclusion, jealousy, and insecurity (Parker et al., 2020). There have also been higher reported rates of sibling rivalry, jealousy, and feelings of neglect (Parker et al., 2020). Because a complex congenital heart defect diagnosis affects more than just one member of the system, healthcare providers need to understand the impact on siblings as well as their patients. Thus, the purpose of this study is to explore the experiences of well-children living with a sibling diagnosed with a complex congenital heart defect.

Complex Congenital Heart Defects

A congenital heart defect (CHD) is a structural problem occurring before birth that arises "from abnormal formation of the heart or major blood vessels" (American Heart Association, 2013). Occurring in approximately eight of every 1000 live births in the United States, congenital heart defects are the most common birth defect (Center for Disease Control, 2020). Congenital heart defects range in severity, with approximately one in four being classified as

complex and requiring surgery within the first year of life (Centers for Disease Control, 2020). Due to advancements in care and technology, the mortality rate associated with CHDs has been steadily declining over the years; however, CHDs are still the leading cause of death amongst infants and babies (Gilboa et al., 2016).

Impact of Living with Complex Congenital Heart Defects on Families

When an infant is diagnosed with a CHD, significant changes to family life and functioning often follow. Financial strain drastically increases along with the cost of special healthcare needs, therapies, and behavioral treatments. As more hours are required for caregiving, many parents are forced to either quit or reduce their hours at work (Centers for Disease Control, 2020). The child with the diagnosis is often prevented from participating in extracurricular activities, tends to miss more days of school than their peers, and is at higher risk for extended healthcare needs (Centers for Disease Control, 2020). Many well-siblings report experiencing increased levels of stress and decreased parental attention (Parker et al., 2020). Oftentimes, well-siblings report feeling excluded as the intensity and frequency of their sibling's treatment increased (Parker et al., 2020). All of these factors can lead to increased sibling rivalry and jealousy, parental strain, and increased well-sibling behavioral problems (Janus & Goldberg, 1996).

Chronic Conditions

A chronic condition is defined as an indefinitely occurring experience of symptoms and suffering with an onset in early childhood (Larsen, 2002). Chronic conditions are subdivided into three categories: chronic medical illness, chronic disability, and chronic mental illness, (Knottnerus et al., 1992). A chronic medical illness is a long-term diagnosis that may or may not have a cure (Knottnerus et al., 1992).

A chronic disability is defined as an individual's experience of a bodily difficulty in functioning that affects at least one activity of daily life (Leonardi et al., 2006). Although cognitive disabilities are the most common as of 2019, other areas of disability include vision, hearing, memory, motor skills, activities of daily living, and independence (Young & Crankshaw, 2021). As of 2019, over three million children in the United States were considered to have some type of disability (Young & Crankshaw, 2021).

The United States surgeon general defined a mental illness as being a health condition resulting in an alteration in an individual's thinking, mood, or behavior and include diagnoses such as schizophrenia and bipolar disorder (Goldman & Grob, 2006). Chronic mental illnesses, which are representative of about five percent of the population, are severe and persistent mental disorders that negatively affect at least one area of social functioning (Goldman & Grob, 2006).

Impact of Living with Chronic Conditions on Well-Siblings

While the three categories differ in their definitions, they are similar in that they can have an adverse impact on the quality of life of well-siblings. There is extensive research regarding the effect chronic conditions have on the child with the diagnosis. Less is known, however, about the effect of a chronic condition on well-siblings. Literature suggests that the impact presents in well-siblings' mental health, adjustment, and coping mechanisms, although it is unclear the extent of impact on the severity. Additionally, some studies have concluded that well-siblings are at a greater risk for adverse effects while others have concluded that a family member's chronic illness has no effect on well-siblings' adjustment, mental health, and coping (Brennan et al., 2012; Derouin & Jessee, 1996; Janus & Goldberg, 1996). Many of these studies have included cancer within their categorization of chronic conditions, which may affect the results and well-siblings' abilities to cope and adjust. Existing literature also suggests that having a child with a

chronic condition increases the level of stress placed on each family member, resulting in emotional and behavioral problems in many well-siblings (Fisman et al., 2000). In school, well-siblings have been reported to have higher levels of internalizing behaviors as compared to their peers from healthy families (Fisman et al., 2000). Well-siblings have reported increased levels of anger, guilt, and loneliness (Jackson et al., 2015).

Theoretical Framework

Family Systems Theory provides an explanation for the various interacting systems and patterns that affect an individual's development. Families are considered to be social systems which develop and maintain patterns of behavior over time. These family systems, however, are created from a series of subsystems that adapt depending on their present circumstances. For well-children being raised in a system affected by chronic illness, these subsystems include both the parent and sibling subsystems as well as outside systems, such as those containing medical care professionals. When coping with the introduction of a childhood chronic illness, Family Systems Theory aims to understand how various subsystems affect an individual and identify existing patterns of behavior, thus shifting the focus to managing relationships to create healthy patterns of behavior for subsequent generations (Gottlieb, 2018).

Gaps in the Literature

Much of the existing literature regarding chronic illnesses and the effect on family, particularly well-siblings, is somewhat dated and focuses on chronic illness in its entirety rather than the effect of an individual diagnosis (Parker et al., 2020). Additionally, many published studies include a cancer diagnosis within their classification of chronic illness. While this area of research is emerging, even fewer studies exist regarding the impact on siblings in particular and many utilize data collected from parental perceptions of sibling functioning (Parker et al., 2020).

Purpose of the Present Study

The present phenomenological study aims to understand how the daily lives of siblings of individuals with complex congenital heart defects can be affected and to gain awareness of their experiences both with family members and other members of their system. Existing research regarding the effects of complex congenital heart defects on well-siblings largely focuses on data collected from parental perceptions rather than directly from affected siblings. The present study aims to explore the overall experiences of well-siblings of individuals with complex congenital heart defects by collecting and utilizing data directly from the population of interest. The present study aims to answer the following overarching question: How do school-aged children experience living with a sibling with a complex congenital heart defect? This research question introduced the following sub-questions:

1. What are the perceived roles of school-aged siblings of individuals with complex congenital heart defects?
2. What are the experiences of school-aged siblings of individuals with complex congenital heart defects with people outside of their immediate family system?
3. How can experiences of school-aged siblings of individuals with complex congenital heart defects change when their sibling is staying in the hospital?
4. What is the perceived level of support received by school-aged siblings of individuals with complex congenital heart defects?
5. What role does health literacy play, if any, into the experiences and coping of school-aged siblings of individuals with complex congenital heart defects?

CHAPTER 2: REVIEW OF LITERATURE

Complex Congenital Heart Defects in Children

Since 2000, the prevalence of congenital heart defects has risen by over 50 percent (Marelli et al., 2014). Congenital heart defects are currently the most common birth defect, affecting about eight to ten of every 1,000 live births (Abqari et al., 2016; Marelli et al., 2014). Recent medical advances have improved outcomes, quality of life, and life expectancy for individuals living with a complex congenital heart defect (Azhar et al., 2016). Despite these advances, many children living with complex congenital heart defects may experience recurrent hospitalizations, frequent doctors' appointments, irregular attendance at school, and stigmatization (Azhar et al., 2016).

Complex congenital heart defects are structural heart defects present at birth that occur due to improper development in the womb (Children's Hospital Los Angeles, 2021). The presence of a complex congenital heart defect in childhood affects all members of the family system, although these impacts can be both positive and negative. A study completed by Werner and colleagues (2013) investigated the impact complex congenital heart defects in childhood had on the family using the Impact on Family Questionnaire. Data suggest that the impact of the child's complex congenital heart defect was felt more strongly in families who lacked social support, in children who had a longer duration of hospitalization, and in children whose defects were related to a genetic cause (Werner et al., 2013). In line with these data, it was concluded that complex congenital heart defects tend to affect personal aspects of family member's daily lives and that increased social support and knowledge regarding the defect aided in mediating some of these effects.

Chronic Illnesses in Children

The term chronically ill spans over many diagnoses, symptoms, and levels of functioning. Broadly defined, chronic illnesses are medical conditions that last for more than three months, require continuous medical attention, and can negatively affect activities of daily living and development (National Institute of Mental Health, 2021). To be diagnosed with a chronic illness, a child needs to experience at least one of the following: inappropriate functioning for current age and developmental stage; disfigurement; a dependency on medical technology, medication, or diet; an increased need for medical care and services; or ongoing special treatment in school or at home due to extenuating medical needs (Judson, 2004). Chronic illnesses must also be diagnosed by a medical provider and span over a duration longer than six months (Williams, 1997).

Although the exact number is unknown, statistics suggest that approximately 27 percent of children in the United States have been diagnosed with some type of chronic illness (Rezaee & Pollock, 2015). These illnesses range in severity from common to severe and include diagnoses such as asthma, complex congenital heart defects, diabetes, cancer, and cystic fibrosis. Chronic illnesses also affect all members of the family due to an increased responsibility in caretaking and a strain on family resources. The number of affected family members was previously estimated to be around three million (Williams, 1997). This number, however, has increased as the prevalence of chronic illnesses continues to increase.

Impact of Chronic Illnesses

Parenting Children with Chronic Illnesses

There has been a recent and ongoing shift in healthcare, resulting in increased survival rates for many children with chronic illnesses and an increase in home-based care (Kepreotes et al., 2009). Along with this, many parents undertake a change in their role, moving from a parent-

nurturer to the child's main healthcare provider (Kepreotes et al., 2009). This new role in combination with the chronic illness can result in an increased level of parenting stress, which can affect both parents and their children. A study completed by Cousino and Hazen (2013) reviewed existing literature related to parenting stress of caregivers of children with chronic illnesses. The researchers aimed to determine if parenting stress differed in parents with children with chronic illnesses and if this was due to the presence of a chronic illness or a cofounding variable. Results supported their hypothesis and indicated that parents of children with chronic illness were at an increased risk for greater parenting stress than their counterparts with healthy children (Cousino & Hazen, 2013). This stress, however, was mediated through improved coping mechanisms and less engagement in avoidance behaviors (Cousino & Hazen, 2013).

The presence of parenting stress has the potential to impact parent-child relationships, especially in families affected by chronic illness. Parenting stress is increased as a multitude of factors are affected, such as responsibility, financial strain, and parents' depressive symptoms (Pinquart, 2013). A meta-analysis completed by Pinquart (2013) analyzed existing literature to determine if families of children with a chronic illness reported differing levels of responsiveness, demandingness, and overprotection than their counterparts with healthy children. This study also analyzed these two groups of parents for differences in reported parenting styles. Upon analysis, the most significant differences were found in reported parental overprotection. Related to chronic illness, overprotection of children can have opposing results. Some literature suggests that parental overprotection can result in negative effects while others found it beneficial in aiding children to adhere to their strict treatment regimen. Thus, it was concluded that parenting styles continue to differ on an individual basis, with chronic illness being just one factor affecting the present parenting style (Pinquart, 2013).

Impact of Living with Chronic Illness on Well-Siblings

There is prior research suggesting that childhood chronic illness is a stressful life event for all family members and affects the entirety of the family system, including parents, siblings, and other caregivers (Menke, 1987; Tritt & Esses, 1988). Existing literature points to the suggestion that the presence of a childhood chronic illness introduces increased stressors into the home such as: an increased cost of care from therapies, hospital visits, doctors' appointments, and a change in daily needs; perceived differences in parenting; differences in family members' feelings regarding the diagnosis and the uncertainties that accompany it; and differences in each members' coping mechanisms (Menke, 1987). Despite these findings, research concerning the impact on well-siblings and the implications for a family-oriented approach to healthcare is still lacking. For the few studies that do exist, results often utilize the reports of parents rather than obtaining data and information directly from well-siblings. Results also tend to focus on negative outcomes rather than providing a comprehensive overview of adjustment, including both positive and negative effects. Finally, much of the literature obtaining data directly from sibling reports tends to be dated and focuses on chronic illness in general rather than parsing out results based on specific diagnosis.

Early research conducted by Lavigne and Ryan (1979) focused on the psychological adjustment of 200 well-siblings to the presence of a chronic illness. Parents were asked to complete the Louisville Behavior Checklist, a 164-item questionnaire concerning adjustment behaviors, and provide information regarding their child's chronic illness. Results were then compared with a control group of siblings from healthy families and found that siblings of children with a chronic illness were at an increased risk of experiencing adjustment or behavioral

problems. It was also found that the severity of the chronic illness can have an impact on the level of stress placed on each family member.

In line with these findings, further research suggests there are many factors that impact family member's ability to cope with and adjust to a childhood chronic illness, including the type and severity of the illness, family size and ages, socioeconomic status, and outside support (Williams et al., 1993). The effect of a chronic illness on well-siblings depends on when the illness was introduced into the system, how long it has been present, and the level of impact it has on well-siblings' wants (Travis, 1976). To support these claims, Williams, Lorenzo, and Borja (1993) interviewed the mothers of 100 families affected by chronic illness on changes they had observed in their well-children since the introduction of a chronic illness. Mothers reported they spent less time caring for and tending to their well-children after having a child with a chronic illness, thus increasing their household responsibilities, and decreasing their participation in extracurricular activities. Consistent with these findings, it is imperative that families are assisted in their adjustment to chronic illness through education on its effects, positive reinforcements, and support of positive coping mechanisms (Williams, Lorenzo, & Borja, 1993).

Although many findings support well-siblings being at an increased risk for adjustment and psychosocial problems, other studies have found well-siblings to fall within normal limits on measures of psychosocial functioning (Gayton et al., 1977). Additionally, there are many studies focusing on factors affecting adjustment in children from physically healthy families, including socioeconomic status, parents' marital status, and differential parenting styles (Dunn, 1988; Menaghan & Parcel, 1991). With these factors combined, it becomes increasingly evident that there are more factors at play than the presence of a chronic illness that can impact well-siblings' adjustment and psychosocial wellbeing. Including family structure, child characteristics, and

parenting styles, Thompson, Curtner, and O'Rear (1994) examined the extent to which a combination of factors impacted well-siblings' psychosocial adjustment to chronic illness. Results supported previous findings that there are many interacting factors that impact coping and adjustment and that problems experienced by well-siblings may not be directly related to the presence of a chronic illness. These findings, however, do not suggest that well-siblings have little need for assistance in adapting to their sibling's chronic illness and further support the need for family-oriented care (Thompson, Curtner, & O'Rear, 1994).

While the results from the previously mentioned studies are essential in creating a foundation for sibling-focused research, their results are yielded entirely from parent perceptions of sibling experiences. Using a modified version of the Child Behavior Checklist, Cadman, Boyle, and Offord (1988) collected information regarding mental health and social adjustment of well-siblings of children with chronic illnesses. The checklist was administered to parents and teachers of each participant with additional self-reports obtained from participants over the age of twelve. Upon analysis, results suggested that well-siblings were at two times the risk of being diagnosed with anxiety, depression, and obsessive-compulsive disorder but were not at increased risk for adverse social adjustment (Cadman, Boyle, & Offord, 1988). Although these findings do support well-siblings being at increased risk for maladjustment and further support a need for sibling involvement in patient care, discrepancies may be due to differing perceptions among well-siblings, parents, and teachers about the experiences of participants.

As aforementioned, and supported through previous articles, much of the literature existing regarding well-sibling experiences comes from the reports and perceptions of parents rather than the siblings themselves (Menke, 1987). Using structured interviews, Menke (1987) conducted a study to obtain data from both well-siblings and their parents regarding adjustment

and emotional health. The results were then compared to find discrepancies in parent perceptions and identify the needs of well-siblings. Out of 72 participants, 49 reported that they worried about their sibling with a chronic illness, 43 identified difficulties in living with a child with a chronic illness, and 51 reported their parents paid more attention to their sibling with a chronic illness (Menke, 1987). When compared with parent data, there was agreement that well-siblings expressed worry, but the nature of these worries varied with parents assuming well-siblings worried more about themselves. Due to these discrepancies, this study furthered the need to use well-siblings as primary data sources and encouraged the inclusion of well-siblings in patient care.

Focusing specifically on well-siblings, Tritt and Esses (1988) compared the behavioral and emotional adjustment of 27 well-siblings to 27 siblings coming from healthy families. Each participant was administered the Behavior Problem Checklist, Self-Appraisal Inventory, and What I Think and Feel Questionnaire with well-siblings completing an additional interview. The interview questions focused on well-siblings' knowledge of the chronic illness, their perception of their functioning, family relationships, and family life, and positive and negative effects of their experience. Their findings confirmed the suggestion that well-siblings are affected in some capacity by the chronic illness, with many reporting feelings of abandonment and distress. Findings also suggest that, for many well-siblings, anxiety was reduced when they were included in the care of their sibling's chronic illness and when their parents were willing to respond to questions openly and honestly.

Despite growing research focused on well-sibling coping and adjustment, there is little literature regarding well-siblings' experience with participation in everyday activities (Woodgate et al., 2016). Woodgate and colleagues (2016) interviewed sixteen siblings about their

participation in daily and extracurricular activities and what it meant for them to be able to participate in these activities. Results indicated that well-siblings experienced difficulty when they were asked to avoid activities to maintain the safety and comfort of their sibling with a chronic illness. Researchers also noted that many siblings reported increased feelings of guilt and expressed a need to take on responsibility for others' problems (Woodgate et al., 2016). These findings indicate that the ability of well-siblings to be able to participate in activities with their peers is essential in their coping and adjustment and may even serve to bolster their sibling relationships.

Impact of Living with Chronic Illness on Sibling Relationships

Chronic illnesses, especially in childhood, are a stressful life event for all members of the family system (Hamlett, Pellegrini, & Katz, 1992). The impact of sibling relationships is lifelong and can serve as integral sources of support. Research regarding the impact of chronic illness on sibling relationships, however, is lacking. Existing literature suggests that chronic illness in childhood can result in increased reports of sibling jealousy and perceived parental favoritism. A study by Derouin and Jessee (1996) investigated siblings' perceptions of disruption when their brother or sister was diagnosed with either cystic fibrosis or asthma. Each participant was interviewed regarding their perception of the chronic illness on their family as well as their feelings associated with living with a sibling with a chronic illness. Over half of the participants responded that living with a sibling with a chronic illness resulted in their family relationships being strengthened while the other half reported that their family unity had been negatively impacted by the presence of a chronic illness. Along with a lack of cohesiveness regarding the impact on family unity, there was no clear distinction regarding the impact on sibling relationships in particular.

A study by Janus and Goldberg (1995) investigated the impact of living with a congenital heart defect on well-siblings' empathy and adjustment. In addition, they also studied the relationship between the well-siblings' empathy and the effect on sibling relationships. The Bryant Empathy Task was utilized to determine each participant's level of empathy while the Sibling Inventory of Behavior was utilized to assess well-siblings' behavior towards their brother or sister with a congenital heart defect. While a relationship was not found between the presence of a congenital heart defect and levels of empathy, researchers did find a correlation between higher levels of expressed empathy and frequency of perceived positive interactions. Mothers of participants, however, reported that their well-children were more resentful of the child with a congenital heart defect.

Previous literature suggests that living with childhood chronic illness and disability is a stress factor for well-siblings. There are, however, many other factors that can impact the level of risk such as socioeconomic status, birth order, and children's ages. Lobato and colleagues (1988) examined the relationship between chronic illness and disability on sibling relationships while aiming to simultaneously control for coexisting variables. Data suggested that sibling birth order played a role in predicting sibling relationships, with younger well-siblings undertaking a caretaking role typically associated with older siblings and expressing greater rates of tension and confusion. Additionally, the timing of the onset of the chronic illness or disability affected the quality of sibling relationships. Diagnoses that were assigned at birth typically had less of an impact on sibling relationships than diagnoses that progressed over time.

Impact of Complex Congenital Heart Defects on Well-Siblings

Despite the growing body of literature concerning the effects of chronic illness on families, there is little information regarding the impact specifically of living with a sibling with

a complex congenital heart defect. Interviews with parents suggest that well-siblings are more frequently asked to undertake more responsibilities and are more often excluded from activities that increase the exposure to outside germs and illnesses (Connor et al., 2010). There is growing data suggesting that well-siblings are at increased risk for poor adjustment and coping as well as internalizing and externalizing behaviors. Furthermore, a growing body of literature suggests that there are more factors at play than the presence of a complex congenital heart defect that affect the severity of the impact on well-siblings.

Well-siblings of children with complex congenital heart defects tend to report a lower quality of life than their healthy peers. Oftentimes, children with complex congenital heart defects are subject to recurrent and extensive hospitalizations, stigmatization, and limitations placed on them both by overprotective parenting and functional limitations (Azhar et al., 2016). These situations raise concerns regarding quality of life for both the patient and their family members. Historically, well-siblings of children with chronic illness have reported a lower quality of life than their peers (Sharpe, 2002; Vermaes et al., 2012). There is, however, a lack of information regarding the impact of complex congenital heart defects on well-siblings' quality of life. In Saudi Arabia, a study by Azhar and colleagues (2016) investigated quality of life, specifically focusing on siblings of children with complex congenital heart defects. Analysis of siblings' assessments indicated that approximately 33 percent reported feeling jealous of their sibling with a complex congenital heart defect while close to 20 percent reported feeling neglected by their parents as a result of their sibling's complex congenital heart defect.

In addition to endorsing a lower quality of life, well-siblings of children with chronic illness tend to report higher rates of both internalizing and externalizing behaviors. Presently, however, most of the data tend to report on chronic illness as a whole rather than parsing out

results based on diagnosis. A study by Caris and colleagues (2018) reported on the quality of life of children with a sibling diagnosed with hypoplastic left heart syndrome. Parents and well-children each completed the Sibling Perception Questionnaire, a survey designed to assess adjustment in children impacted by a chronic illness. While parents tended to report higher levels of adjustment problems, siblings tended to report higher levels of adjustment as they aged. Participants younger than their sibling with hypoplastic left heart syndrome tended to report higher levels of physical symptoms while older siblings reported higher levels of emotional and psychosocial problems, indicating that siblings of all ages are impacted by the presence of a complex congenital heart defect. These findings indicate that there is a need for well-siblings to be involved in interventions that aim to improve their functioning, adjustment, coping, and quality of life (Caris et al., 2018).

A study by Janus and Goldberg (1996) examined the relationship between the intensity of treatment for the complex congenital heart defect and the impact on behavioral problems of well-siblings. Although the data were reported from the children's mothers, there seemed to be a positive correlation between perceived level of accommodation and well-siblings' behavioral problems. These problems were further correlated with well-siblings' rates of internalizing problems, such as increased guilt, responsibility, and anxiety. Data regarding well-siblings' knowledge about the complex congenital heart defect suggest that there is an increased need in aiding well-siblings in their understanding of the diagnosis and the treatment implications that coexist.

Coping

Coping with Chronic Illnesses

Related to a chronic illness, coping is defined as the ability of an individual to understand the meaning of their diagnosis and various treatments while simultaneously managing emotional reactions, fulfilling responsibilities, and providing support to others within their system (Jackson et al., 2015). While previous literature reported primarily on the impact of a chronic condition of the diagnosed child, there has recently been a growing interest regarding the impact on family members and understanding the impact on their bodies and minds (Feigin et al., 2008). Using overall quality of life as a measure, Feigin and colleagues (2008) conducted a study investigating the systemic quality of life of individuals living with a family member with a chronic illness. Data analysis indicated that being a caregiver for an individual with a chronic illness was negatively correlated with overall quality of life. Family relationships were shown to be negatively impacted, likely due to an increased burden, decreased feelings of security and control, and decreased vulnerability on the part of the caregiver (Feigin et al., 2008). While these results are crucial in demonstrating the relationship between chronic illness and caregiver fatigue, coping mechanisms were not assessed for which may have an impact on a caregiver's ability to provide for themselves, the person they are caring for, and other members within their various systems.

Focusing specifically on caregivers in Brazil, a study by Machado and colleagues (2018) aimed to identify coping mechanisms caregivers used in daily life. This research team included 30 caregivers who were caring for a family member one-month post-discharge from a hospitalization. Coping mechanisms were assessed through interviews and questionnaires and were identified as falling within four categories: problem-focused, religious involvement, social support, and emotional (Machado et al., 2018). Data indicated that the most prevalent coping mechanism was problem-focused, demonstrating that caregivers generally tend to directly face

problems with an attempt to solve or fix it. This strategy brought about both positive and negative perceptions, with caregivers reporting they felt capable, useful, and happy while simultaneously feeling sad, angry, and betrayed (Machado et al., 2018). These results indicate that various coping mechanisms are present for caregivers but omit their impact on overall quality of life both for the caregiver and other members of the family system. It also overlooks the impact of coping and chronic illnesses on other members of the family who might not be in a direct caregiving role but are still affected.

Assessing coping mechanisms in every family member is beneficial because it provides a lens into how the family is managing and adapting to additional stressors as well as indications for beneficial interventions. Literature indicates that coping mechanisms vary between each family member, with many parents attempting to guard against stress and anxiety and demonstrating a strong and positive demeanor while the impact on well-siblings is largely dependent on the parents' approach (Pietromonaco & Collins, 2017). Thus, a study by Nabors and colleagues (2018) aimed to determine how parents viewed their family's coping and the impact of hospitalization when their child with a chronic illness was hospitalized. Parents reported that it was beneficial for them to rely on faith and prayer as well as listening to other parents speak about their children with chronic illnesses who were improving in their conditions and coping well. Parents also stressed the importance of focusing on positive aspects in an effort to keep moving forward and avoid feeling sad or worried. Additionally, many parents reported situations that made coping difficult, including job loss, a lack of preparation for their situation, and discussing their child's situation with others. Regarding well-siblings, parents reported that they were well-adjusted in their home and school lives and coping well. They described well-siblings as wanting to protect and help during times of hospitalizations and as wanting to provide

emotional support for their sibling with a chronic illness. Overall, parents reported that their families were coping well, both in daily life and during times of hospitalization. These reports, however, were all from parents and neglected well-siblings' perceptions of their situation and current coping.

Recruiting participants from a children's hospital near England, Brennan, and colleagues (2012) interviewed 31 well-siblings of children with chronic illnesses regarding their general experiences and current coping mechanisms. Data indicated that although some siblings did report emotional and behavioral difficulties, many had developed strategies to manage and balance their home and school lives. Siblings reported compartmentalizing to both manage concern for their sibling while creating a sense of normalcy for themselves, indicating a reliance on avoidant coping strategies. Because avoidant coping strategies are less effective for long-term implications, children employing these are at higher risk for anxiety and depression (Gomez & McLaren, 2006). Siblings also tended to view their own needs as being secondary to the needs of their family, often not seeking support and coping with difficult situations alone (Brennan et al., 2012). Finally, many of the siblings participating in this study tended to place themselves into roles traditionally associated with adults and take on an increased caregiving role. These findings suggest that, although many well-siblings do adopt coping strategies, many of these only work for the short-term and continue to raise concerns about well-siblings' long term wellbeing.

Specifically related to complex congenital heart defects, an individual's ability to cope is impacted by both individual and familial factors (Jackson et al., 2014). Much of the research suggests that the ability of children to cope is directly related to their parents' adjustment and coping, however coping mechanisms have been identified as being poorer in families affected by complex congenital heart defects (Graf et al., 2006; Kupst & Shulman, 1988; Kupst et al., 1995).

Health Literacy

Health literacy is the ability of an individual to obtain, process, and understand information regarding their health, make appropriate health decisions, and appropriately manage their health on a daily basis (Nielson-Bohlman et al., 2004). There are four factors associated with health literacy: knowledge of the disease and self-care, risk behavior, preventative care and routine visits, and medication compliance (Lee et al., 2004). Poor scores in these four areas are associated with lower levels of health literacy, often leading to a delay in accessing health care and an overuse of emergency medical services. Children who do have high scores of health literacy, however, demonstrate an increased ability to understand and manage their health (Abrams et al., 2009).

Research suggests that assisting parents in knowing how and when to present information to their well-children is crucial. There are still many parents, however, who are not providing their well-children with the amount or quality of information necessary to counter adverse effects of having a sibling with a chronic illness. Parents cite many reasons for withholding information, including not knowing how and when to share information, discomfort with potentially upsetting or frightening their well-children, not knowing what information is appropriate to provide, not having the time necessary to have an in-depth conversation with their well-children, not wanting to negatively alter family relationships, thinking the information may be better received coming from another source, and needing guidance in sharing sensitive information (Kleiber et al., 1995; Lobato & Kao, 2005; Menke, 1987; Newton et al., 2005).

Sibling Directed Intervention

The presence of a chronically ill sibling has been linked to negative outcomes for well-siblings, such as increased levels of stress and anxiety, negative adjustment, and strained

intrapersonal relationships (Lobato & Kao, 2002). Some of these outcomes can be alleviated through intervention, specifically psychoeducational programs focusing on increasing health literacy. Increasing health literacy in well-siblings has been correlated with stronger family relationships, reduced rates of stress and anxiety, and overall better adjustment and psychological well-being. These programs, however, are difficult to implement due to the cost, increased need for personnel, and parental unawareness regarding the appropriate time to include their well-children in education (Utens, 2018).

Positive outcomes have been found when well-siblings are permitted to visit their sick brother or sister in the hospital. Visitation can serve to reduce feelings of stress because they are able to see what is happening and form an understanding of the situation. Michigan's Helen DeVos Children's Hospital restructured their Newborn Intensive Care Unit (NICU) Visitation Policy, allowing unlimited access for all well-siblings under parental supervision and completion of a health screening (Levick et al., 2010). In addition, an intervention program for well-siblings was implemented. This group focused on increasing well-siblings' knowledge in a developmentally appropriate way and providing social support. The combination of the intervention program and new NICU policy resulted in siblings reporting decreased feelings of anxiety and increased connectedness to their sick brother or sister.

In addition to visitation rights, the emphasis has increased on creating education-based intervention programs for well-siblings. Although sparse, literature suggests that these programs are crucial in aiding well-siblings in their adjustment and coping. These intervention programs are most efficient when providing well-siblings with educational as well as social support. A study by Williams and colleagues (1997) aimed to determine the effect of intervention on well-siblings' coping and adjustment. Well-siblings were divided into siblings into groups based on

their brother or sister's diagnosis and attended six hours of educational sessions focused on teaching the characteristics and management of each condition. At the conclusion of the study, siblings reported having more knowledge of the diagnosis and reported lower rates of isolation, resentment, guilt, anger, and depression (Williams et al., 1997).

Lobato and Kao (2002) examined the impact of the SibLink program which was designed to improve well-siblings' adjustment and understanding of their sick brother or sister's diagnosis. Results indicated that participating siblings demonstrated an increase in their ability to accurately name and describe the diagnosis as well as an increase in their sense of sibling connectedness. Measures of negative adjustment and behavioral problems decreased significantly in post-intervention measures.

In 2005, the previous study on the SibLink program was extended to study the impact of education on overall wellbeing. Prior to onset, participants were asked to name their sibling's diagnosis, explain it, and provide information regarding symptoms and treatment to assess their baseline knowledge. They were also asked to complete the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children to measure how they perceived their ability to handle information and acceptance amongst their peers and family members (Lobato & Kao, 2005). Participants then engaged in activities aimed to improve knowledge and foster healthy family discussion, identify, and manage their emotions and improve problem solving in challenging situations, and identifying their personal strengths and needs within the family. Finally, they were instructed to read about the diagnosis with their parents. At the conclusion of the study, siblings demonstrated increased knowledge of the diagnosis in terms of their ability to name and describe it. They also reported increased levels of perceived sibling connectedness.

Williams and colleagues (1997) studied the impact of a community-based intervention on well-sibling knowledge and well-being. Six siblings were enrolled in a year-long nurse-led intervention program with the aim of increasing their knowledge, social support, self-esteem, mood, and attitude. Sessions included education about their sibling's diagnosis, psychosocial sessions, and booster sessions. A proportion of the participants were also invited to attend a residential summer camp. Upon analysis, data demonstrated that children enrolled in the full intervention (all sessions and the residential camp) showed improvements in all measured aspects while children who only attended the camp experience increased in their feelings of self-esteem and perceived social support.

Gursky (2007) investigated the impact of an education-based intervention on well-siblings' levels of stress and anxiety. Fifty well-siblings of children staying in the hospital were enrolled and given an initial pretest to determine their current level of knowledge regarding the hospitalization and their level of stress and anxiety. They were then enrolled in a child-life led educational session designed to increase their knowledge of the hospitalization. Each session lasted between twenty and twenty-five minutes and included a description of the illness, treatment and therapies, equipment found in the hospital room, the child's daily routine, and their expected length of hospital stay. At the conclusion of the study, participants indicated that their levels of stress and anxiety decreased as their knowledge increased (Gursky, 2007).

Despite the positive results shown in the literature, these programs are largely unavailable in hospitals across the United States. In 2009, Newton and colleagues completed a study to find the amount of sibling support provided in children's hospitals across the United States. Of 109 hospitals, 48 percent of them offered sibling support, but only one-fifth of hospitals offered educational resources. Of these, over half reported the materials had not been evaluated for

effectiveness, meaning no determination could be made as far as any effects the materials had on well-siblings (Newton et al., 2009).

Impact of Family

Family Relationships

It is widely accepted that families are the foundation of society, thus presenting the task of defining what constitutes a healthy, strong, well-functioning family. The answer to this question has tasked researchers with developing theories and models detailing attributes that contribute to a family's ability to succeed. Although this body of literature continues to grow, there are very few articles focusing on lay conceptualizations of family (Williamson et al., 2018). To address this gap, a study was conducted by Williamson and colleagues (2018) with the aim of drawing attention to laypeople's definitions and conceptualizations of family. Interviewing 34 members of 20 different families, they asked participants what it meant for a family to work well and to discuss their understanding of a good family. Analysis of the data indicated that many of the attributes included by participants, such as good communication, shared roles and responsibilities, and positive interactions, were consistent with those identified within the existing literature. Data, however, were only collected at one point in time and did not account for the impact of a good family relationship on member's development throughout the lifespan.

The quality of family relationships can impact children's development, with a correlation between higher parental difficulties and greater difficulty in children reaching developmental milestones (Sturge-Apple et al., 2006). Viewing development through a family systems lens, however, suggests that family relationships are impacted by systems much broader than solely the nuclear family, with all systems being interdependent and governed by boundaries. Thus, there are three distinct ways to characterize family interactions: harmonious, disengaged, and

enmeshed (Minuchin, 1974). Harmonious families are characterized as having well-defined but permeable boundaries, warm, and close relationships, allowing children to have support and warmth without affecting relationships amongst other family members (Cox & Paley, 1997). Disengaged families, in contrast, are characterized by cold, rigid boundaries and are largely unsupportive and emotionally withdrawn (Sturge-Apple et al., 2010). Finally, enmeshed families are characterized being entangled, with children having access to resources at the cost of hostility from another subsystem (Sturge-Apple et al., 2010).

These differing family patterns impact children's development and adjustment, especially as they begin their early years of schooling. Operating from a family systems lens, a study by Sturge-Apple and colleagues (2010) examined how the characterization of children's family system of origin affects their development and participation in school. They followed 234 children beginning in kindergarten through second grade. Viewing and analyzing parenting tasks, play tasks, and clean-up tasks they assessed parent-child and parent-parent relationships at multiple points throughout the duration of the study. Data suggested that family interaction patterns did influence children's adjustment when beginning school, with children from enmeshed families demonstrating greater rates of internalizing symptoms and difficulties with emotional adjustment than their peers from harmonious families. Additionally, children from disengaged families demonstrated increased levels of externalizing systems and difficulties with classroom engagement than their peers from enmeshed and harmonious families.

The quality of family relationships has a strong association with children's adjustment and formation of identity; however, much of the literature on family relationships is from a lens of parent-child relationships and is based on self-report. In the Netherlands, a study by Dekovic and Buist (2005) examined multiple dyads of family relationships to provide insight as to their

effect on children's development. To increase understanding regarding the influence of family on children's development, this study assessed marital relationships, sibling relationships, and parent-child relationships from the perspective of each member of the family. Researchers followed 288 families, consisting of two married parents with two children between the ages of 11 and 16. Quality of relationships was measured using a modified Inventory of Parent and Peer Attachment and each child was asked to complete a self-reported Child Behavior Checklist to assess for problem behaviors. Data indicated that the only relationships whose quality is measured independently of one another are the marital and sibling relationships. The association between children's problem behavior and family relationships was found to be significant for all relationships except mother-father, thus leading to the conclusion that problem behavior increases as the quality of family relationships decreases. The best predictor of adjustment was found to be parent-child relationships and sibling relationships.

Family relationships are more stable and organized during childhood and become increasingly unstable as adolescence sets in and introduces novel dynamics (Parra, Oliva, & Reina, 2015). Despite these changing dynamics, there is suggestion that patterns of interaction and quality of relationships amongst family members are most predictive of the stability of family relationships over time. A study by Parra, Oliva, and Reina (2015) investigated the relationship between gender, conflict, and affection on family relationships. Following ninety participants over ten years, their findings largely indicate that females tended to be more talkative at home than were male participants and that females demonstrated an increase in their frequency of communication during adulthood while males tended to remain the same, if not demonstrating slightly decreased levels. As related to family affection, data indicated that females tended to perceive higher levels of affection from their parents than did males, which

was especially profound during the mid-adolescence period. These changes in communication and affection led to the conclusion that perceived family cohesion does increase throughout adolescence and emerging adulthood, especially when these levels are higher to begin with during mid-adolescence.

Sibling Relationships

There are many factors, both biological and systemic, that contribute to a child's social development. Systemically, social development is influenced not only by a child's parents and siblings but also by their peers, teachers, interaction with media, and culture (Smith & Hart, 2002). It is estimated that about 80 percent of people in the United States grow up with at least one sibling and will spend more time interacting with their siblings than other members of their family (Feinberg, Solmeyer, & McHale, 2012; Gass, Jenkins, & Dunn, 2007). For many children, the parent-child relationship serves as their largest source of support and protection. There is growing evidence, however, that sibling relationships can also serve as a source of support for many children, especially during times of immense stress (Gass, Jenkins, & Dunn, 2007). Thus, Gass and colleagues (2007) investigated the potential of sibling relationships to serve as a protective factor during exposure to stressful life events and the impact these relationships had on children's experiences of behavioral difficulties. Using the Sibling Relationship Inventory, researchers found that children who considered themselves to have affectionate sibling relationships demonstrated lower rates of internalizing behaviors, especially during times of stressful life events. The data and findings suggested that sibling relationships, when perceived to be positive and loving, can serve as a protective factor for many children against maladjustment and behavioral difficulties.

In line with the previous findings, there is growing support that sibling relationships may serve as a protective factor especially during times of increased interparental conflict (Davies & Cummings, 2006). Davies and colleagues (2019) conducted a study in which they examined the quality of sibling relationships and the impact on their experiences with interparental conflicts, emotional insecurity, and psychological problems. Data from 236 families were collected over a four-year time span at three collection points. Each wave of collection asked parents to discuss disagreements and assessed the quality of sibling relationships through interviews from each member of the family. Various checklists and interviews were completed to assess for quality of sibling relationships, emotional attachment, and psychological problems. Data supported the hypothesis that strong sibling relationships served to mediate associations between interparental conflict and psychological problems. Siblings whose relationships were characterized as being warm and close demonstrated lower levels of insecurity and fewer psychological problems. Interestingly, however, sibling relationships that were rated as being of lower quality still provided protective factors during times of conflict, suggesting that having a sibling bond defined as being civil may be protective in nature to counteract interparental conflict. These findings introduce the potential for siblings to serve both as parental figures and peers, providing a protective buffer during times of interparental conflict and mediate concerns about safety and security, and diverting attention to shared activities during times of conflict.

In addition to protective factors during times of conflict and stress, sibling relationships are essential for adjustment in adolescence. Throughout the lifespan, siblings provide support and companionship, and the quality of sibling relationships is predictive of deviance, internalizing and externalizing behaviors, and self-esteem (Fuhrman & Holmbeck, 1995). Literature regarding perceived support based on varying birth order, however, is scarce, thus

providing the rationale for the following study conducted by Branje and colleagues (2004). Including 158 families in their study, each family member participated in a home interview during which they were asked to report on family relationships, personality, and adjustment. Data indicated that younger sibling's perceived support from their older siblings increased between the ages of 11 and 13 years and stabilized after the age of 13 years. Perceived support of older siblings from their younger siblings remained stable throughout the entirety of the study, indicating a difference in birth order and perceived sibling support. Furthermore, higher levels of sibling support were correlated with lower levels of internalizing behaviors and externalizing behaviors but, surprisingly, not for psychological problems. One limitation of this study is the difficulty in generalizing the findings due to the sample being limited to two-parent households and a non-diverse sample.

A study led by Whiteman and colleagues (2015) focused specifically on the correlations between sibling relationship and adjustment in African American families. Following 189 families over a 3-year course, data were collected annually utilizing home interviews with all family members. Sibling positivity and negativity, acceptance, conflict, depressive symptoms, and risk behaviors were assessed at each point of collection. In contrast to previous findings, there was no relationship found between perceived positivity in sibling relationships and adjustment. There was, however, a relationship between perceived negativity and adjustment, with an additional correlation between increased perceived negativity and increased symptoms of depression and participation in risky behaviors.

Sibling relationships are unique in the fact that they span across the lifespan and can vary based on a multitude of factors, such as siblings' gender, birth position, and age difference. Literature suggests that older siblings tend to be more directive in initiating interactions and

assume a greater power dynamic amongst their siblings whereas younger siblings tend to be viewed as the baby of the family (Abramovitch et al., 1986; Furman & Buhrmester, 1985). Many of these power dynamics, however, tend to balance out amongst adult siblings (Cicirelli, 1982). Literature existing on the other two aforementioned factors tends to be limited and findings are contradictory; thus, a study by Riggio (2006) examined the impact of birth order, position within the family, and family size on adult sibling dyad relationships. Each participant was asked to complete the Lifespan Sibling Relationship Scale, which measures attitudes about sibling relationships throughout childhood and adulthood. In total, 1,053 were involved in the study. Their data indicated that family size and birth position impacted adult siblings' perceptions of their relationships. Age difference and adjacency of positions appeared to have the most influential impact on recollection of sibling relationships in childhood. While these results do contribute to the literature as a whole, this study was limited in the following ways. Firstly, sibling dyad reports were obtained from only one member of each dyad, thus excluding the experiences and perceptions from the other half of the dyad. Secondly, participants with multiple siblings were asked to provide a report on only one, specifically the sibling with the greatest impact on their life, increasing the potential for participants to select the relationship they view as being the most positive. Finally, factors in adulthood such as marital status, children, and employment were not included in the assessment of adult sibling relationships.

Parent-Child Relationships

The parent-child relationship is thought to be one of the most important in the formation of attachment, caregiving, and communication behaviors (Main & Cassidy, 1988; Noller, 1995). Furthermore, healthy parent-child dyads have been found to be positively correlated with both physical and mental health (Szkody & McKinney, 2019). Given this, parent-child relationships

are considered to be multi-dimensional. They are constantly changing over time as children continue through stages of develop, perspectives shift, and life situations change (Smith & Hart, 2002).

Interactions with parents affect children's mental, emotional, and behavioral development. Healthy development in these three domains requires a secure attachment and stable foundation, characterized by high emotional responsiveness, positive parenting behaviors, and positive linguistic interactions (Klass & Navsaria, 2021). Healthy parent-child relationships are also associated with adolescent's views of their self-worth, with higher levels of self-worth correlated with relationships characterized as being close, affectionate, and positive (Birkeland et al., 2012). Many of these studies, however, have been difficult to replicate due to cofounding variables such as genetic factors, environmental and social effects, and varying patterns of interaction amongst parents with multiple children (McAdams et al., 2017). Twins provide an interesting area of study due to their genetic overlap and shared environments. On this basis, McAdams and colleagues (2017) utilized both monozygotic and dizygotic pairs of adolescent twins to examine the effect of parent-child relationships on adolescent's self-esteem. Each dyad provided a self-report on perceived closeness, expressions of affection, and adolescent self-worth. Interestingly, data demonstrated no overlap between parent-child relationships, adolescent's report of self-worth, and genetic variables. There was, however, an association between close, affectionate parent-child relationships and adolescent reports of self-worth. Adolescents with closer parent-child relationships were better able to form healthy bonds and relationships with others.

Even as children begin to enter emerging adulthood, parents continue to play an important role in their wellbeing and support (McKinney et al., 2018). There is evidence that

adjustment is correlated with children's interactions with parents as they grow and develop (An & Cooney, 2006). A study by An and Cooney (2006) examined the relationship between parenting experiences and well-being in later adulthood. Including 4242 adult participants in their sample, each was asked to recall and describe their relationship with their parents as they were growing up and at the present moment, to rate their relationship with each of their parents, and describe any behaviors by their parents that displayed affection and trust. Upon analysis, data demonstrated that well-being and mental health in adulthood were significantly correlated with positive parent-child interactions in childhood. Adults who had positive relationships with their parents throughout childhood were better able to provide favorable experiences and form healthy relationships with their own children.

The positive effects of parent-child relationships can progress through adulthood. Existing literature suggests that the parent-child relationship can impact children's levels of internalizing and externalizing behaviors just as parents' externalizing and internalizing behaviors can have an impact on the parent-child relationship. Additionally, some literature has found an effect of gender on both parent-child relationship quality and adjustment, though these results are largely inconsistent (Ohannessian et al., 2005). Franz and McKinney (2018) examined the association between the parent-child relationship on both party's externalizing and internalizing behaviors and the level of moderation gender had on this association. Data indicated that, in the context of mothers and sons, higher rates of internalizing problems were correlated with a stronger parent-child relationship. Additionally, variance between the quality of parent-child relationships was largely correlated with parental levels of internalizing and externalizing behaviors. Finally, researchers found significant differences between gender perceptions of the parent-child relationship and levels of psychopathology.

Parent-child relationships are important for the wellbeing of children; however, they are equally as important for preserving the psychological wellbeing of parents. Studies in this domain, however, appear to be scarce with existing literature focusing on the presence of minor children and negating the lasting impacts into adulthood. Using a life-course approach and following participants over an elongated time span, Reczek and Zhang (2015) investigated how the parent-child relationship can impact parental psychological wellbeing as their children enter into adulthood. Following approximately two thousand parent-child dyads over the span of fifteen years, the research team measured psychological distress, perceived support and strain from children, and parental dissatisfaction. Data indicated that parent-child relationships are essential to parents' wellbeing, especially as their children begin to age and enter into adulthood.

Theoretical Framework

A core belief of systems theory is that a family is influenced by more factors than solely its individual members and that the reality of each person differs from individual to individual (Bornstein & Sawyer, 2006). The following, adapted from work by Bornstein and Sawyer (2006), outline the principal characteristics of a family system.

1. A family system includes the immediate family as well as subsystems consisting of individuals and their relationships with others. Because of these interlocking systems, the cause of behavior cannot be narrowed down to one individual or system. Thus, each system is thought of as being "greater than the sum of its parts" (Bornstein & Sawyer, 2006, p. 382).
2. Interactions within systems are circular and multidirectional. A change in one subsystem results in a change in another and so on.

3. All subsystems are organized in a hierarchical structure. These structures are defined by power dynamics and boundaries. A prime example of this is illustrated through the parent-child dyad. Viewing the parent as being in higher power, they become responsible for interactions with the child that aide in their development and raise their level of competence.
4. Family systems can adapt and reorganize when faced with new circumstances and situations. As each member within the family reacts and responds to change, the system strives to reach a state of homeostasis. As this process occurs, new structures and patterns emerge, consequently affecting each individual and dyad within the overall family system. This process is ongoing and as families move amongst developmental stages, the state of homeostasis is disrupted and redefined.

At its core, a family system is composed of individuals. To understand individual processes requires understanding individual characteristics, which are shaped by their dyadic subsystems. As previously stated, these subsystems are bidirectional; each part influences the other. Examples of these dyadic subsystems include parent-child relationships, sibling relationships, and the couple relationship. These dyads are interdependent, with the quality of relationship in one dyad subsequently affecting the quality of the relationship in another. Another influencing factor in quality of relationships is sibling position, referring to specific patterns of behavior and relationships as based on birth order (Bowen, 1978). Oldest children were identified as assuming leadership positions within their family while middle children were thought to be more adaptive and have better social skills (Toman, 1961). These patterns, however, are not equal and can be altered in response to family stress level (Bowen, 1978).

As applied to the present study, systems theory serves as a means to investigate the impact of a childhood complex congenital heart defect on numerous family subsystems. The subsystems of focus in this research include the family as a whole, the parent-child dyad, and the sibling dyad as well as broader, interconnected systems. These systems include schools, neighborhoods, and the family's community at large. To capture these systems in interview questions, participants will be asked about their view of their family, their perceptions of family relationships, support they feel from outside systems, and how the functioning of these systems change when their sibling is staying in the hospital or receiving surgery. Siblings and other family members play a crucial and systemic role in the lives of children with a chronic illness. Given the disruptive nature a chronic illness can have on the family system, specifically the well-siblings, the purpose of this study is to examine the lived experiences of well-children living with a sibling who has been diagnosed with a complex congenital heart defect.

CHAPTER 3: METHODOLOGY

This chapter will provide an overview of the design plan that was followed, participants, instruments, data collection procedures, data management, and data analysis for the present study. This study has been approved by East Carolina University's Institutional Review Board (IRB). The IRB approval letter is located in Appendix A.

Design

This study implemented a qualitative phenomenological design using semi-structured, in-depth interviews. Qualitative research is used when a researcher wants to make sense of experiences in participants' natural settings through the individual meanings brought by each participant (Creswell & Poth, 2018). Primarily using interviews, phenomenological research is a way by which qualitative research is conducted. Phenomenological research offers participants the opportunity to report on their experiences with the objective of determining what it is like to live in their world and through their personal experiences (Smith et al., 2009; Creswell & Poth, 2018). Because siblings of individuals with complex illnesses in general have been frequently overlooked in the literature, a phenomenological study is the best fit to allow this population the opportunity to document their lived experiences. By utilizing interviews, the researcher will be able to explore lived experiences, emotions, reactions, and feelings of children living with a sibling with a complex congenital heart defect.

Participants

This study's target population was children ages twelve through seventeen years with a sibling diagnosed with a complex congenital heart defect. To be eligible, children were required to speak English, fall between the age range of 12 through 17 years, and have a sibling diagnosed with a complex congenital heart defect. Because camp contacts were utilized to recruit potential

participants, children were also required to have a sibling who currently or previously attended either Camp Braveheart or Camp WholeHeart. These camps are held in facilities in Rutledge, Georgia and Arapahoe, North Carolina, respectively. Camp Braveheart is organized through Children's Healthcare of Atlanta. Camp WholeHeart is organized and implemented through collaboration of ECU's Human Development and Family Science and Pediatric Cardiology Departments. Although the type of heart defect does not determine sibling participation in the study, children are required to have a complex heart defect to be eligible to attend camp.

Recruitment

Qualified participants were recruited from both Camp Braveheart and Camp WholeHeart contacts. Contacts for both camps, including present and past campers dating back to the year 2017, were contacted by each camp's respective representative (Appendix G and Appendix H). The parents of campers from Camp Braveheart received an email recruitment flier for the study and parents of camp WholeHeart were mailed the study information. A follow-up email was sent to parents of potential participants after two weeks. The email included the purpose of the study, eligibility requirements, a flier for the study, and contact information for the PI and thesis advisor. Interested participants' parents were instructed to contact the PI or thesis advisor via email to confirm their interest in the study and provide phone contact information. The parents of interested participants were then contacted via phone by the PI from a phone number associated with ECU. During this phone call, parents were encouraged to ask any questions they had about allowing their children to participate in the study. The script for this conversation is in Appendix J. After all questions had been answered and parents confirmed they were interested in their child participating, the PI asked for a mailing address to send a study packet. The study packet included the consent and assent forms, demographic questionnaire, health literacy questionnaire,

mental health screeners, and a pre-paid postage envelope. The PI allowed the participant and their parents to complete these either over the phone or by mailing them back. The PI also obtained verbal consent to contact the parent by email to set up a date and time for an initial interview.

This process continued until interviews were scheduled and completed, scheduling on a first come, first serve basis. In cases of participants not attending their scheduled interview, the PI reached out to the participant's parent via phone to attempt to make contact. If no contact was made after two attempts, an email was sent to the parent to reschedule. After the interviews had been completed, parents of participants were mailed a $10 Target gift card to give to their child as a token of appreciation for their time. Parents were also emailed a debriefing letter (Appendix P), which included a statement of appreciation for the time dedicated to this study, information about feelings their child may experience after completing the interview, and information about how to seek additional resources for their well-children.

Six well-siblings participated in this study. Data were collected until saturation was reached. Interviews were scheduled on a first come, first serve basis and all participants were asked to schedule a follow-up interview, during which they were asked questions from the interview schedule that were not initially asked, asked to elaborate on information provided in their initial interview, and to further member checking. While member checking was ongoing during the first interview to clarify and confirm the intent of each participant's expressed information, the follow up interviews also were used as ongoing member checking. These interviews were shorter in length, lasting approximately 15 to 30 minutes. One participant completed a third interview, which lasted approximately 10 minutes.

All participants were from Camp Braveheart families. Efforts were made to recruit children from Camp WholeHeart families. Whereas 229 Camp Braveheart families were contacted, only about 16 Camp WholeHeart families were eligible for this study, and study packets were mailed to all of them. Two of these mailed packets were returned as undeliverable by the post office. Two families expressed interest, but the well-siblings were older and did not meet the age eligibility criteria. One other parent expressed initial interest but did not follow through even after PI reached back out two more times. Camp WholeHeart is a relatively newer camp than Camp Braveheart and thus has fewer contacts. Additionally, camp was not held in person for the past two years due to the COVID-19 pandemic, so newer campers were not recruited. As such the organizers do not know how many siblings would have been eligible.

Instruments

Semi-structured, in-depth interviews, a demographic questionnaire, a health literacy questionnaire, and two mental health screeners were used for data collection. The researcher used a demographic questionnaire (Appendix K) and pre-selected interview questions (Appendix O). The demographic questionnaire consisted of approximately 23 questions regarding the participant, their family, and their sibling with a complex congenital heart defect. The interview consisted of eight research sub-questions and 39 follow-up questions and probing questions to be used as needed. Questions were altered, added, or omitted depending on participant responses. The interview questions focused on general experiences of well-siblings within their families and community as well as their perceived level of social support and inclusion in support groups. The health literacy questionnaire (Appendix L) consisted of eight questions intending to gauge each participant's understanding of their sibling's heart defect. Finally, the mental health screeners (Appendix M and Appendix N) asked each participant to complete Patient Health Questionnaire-

8 (PHQ-8) and Generalized Anxiety Disorder-7 (GAD-7). These are intended to measure the severity of participant's symptoms of depression and anxiety.

Qualitative interviews obtain information from each participant's individual point of view with the aim of better understanding their lived experience (Roberts, 2020). To best accomplish this, interview questions should be open-ended and provide a means towards further dialogue and understanding. Qualitative interviewing commonly utilizes questions beginning with "how" or "what" to elicit thoughtful, detailed responses from participants. Interview questions frequently focus on specific events or experiences and their meanings (Roberts, 2020). The present study developed interview questions based on family systems theory and current gaps in the literature. Some questions were adapted from a previous study by Menke (1987) which were validated through critiques by three experts in the field of care for chronic illness. Content validation is the process through which the instrument tool is evaluated to determine if it appropriately and meaningfully reflects the perspectives of the population of interest (Brod et al., 2009). The demographic questionnaire was pilot tested by the parent of an individual with a complex congenital heart defect and questions about the evolution of conversations surrounding the complex congenital heart defect over time were added. The health literacy survey and interview tool for the present study were pilot tested by an adult well-sibling who grew up with a with a sibling with a complex congenital heart defect. Questions were added to the health literacy survey based on this pilot feedback about the current level of knowledge about their sibling's complex congenital heart defect and included an open- ended question that explored if there is more information that the well-siblings would wish they knew. The questions in the interview tool regarding experiences within systems outside of the immediate family were restructured to

be more open-ended and create space for participants to discuss the positive as well as negative impacts of their experiences.

Data Collection

Interviews were scheduled on a first come, first serve basis. Participants' parents were sent an email approximately 24 to 48 hours before their child's scheduled interview to both confirm their time and serve as a reminder. All interviews were conducted over WebEx with the PI located in East Carolina University's Family Therapy Clinic and utilized WebEx to record. Initial interviews lasted between 20 minutes to 60 minutes and follow-up interviews approximately 15 minutes to 30 minutes. Signed consent forms from a parent and signed assent form from the participants were obtained before conducting the interviews.

Data Monitoring and Management

All interviews were coded in the order in which they were completed, with the letter representing the state in which the camp the participant's sibling attended. Therefore, interviews conducted from Camp Braveheart siblings were coded as G1, G2, and so on. Thematic data saturation was marked as the point in which new data does not significantly contribute to the already emerging themes and explanations (Creswell & Poth, 2018). As interviews were being conducted, they were simultaneously being transcribed and analyzed. To ensure data and transcription accuracy, each interview recording was listened to at least two times. The initial transcriptions were completed automatically by WebEx and listened to at least two times by a member of the research team and the PI to ensure accuracy of the transcriptions. An additional research team member listened to selected portions of the remaining interviews to ensure transcription and analysis accuracy.

Data were stored to the researcher's Pirate Drive, which is secured through the university. To ensure confidentiality of all participants, data were accessed only by the researcher. Additionally, the length of time data will be stored will be per university guidelines.

Data Analysis

After each interview had been listened to and transcribed, the data were analyzed by the PI and the thesis advisor. Data analysis involved organizing the data, condensing it into meaningful themes, and representing these themes through figures or discussion (van Manen, 1984). Each interview was reviewed and analyzed by the PI. Interviews were listened to at least two times each to ensure that the PI understood the data as a whole before breaking it into parts (Creswell & Poth, 2018). After each interview had been listened to multiple times, the PI then read each while making notes in the margins of the page. These notes, also known as memos, highlighted short phrases, ideas, or key components that stood out (Creswell & Poth, 2018). Once this process had been completed, data analysis began using the van Manen approach (van Manen, 1984). Themes were pulled from the interview that were descriptive of the overarching experience of the study (Creswell & Poth, 2018). During analysis, the PI highlighted and made note of words, phrases, and sentences found within each interview to find commonalities, linkages, or differences amongst the data. The thesis advisor independently read all the interview transcripts at least two times and followed the similar process of coding and identifying themes. Both researchers met to discuss their findings and identify commonalities (Cypress, 2017). During discussion, the PI and the PI's thesis advisor analyzed themes until a consensus had been reached regarding themes and subthemes. The PI then reflected on these to conclude the themes that emerged from the data. The initial list of fifteen themes were then consolidated into three themes and ten subthemes and interviews were coded to reflect these. To ensure the

confidentiality of the transcriptions as well as the participants, the PI and the PI's thesis advisor met in a research office on campus for transcriptions and discussion.

Considering this study was a qualitative phenomenological study, it was important to adhere to the rigor. This was done in four ways: credibility, transferability, dependability, and confirmability (Cypress, 2017). To ensure credibility, different means of data collection were utilized, including interviews and questionnaires. Analysis consisted of another member of the research team to review and confirm findings. Transferability was attuned to by recognizing homogeneity amongst participants in aspects such as birth order, socioeconomic status, proximity to a major hospital, and ethnicity. To ensure dependability, a member of the study team not involved with data collection was included in the process of data analysis and results confirmation. Finally, to adhere to confirmability, the PI underwent the bracketing process to exclude personal experiences of being a well-sibling of an individual with a CHD and to remain neutral to meanings identified by participants. The PI made every effort to listen authentically to the lived experiences as expressed by the participants by undergoing the bracketing process. During this, the PI reflected on her experiences and perceptions of growing up with a sibling living with a CHD as well as the potential influences of her training in a Masters level therapy program. This bracketing statement is located in Appendix B.

CHAPTER 4: RESULTS

This study aimed to understand the daily lives of siblings of individuals with complex congenital heart defects and to gain awareness of their experiences with family members and other members of their systems. In-depth, semi-structured interviews were completed to understand the lived experiences of these well-siblings, how these experiences changed when their sibling is in the hospital or at camp, the impact of members of larger systems, and their perception of interpersonal relationships. A health literacy questionnaire was completed by each participant to better understand their knowledge regarding their sibling's heart diagnosis and how this level of knowledge impacted their experience when having conversations about the diagnosis with others. Additionally, each participant completed two standardized mental health screeners, the GAD-7 and PHQ-8, to measure for symptoms of anxiety and depression. This study included six participants who each completed between one and three interviews. Interviews were conducted until data saturation was reached.

Demographic Characteristics

All six of the participants were white, between the ages of 12 years and 17 years, and younger than their sibling with a CHD (n = 6). One participant reported she was partially Asian Pacific Islander. Two participants identified as male and four identified as female. Table 1 includes all reported demographic information and characteristics of the participants. Table 2 includes reported information about each participant's mental health, obtained from self-reports on the GAD-7 and PHQ-8, involvement with outside support, and experience speaking with care professionals.

The parents of participants reported demographic information about themselves, which is reported in Table 2. The identified genders of parents living in the home were male and female.

Table 1

Demographic Characteristics of Well-Sibling Participants and their Sibling Living with a CHD

	Age (years)	Participant Gender	CHD Sibling Age (years)	CHD Sibling Gender	CHD Diagnosis	Other Health Diagnoses	# Of Heart Related Surgeries	Most Recent Heart Surgery
G1	14	Female	16	Female	Subaortic Membrane	Yes	2	May 2020
G2	14	Male	18	Male	Truncus Arteriosus; Interrupted Aortic Arch; Ventricular Septal Defect	Yes	2	June 2009
G3	14	Female	21	Male	Partial Anomalous Pulmonary Venous Return	Yes	1	January 2007
G4	12	Male	15	Male	Coarctation of Aorta; Bicuspid Valve; Aortic Stenosis; Aortic Insufficiency	Yes	3	Not Reported
G5	17	Female	18	Female	Dilated Cardiomyopathy; Heart Transplant Recipient	Yes	1	April 2010
G6	16	Female	18	Female	Not Reported	Yes	Not Reported	Not Reported

Note: Responses regarding other health diagnoses reported in the demographic survey are provided in-text.

Table 2

Demographic Characteristics of Parents of Well-Siblings of Individuals with a CHD

	Age (years)	Gender	Education	Marital Status	Occupation	Household Income (USD)
G1	56	Male	Bachelors	Married	Computer and Mathematical Operations	>149,999
G1	57	Female	Doctorate	Married	Other; Not Specified	
G2	46	Male	Bachelors	Married	Other; Not Specified	Not Reported
G2	52	Female	Bachelors	Married	Homemaker; Unemployed	
G3	51	Male	Bachelors	Married	Other; Not Specified	Not Reported
G3	53	Female	Doctorate	Married	Other; Not Specified	
G4	39	Male	Masters	Married	Management	100,000-
G4	40	Female	Bachelors	Married	Education	149,999
G5	47	Female	Masters	Divorced	Education	50,000-74,999
G6	52	Female	Not Reported	Married	Business Owner	Not Reported

Note: Responses to questions regarding conversations about the child's heart defect are provided in-text.

All parents except one were white and all had received college education. One parent identified as Asian Pacific Islander. The parents ranged in age from 40 years to 57 years old.

Finally, demographic characteristics were reported for the individual living with a CHD and are reported in Table 1. The six children ranged in age from 15 years to 18 years. All were white and identified genders were male and female.

All parents reported their child with CHD had additional health diagnoses. The specifies of these diagnoses, however, varied for each family. Parents of G1 reported their child had additionally been diagnosed with cancer, kidney failure, and neurogenic bladder and colon dysfunction. Parents of G2 reported their son had been diagnosed with hypothyroidism, a growth hormone deficiency, Tourette's, attention deficit hyperactivity disorder, and obsessive-compulsive disorder. Parents of G3 reported congenital scoliosis. Parents of G4 reported their son had been diagnosed with asthma, allergies, and an essential tremor. Parents of G5 reported their daughter had been diagnosed with stage III kidney disease, eosinophilic esophagitis, rumination syndrome, anxiety, and depression.

As part of the demographic questionnaire, parents reported on their experiences having conversations with their well-children about their child's heart diagnosis. All parents reported having engaged in such with their well-children at least one time. Two of the families reported no problems with these conversations, one reported that the well-children were initially concerned but also reacted positively, and one family reported mixed responses and some discomfort from the well-child. All parents stated that the conversations regarding their child's heart diagnosis have become more in-depth, especially during times of hospitalization, and included more information as the well-children have gotten older. The parents of G4 reported that these conversations have prompted their well-children to ask about the health of their own

hearts. During times of hospitalization, three of the participants were reported to have visited their sibling in the hospital while three were reported to have never visited. When reporting on visits with a child life specialist, parents of two well-siblings reported having spoken with one at some point and four reported never speaking with one. In interviews, however, all well-siblings reported never having spoken with a child life specialist.

Participants completed a health literacy questionnaire to gauge their understanding of their sibling's heart diagnosis. Three of the participants reported not knowing the name of their sibling's heart diagnosis and one participant was unable to provide a description of her sibling's heart defect. All participants reported initial and ongoing conversations about their sibling's heart diagnosis happening with their parents. G3 and G5 reported feeling comfortable talking with their friends about their sibling's heart diagnosis while the remainder of the participants reported they did not feel comfortable talking to anybody outside of the family. G3 was the only participant to report not having adequate information regarding her sibling's diagnosis, reporting she would like to know the name of it.

Finally, participants completed two standardized mental health screeners, the GAD-7 and PHQ-8. The GAD-7 measures for symptoms of anxiety while the PHQ-8 measures for symptoms of depression. These screeners were scored by the PI and scores were determined to be either minimal, mild, moderate, or severe as determined by preset cutoff ranges. Related to the GAD-7, one participant was found to have mild symptoms of anxiety and one participant scored within the minimal range. Three participants were found to have moderate levels of anxiety. Two participants scored within the minimal range for levels of depression while the scores of three were reflective of moderate ranges.

Qualitative Analysis

All qualitative interview data were transcribed by the PI and another member of the research team. Data were reviewed and coded by the PI and the PI's thesis advisor to acquire themes. A total of three overlapping themes and ten subthemes emerged from the data. These themes and subthemes are reported in more depth in Table 3. The first theme is the viewpoint of daily life and includes the following sub-themes: normalcy, changes to the normal routine, and family dynamics.

Table 3

Themes of Experiences of Well-Siblings of Individuals Living with a Complex Congenital Heart Defect

Theme	Subtheme	Supporting Quotes
Viewpoint of Daily Life in the Family	Normalcy Routine Hobbies Medications Changes to Normalcy Hospitalization Camp COVID-19 Pandemic Family Dynamics	**Normalcy** "It's not normal to [my friends], but it's just what it is." -G2 "It's something I've known, but it's not something that's extremely affected my life." -G3 **Changes to Normalcy** "COVID worried me because it affects the heart and lungs… I was afraid that anyone could get it and especially him." -G3 "Sometimes it feels not normal when he's not home for a week all the time. But whenever he comes back, I feel better." -G4 "Sometimes it feels less stressful at home… it's kind of like a breather." -G6 **Family Dynamics** "It's kind of expected to keep her happy… She [sister] gets special treatment because she is different. My parents pay more attention to her… I feel like they think I have to measure up more… like they expect me to be better." -G1 "We get mad at each other sometimes, but I guess it's just brotherly love." -G2 "It just feels like I'm hurting his feelings just because I was trying to do something

		that I wanted to do, knowing he [brother] can't do it." -G4 "I was kind of thrown to the side cause she was getting a heart transplant, and I understand that now, but when I was little, I was jealous of her… In that moment, it felt that I was jealous of my sister that got a heart transplant." -G5
Understanding of Heart Diagnosis	Health Literacy Fears about the Heart Diagnosis Advice for Other Children	**Health Literacy** "It was mostly just kind of curiosity on why does he have scars on his stomach and back." -G3 "Over the years, I've looked back at scrapbooks and my mom's definitely talked to me and had many conversations with me about [my sister's] surgeries." -G5 **Fears about the Heart Diagnosis** "It makes me nervous because some stuff could go wrong and did go wrong." -G1 "[I get worried] that she won't live that long." -G6 **Advice for Other Children** "Be good. Talk to your sibling, and make sure that they feel safe, and you can just get through it all whenever a challenge comes by." -G2 "Don't try to make him or her feel different than anybody else." -G1
Well-Child's Support Champions	Family and Extended Family Friends Professionals Support Groups	**Family** "My mom's more of my best friend." -G6 "It's my family and I love them, but it's also a complicated kind of space." -G5 **Friends** "I love going to school because I can have friends that we don't share, and they don't know who she is… I can talk about other stuff than my sister." -G1 **Support Groups** "There are little events that happen. I can learn things about how to help my brother. There are a lot of activities I can do that I wouldn't normally be able to if that [brother's heart diagnosis] didn't happen." -G4

Viewpoint of Daily Life in the Family

Participants were asked about their daily life within their family, how it compared to that of their friends, and various relationships they have with family and friends. They reported feeling a sense of normalcy about their sibling's heart diagnosis and their experiences during changes to their daily routine. Participants also discussed relationships with their immediate family, extended family, and their friends.

Normalcy

Daily Routine. All six participants were younger than their sibling living with a CHD. Of the six, five reported feeling a sense of normalcy and not knowing anything different. G1 shared that her life has been "normal but I don't know anything else." Regarding her experiences, G3 shared:

> It didn't really affect my life particularly because…I wasn't born yet when my brother's heart was being fixed. It's something I've known but it's not something that's extremely affected my life. You grow up with someone who has to take meds, you're gonna remember that they take their meds, but that's normal. Normal shifts. The meds being out [on the counter] has just always been a normal part. Everyone's baseline is different.

G4 explained that his brother's heart diagnosis did not affect his life, sharing that "it feels normal to me because that's just how it has always been." G5 echoed the same sentiment, explaining "it's kind of always been that way my entire life because she was diagnosed when she was an infant, pretty much, so I was kind of born into it." One participant, G2, shared that he tries not to compare his life to others' and tries to maintain a sense of normalcy with his brother, explaining:

> It's pretty normal. I try not to think of it anything different. And not trying to treat him [brother] anything differently. It's just not normal to them [friends] but it's just what it is.

Hobbies. Within their sense of normalcy and daily routine, participants discussed their participation in various hobbies and extracurricular activities. All six participants reported activities they enjoy participating in outside of the house, both with friends and with other family members. G1 shared that she goes roller skating with her friends, is a member of the soccer team, and enjoys going to soccer games with her dad. G2 is a member of the baseball team and enjoys spending time outside with his friends and brother, playing with his dog, and playing video games. G3 enjoys drawing and fencing. G4 is a member of the tennis team and enjoys spending time outside with his friends and siblings. G5 is a member of the swim team, art club, and beta club. G6 enjoys shopping and is a member of her school's color guard.

Regarding activities changing or not being able to participate in activities that their peers can, only one participant reported that he has consistently been involved with the same activities. Four participants reported changes in activities but attributed these changes to factors outside of their sibling living with a CHD. Commonly reported reasons were age-related, moving houses, and a loss of interest. One participant reported that, although the activities have changed because of his brother's heart condition, these changes have been positive, explaining:

> There's a lot of fun things I'm able to do because of my brother being like this. There are a lot of activities I can do that I wouldn't normally be able to if that didn't happen.

Four participants reported that they are unable to participate in activities that their friends can, with three providing reasons directly related to their sibling living with a CHD. G1 elaborated:

> They [friends] have more freedom. They can do more stuff, like maybe go out with friends, whereas for me if my sister can't do something then the whole family can't do it.

G2 explained the impact of the COVID-19 pandemic, stating he was unable to participate in activities during the pandemic due to his brother's health conditions and wanting to keep him

safe. G4 expressed some guilt related to being able to participate in activities that his brother cannot, stating:

> Sometimes there are things I want to do that my brother also wants to do them and can't. And it makes me feel a little guilty to just do it without him. It just feels like I'm hurting his feelings just because I was trying to do something that I wanted to do, knowing he can't do it.

Medications. Two participants identified medications as being cornerstones in their daily experiences. One participant identified her family as a "medical family" due to the daily medications that she and her sister both take. G3 elaborated on her experiences, stating:

> We all have meds that we're supposed to take… He had more meds, I guess. Things that I notice are when you go to other people's houses and see how they function… Whenever they have those videos where they're like 'don't keep your meds in a place that children could reach' and I have distinct memories of all of us… before we go to school, we take our meds. And so, our meds are rather…in a very easy place for easy access cause we'd rather not have to fight the door to get those meds.

G5 compared her experiences to that of her perceived sense of normal, sharing that she believes if her sister did not have a heart defect, "there's not as many hospital visits [and] there's not as much med stuff."

Changes to Normal

Participants discussed three events that shift their daily routine: times of hospitalization, their sibling going to camp, and their experiences during the COVID-19 pandemic.

Hospitalization. Five participants reported adjustments to their daily routines when their sibling is staying in the hospital. For each these changes centered around their parents being

present at the hospital and having others provide care. G5 explained the changes to her routine that occurred while her sister was receiving a heart transplant, highlighting the response of her grandparents and community in providing care:

> We had a routine of my mom would stay with her [sister] through every other day… and my dad would stay with her when my mom wasn't there. My grandparents would watch me a lot of the time and I would have to stay at preschool for more than I probably should.

With his brother's recent surgery, G3 explained the changes that occurred to his daily routine, sharing:

> I wasn't able to go hang out with my friends much, so I didn't bring a sickness or germs to him. I wasn't able to do much things, and I had to stay home from school for a little bit. I stayed with my friends.

Two participants highlighted an increase in their responsibility while their sibling was staying in the hospital. G5 explained:

> I had to go to the bus. Usually, my mom drives me to school, but she stayed overnight at the hospital, so I had to wake myself up, take the dogs out, and all that stuff.

G6 shared her experience, stating:

> It's lonely cause I'll normally be home alone half of the time because my parents will be with her so…that's normally what it's like. And worried a little bit.

Camp. All participants reported that their sibling attended a five-day residential summer camp in Georgia for children living with CHD. Three participants described this time as being a break and having the opportunity to engage in activities they would not otherwise be able to. G1 explained that she "personally liked it, just having her away for a little bit. I got to get out of the

house more and do things that she wouldn't be able to do." G2 shared that he was able to choose the restaurants to go to while his brother was away and go places that he knew his brother did not like. G6 shared the following about her experience having her sister away at camp:

> [It was] kind of relieving. Sometimes it feels less stressful at home cause there's not as much of me getting yelled at by her for little things, and stuff like that. So, it's kind of like a breather.

While she was typically away at the same time as her sister, G5 described time when her sister was away as being peaceful due to getting a break from listening to arguments between her mother and sister.

Three participants reported feeling lonely while their sibling was away. Reflecting on her experiences while her brother was at camp, G3 shared knowing "that he wasn't there, and it was kind of lonely." G4 reported feeling a disruption to his sense of normalcy, stating "sometimes it feels not normal when he's not home for a week all the time. But whenever he comes back, I feel better. I don't like it when he's away, but I still have fun." G2 explained:

> I like it when he's gone sometimes, but at the end I kind of miss him. It's quiet. There's nothing really weird about it. But it gets kind of boring when you want to do something like outside or something and there's no one there.

One participant described her experience as being like any other summer camp. She shared:

> Every so often, he'd go to Camp, and we'd go pick him up, but that's really similar to any other camp, like sleepaway camp, that I can remember when we'd go to pick up a

> sibling from. To me, as a kid, it just felt like we're dropping my brother off at summer camp. It didn't feel like anything distinct. It's like the same as dropping my sister off to another camp, or just didn't seem like anything to me when I was younger.

COVID-19 Pandemic. Three participants shared their experiences during the COVID-19 pandemic, which were characterized by an increase in worry about their sibling's health and an increased feeling of protectiveness. Regarding his experience, G2 shared:

> With the whole pandemic, when everything started and we were very, very cautious… Everyone was super, super respectful and understood why we were isolating more. It was pretty hard at first, but I got used to it and just took it as a challenge. At one point it was bad, and we couldn't go somewhere… like all our friends would go somewhere and I couldn't because we had to stay back for him. But it was better for that than risking something.

G3 shared a similar experience in worrying about her brother's health during the pandemic.

> COVID worried me because it affects the heart and lungs… At the beginning of the pandemic, I was more worried because of him having asthma and stuff, but it was mostly also, because it was a worldwide pandemic. I was afraid that anyone could get it and especially him. He has his heart condition… His lungs and his heart aren't as strong as everyone else in my family, so if he caught it, he'd be more likely to die from it.

G5 shared that "we [she and her family] went a little stir crazy because we were cooped up for three months. But we [she and her sister] went back to school in-person in September and were able to resume our activities once we received information from [her sister's doctor] that heart transplant recipients weren't as severely affected by COVID."

Family Dynamics

Participants reported on their relationships with their parents and siblings, perceptions about their sibling's relationship with parents, and feelings they have towards their sibling. Three participants reported differences in their relationships with their mothers compared to that with their fathers. Of these three, two felt closer with their mothers and one felt closer with their father. G1 explained:

> I'm closer to my mom than my dad because my dad works more… I was homeschooled until middle school…and my mom homeschooled me, so I'm pretty close to my mom. But I'm quite close to both my parents.

G5 shared differences in the parenting styles of her mom and dad, reporting:

> It's different with my mom than my dad…. With my dad, he's more easy-going…We joke around more than with my mom. She's more the strict parent.

Regarding her relationships with each of her parents, G6 shared:

> [I don't see differences] with my mom but with my dad, definitely. My sister probably definitely has a better relationship with my dad than my mom. And then it's the opposite for me. So, it's like we each have a parent.

Three participants reported differences in the way their parents treated them in comparison to their sibling living with a CHD. G1 elaborated:

> She gets special treatment because she is different. My parents pay more attention to her. I like having more trust put on me, but sometimes I have to do more chores than she does. I feel like they think I have to measure up more…like they expect me to be better. I don't think they expect her to do as much.

G5 shared:

> My mom and my sister, they have kind of an interesting relationship because they… fight

> all the time and it's just… I always used to just go upstairs, just to get away from all of it… If you ask my sister, apparently, I'm the favorite cause I'm the younger sibling. I don't think that's it but…I'm just more nice to my parents than my sister. I have a better relationship with my parents than she does. She just likes attention, no matter what kind of attention. She always likes to be in the center of everything.

Explaining her relationship with her dad in comparison to her mom, G6 explained:

> He lets things go more with her [sister] than he does with me. She misses a lot of school for doctors or just not feeling good. And I'm not allowed to cause my dad yells at me if I do. I kind of just am forced to go even if I'm not feeling good… I get yelled at a lot for little things by my dad and sister. She's kind of like my dad with me. She'll yell for nothing. Sometimes I have both of them chewing at my neck and it gets frustrating.

Three participants described their sibling living with a CHD as being angry or mean and reported underlying feelings of anger and resentment towards their sibling. G1 explained:

> We're [G1 and sister] close but it's usually off and on sometimes…. She gets annoying. Like, very annoying…And then sometimes she blames me for stuff, like gets mad at me when I'm not really doing anything. So, I mean, we're close most of the time, but when she gets mad it gets annoying…I also get mad at her but… I bury it because the responsibility is I can't show that, or I'll get in more trouble than she will. It's kind of expected to keep her happy.

G5 shared that her relationship with her sister fluctuates, explaining that "it depends on the day. If she [sister] wants something she'll be nice, but if she doesn't, she can be mean." G6 shared that "most people don't like my sister [because] she can get angry a lot."

Three participants shared feeling close to their sibling living with a CHD and enjoying spending time together. G2 shared:

> We [G2 and brother] always work together. We get mad at each other sometimes, but I guess it's just brotherly love.

G3 explained that both her siblings are currently away at college, but "when they are home, I think we have a pretty good relationship." G4 described his relationship with his siblings as "good cause I hang out with them often. It's fun."

One participant shared feelings of jealousy towards her sister, especially during times of hospitalization and because of differences in treatment from members of larger systems, explaining:

> I was kind of thrown to the side cause she was getting a heart transplant, and I understand that now, but when I was little, I was jealous of her…I always wondered why don't I get presents every day and stuff like that. She had a whole basketball game… The whole school was there, pretty much the entire town… Then I'm just kind of sitting there like 'okay, so now what do I do?' I felt very much to the side. I didn't feel like… I just knew I was her little sister, but I was kind of in the dark. Over the years, it's gotten a lot better but, in that moment, it felt that I was jealous of my sister that got a heart transplant.

Despite being younger than their sibling living with a CHD, three participants reported feelings and experiences congruent with that of an older sibling. G1 shared differences in responsibility, explaining:

> Even though I'm younger, I think I have more responsibilities in my family. I just feel like they treat me like more of an older sister than a younger sister, so there's more

> responsibility put on me. I like having more trust put on me but sometimes I have to do more chores than she does.

G3 shared some age-related differences in parental treatment towards her and her brother, explaining:

> There might have been more things he was expected to do, though that might have been just because he's older than me and, as I get older, it's like the same age thing.

G4 also attributed some differences to age, explaining that "one of the reasons they treat us differently is cause we have different ages, so we both have different things we take an interest in." He then elaborated on feelings of guilt and protectiveness over his brother when he can participate in activities that his brother cannot, sharing:

> I'm always supposed to look out for my siblings…Sometimes there are things I want to do that my brother also wants to do them and can't. And it makes me feel a little guilty to just do it without him. It just feels like I'm hurting his feelings just because I was trying to do something that I wanted to do knowing he can't do it.

G6 shared some of her fears regarding her sister's heart diagnosis and hesitancies in speaking with her sister about these. G6 shared feelings of guilt and wanting to protect her sister from these fears, explaining "I'm just scared she'll get mad at me for even thinking about it."

Understanding of Heart Diagnosis

Participants were asked to complete a health literacy questionnaire to gauge their understanding of their sibling's diagnosis and experiences in having conversations about it with their family. During interviews, participants were asked about their fears about the diagnosis and advice they had for other children. From these conversations, three subthemes emerged: the role

of health literacy in telling others about the diagnosis, fears about the heart diagnosis, and advice for other children.

Health Literacy

On the health literacy questionnaire, three participants reported not knowing the name of their sibling's heart diagnosis. Five were able to provide a description of it. All participants reported initial conversations occurring with their parents and that they go to their mother if they have further questions. All participants reported that the conversations have become more casual and more detailed as they have gotten older. Five participants reported feeling as if they have enough information and one stated she would still like to know the name of her brother's diagnosis.

Participants were asked about their initial experience in having conversations about their sibling's heart diagnosis. Three participants reported not remembering much of the initial conversation, with G5 stating:

> I was only four when she was in the hospital, so I don't remember much of it. I just remember my mom told me that her heart is too big, so she needs a new heart. I don't remember how I felt about it… Over the years, I've looked back at scrapbooks and my mom's definitely talked to me and had many conversations with me about it… They've gotten more realistic… When I was little, I feel like she… didn't explain what it was… It was like she kind of child-played it to make it sound less scary.

G1 reported that she feels she always "just knew about it" and doesn't like to ask questions because she doesn't "like talking about her [because] she gets more attention." G2 reported the initial conversation as being more of a "general conversation" and not having many memories about it.

Two participants attributed initial conversations to specific memories. G3 elaborated:

> It was mostly just kind of curiosity on why does he have scars on his stomach and back. When I was fairly young, I think that would be why I asked… It's one of those things where I don't remember distinctly asking, but I just knew at one point cause I think it was told to me rather young… I do remember I asked why at one point, but it really wasn't something I distinctly remember asking about.

G4 explained the initial conversation about his brother's diagnosis happened with his parents because of an upcoming surgery.

One participant stated she feels better when she is kept informed while her sister is staying in the hospital. She explained that during a recent hospitalization, she "told her [sister] just to keep me updated and, I mean I was worried, but I just thought about it." G6 explained the relationship between her knowledge of the situation and feelings of worry, explaining "if I know it's nothing bad, then I'll be fine. But if it's something that has to do with her heart, it's scary."

Fears about the Diagnosis

Five participants reported fears directly related to their sibling's heart diagnosis, with these fears largely centered around complications and the possibility of early death. G1 reported feelings of nervousness during times of hospitalization, stating she is fearful of "more stuff happening to her that could actually hurt her more." Elaborating on previous experiences, she explained:

> It makes me nervous because some stuff could go wrong and did go wrong. So just hoping that nothing actually bad happens to her that could actually kill her… When she is in the hospital I am worried that something's wrong with her.

G2 reported only being worried when "something big happens." With his brother's upcoming surgery, he explained that he is worried about "anything that can go wrong or anything… that something bad can happen… if they have a complication or something." G4 shared that his brother was recently in the hospital in August 2020 and explained his experience:

> I was a little bit worried about my brother in the hospital. It felt different. And for my brother to have to go to get a surgery and I knew enough about things that could happen… I was worried he might not survive.

G5, whose sister is the recipient of a heart transplant, identified her largest fear as being about the rejection, sharing:

> I guess that she's [sister] just not doing as much as she probably should be. Like, she's not supposed to drink. She's not supposed to… She hangs around a group of friends that vape and stuff and so she kind of gets that… I don't wanna say rebel because she's not that much of a rebel, but she does misbehave a lot and I feel that would be a lot more towards rejection. She will probably have to go into surgery, and they may have a heart for her, or they may not. It depends on the list. I think the fear is… if she's not taking her meds and she's not doing what she's supposed to do then she doesn't get the heart [and] she passes away.

G6 explained she is most fearful "that she [sister] won't live that long. That something might happen to her and…they can't do anything about it." G6 further shared that when her sister was recently in the hospital, she "opted not to go…because I didn't want to see [her] like that."

Advice for Other Children

All six participants shared advice for other children or things they wish they would have known about having a sibling with a CHD. Advice largely centered around being supportive of

their sibling and finding support for themselves, validation for their sense of normalcy, and not treating their sibling differently. G1 highlighted the need to be supportive, stating "support her or him. And don't try to make him or her feel different than anybody else." G2 emphasized the sibling relationship and resilience, encouraging others to "be good. Talk to your sibling, and make sure that they feel safe, and you can just get through it all whenever a challenge comes by. G3 spoke about validation for her perception of normal, sharing:

> I'd like to tell them that it's okay if your family is different, because not everyone's family grew up with a lot of things. Everyone has a different family, and this is a normal thing for you to grow up with. And, at some point, you are going to get very comfortable at explaining it because it is your normal. Not everyone gets that sense that everyone will be comfortable in it, but… you've grown up in it, so you find comfort in it.

G4 echoed the importance of normalcy, sharing "I think it would have been helpful to know that it may not be a normal thing that happens, but it's still fine." G5 spoke about the importance of siblings taking time for themselves, sharing "just go through it as best you can. Get into activities and just do things for yourself." She shared wishing her parents had "checked in on [her] more and wondered how [she] was doing." G6 also spoke about the need for support, encouraging well-siblings to "try talking to someone, like a therapist, or someone that you trust."

Well-Child's Support Champions

Participants identified members of their support systems, mentioning their parents, siblings, extended family, and friends. They discussed their experiences in speaking with professionals, specifically child life specialists, therapists, and social workers. Participants also discussed their knowledge of and experiences with support groups.

Family and Extended Family

All participants reported their parents as being the primary members of their support system. G3 attributed her comfort in talking with most people in her family to sharing a "common worry that somebody is gonna die from a sickness." G4 stated he felt comforted by the fact that his "mom is able to talk to [him] about it and that she's able to keep him [brother]safe." Specifically related to their parents, all participants reported their mothers as being the first person they went to when they felt worried or overwhelmed about their sibling's diagnosis.

G6 described her mother as being "more of a best friend" and reported that her mother would always be there if she "ever actually [needed] her." In addition to parents, G1, G2, G4, G5, and G6 reported grandparents as being members of their support system. Only one participant, G2, reported that they would feel comfortable talking with their sibling with a CHD about their heart diagnosis.

Friends

While friends were reported to be members of the support system, many participants reported only sharing information about their sibling's heart diagnosis with their closest friends. G1 expressed some relief in not having mutual friends with her sister, sharing:

> I love going to school because I can have friends that we don't share, and they don't know who she is… When you're homeschooled, we all had the same friends and she usually had friends that are my age. So now, she can have her own friends her age and I can have my friends that are my age so I can hang out with my friends…and I can talk about other stuff than my sister and without my sister there. A lot of my friends know about her just because we go to the same school now. But my new friends don't know.

G2 explained that he does not like to talk about his brother's diagnosis with his friends, stating:

> Some of them [my friends] know about him, but…I don't bring it up that much. Pretty

much my close friends know a lot…my friends on baseball and my close friends I've known for a lot that know me personally and they know [my brother].

One participant, G5, expressed some discomfort in sharing information with friends she did not feel close with, stating that the only people that know about her sister's heart diagnosis are her "closest friends and people who are my friends and I like them…But I just don't really feel comfortable telling everything to everyone." G6 reported that "it's [her sister's diagnosis] nothing that we talk about all the time. It's kind of like they just ended up knowing…finding out and stuff by being around my family a lot."

One participant described her experience in telling her friends about her brother's heart diagnosis. She shared:

> I bring it up casually cause… to me, it's not something that is a very scary thing, cause it's been something where it's been just there my whole life… I don't tend to bring it up often, but when I do, it's something where I bring it up casually and will just explain vaguely… The first reaction, if I tell my friends about my brother's heart disease, is 'is he dying?' But then I have to explain more because he's not dying, he's just born with a heart thing. They [friends] just tend to react with… a little bit of 'what' and then start to understand what it means.

Two participants shared specific reasons for not wanting to share their sibling's heart diagnosis with others. G3 explained:

> Unless it adds something to the conversation, I'm not probably going to bring it up. Just doesn't feel necessary. It didn't feel necessary to talk about because there wasn't really a reason to add that to conversation. It kind of is a bit saddening to most. It's like 'yeah my brother has a heart defect, anyway, carry on with our conversation.' This is not adding to

> the conversation any way… A lot of my newer friends, I don't really tell them… First of all, it just comes up with a lot of concern for my brother. It's like 'is he alright' and I'm like 'no, he's fine, he's been living with this all his life.' There's a lot of… [they] don't really start with the concern and then I have to explain more just to make it make sense.

G5 echoed this sentiment, sharing:

> It's a lot of explaining to do, honestly. So, I'll tell certain people but if I do, people are like [mocking tone] 'oh, how's [sister],' even now.

All participants reported they were able to have friends come over to their house with the only limitations being around asking for permission and safety precautions. Two participants shared that although they can have friends over, they frequently do not either due to busy schedules or not wanting to introduce their friends to their sibling living with a CHD. One participant shared that his friends at school do not live close, so they are unable to spend time together outside of school.

Professionals

Three of the participants reported having received support from a professional, mentioning either a therapist or a social worker. Although no participants shared memories of having spoken with a child life specialist, two of the participants' parents shared their child had spoken with one in the past. Although not having previously spoken with one, G2 described a child life specialist as being somebody "to help kids cope with things with their siblings and understand." He explained that he had not previously spoken with one due to only being one year of age at the time of his brother's hospitalization but added that he would be comfortable speaking with one during his brother's upcoming surgery. Two participants were not aware of the role of a child life specialist. G5 shared that she was nervous about being willing to speak

with one in the future, explaining “I’ve kind of put it all behind me. So, it’s just like talking to someone would… just bring up all that history. It’s just so back in the past that I can’t even remember parts of it.”

Three participants reported currently being involved in therapy, two with a licensed therapist and one with a licensed social worker. G3 shared that her time in therapy was attributed to school-related anxiety and not correlated with her brother’s diagnosis. G6 shared that she had recently started seeing her school’s social worker after an incident at school but feels that “she understands what I’m going through.” G5 explained that her time in therapy had been a result of her relationship with her sister, sharing:

> The first time was my sister’s senior year, and she was driving me insane, and I just needed to vent to someone else about it… And I recently went back [for therapy; after] my sister moved back into the house.

Support Groups

Two participants reported being involved with a local support group for families of children with CHD. G2 described his time as being “really fun” elaborating that “everything we’ve done, I’ve been happy with.” He expressed excitement about siblings’ day but added he has not yet been able to attend due to his conflicting baseball schedule. G4 shared his experience as being:

> Kind of cool because there are little events that happen. I can learn things about how to help my brother. There are a lot of activities I can do that I wouldn’t normally be able to if that [his diagnosis] didn’t happen. There are these cool events that happen at [group], like a free trip to the zoo, and it’s just cool because normally I wouldn’t be able to do all that stuff.

In sum, the well-siblings spoke about the importance of family support, especially that of their mothers, and highlighted the gaps in support provided by nonprofit groups and care providers. Their responses highlighted their experiences of differential treatment from parents and members of larger systems on family relationships, resentment, and feelings of sibling rivalry or jealousy. They also provided valuable knowledge about the well-siblings' perceptions and normalization of their daily lives and feelings that come during times of change, both when their sibling is at camp and staying in the hospital.

CHAPTER 5: DISCUSSION

This study aimed to understand the daily lives of siblings of children with complex congenital heart defects and to gain awareness of their lived experiences with family members and other members of their systems. Current literature is limited regarding the experiences of well-children living with siblings who have complex congenital heart defects. Additionally, many present studies on this population utilize data from parental perceptions rather than directly from well-siblings. This study aimed to help fill this gap by focusing on a specific diagnosis, congenital heart defects, and by collecting data directly from interviews with well-siblings. Additionally, this study adds to the current literature by discussing the impact of the COVID-19 pandemic on the experiences of well-siblings and further discussing their levels of support, specifically as it relates to their friends and deciding with whom to share information regarding their brother or sister's heart diagnosis. This study confirmed previous findings regarding well-siblings' feelings of jealousy and rivalry, the influence of having a sibling with a chronic illness on traditional roles associated with birth order, and the need for both professional and personal support networks. This chapter will provide further insight into the results of the present study, discuss the connections to present literature, and explore the connection to family systems theory. Implications for practice and future research as well as study limitations will also be addressed.

Viewpoint of Daily Life in the Family

Normalcy

Daily Routine. Brennan and colleagues (2012) previously have highlighted well-siblings' want to maintain a sense of normalcy. Although the present study supports the sense of normalcy, it may also be impacted by birth order. All participants were younger than their sibling

living with CHD, supporting previous findings that the impact of a diagnosis is dependent on many factors, including when it was introduced into the family system (Travis, 1976). While these participants viewed their daily lives as normal, each echoed G1's sentiment of "not knowing anything else" and G5's feeling of "being born into it." Two participants were able to acknowledge that their friends may not have the same perception of normalcy and that each person's perception of normal shifts based on a myriad of factors. These findings support previous literature indicating that well-siblings want to maintain a sense of normalcy within their daily lives, although it would be bolstered by including the perceptions of well-children who are older in age than their sibling living with a CHD.

Hobbies. Related to siblings' sense of normalcy and fears, existing literature supports the finding that well-siblings are more frequently excluded from activities that increase their exposure to outside germs and illnesses (Connor et al., 2010). While all siblings reported hobbies and extracurricular activities they were presently involved with, three participants spoke about how these activities had changed because of the COVID-19 pandemic, reporting they felt more isolated from their friends as they were unable to participate in their normal activities and were more fearful about the potential of their sibling contracting the virus. Also congruent with existing literature, they reported a want to protect their sibling and undertaking a role more congruent with that of caretaker (Nabors et al., 2018).

Changes to Normal

Hospitalization. During times of sibling hospitalization, five participants reported changes to their daily routine. For each participant, these changes included involving members of the extended family system as well as members of larger systems the family was a part of. While previous literature identified families as being the first line of support, two participants shared

that they had stayed with their grandparents while their sibling was in the hospital. Three participants reported staying with friends while their sibling was in the hospital. One reported staying by herself. These findings highlight the importance of larger systems and the need for extended support, especially during times of hospitalization. They also provide insight into how well-siblings' sense of normalcy may be disrupted and the impact this has on their well-being.

Camp. Every participant reported their sibling attended a week of residential summer camp, with three participants describing this time as a break for themselves. Two participants shared they were able to engage in activities they would not otherwise be able to due to their sibling's limitations. G6 shared feeling relieved while her sister was at camp, describing it as a "breather." Supporting literature about the importance of sibling relationships, three participants described their time with their sibling at camp as being "lonely" and reported that, although they enjoyed it at first, they were ready for their sibling to return home by the end of the week. The attribution of camp to having a break for well-siblings is a finding that is sparse in present literature. These findings, however, support those in present literature. A previous study by Welch and colleagues (2012) suggests that parents having breaks from their child with a disability allows for their well-children to receive more attention and quality time. Well-siblings also reported having the ability to engage in more activities, a finding that was supported in the present study. Future research should aim to further evaluate the relationship breaks have on well-siblings of children with chronic illnesses.

COVID-19 Pandemic. At present, the body of literature specifically regarding the impact of the COVID-19 pandemic is growing, with only one article specifically reporting on the impact on well-siblings of children with congenital heart defects (Bichard et al., 2022). Supporting their findings, participants spoke about a responsibility to protect their sibling living

with a CHD and adjustments they made during the onset of the pandemic. G2 spoke about wanting to protect his brother and a feeling that it was better to isolate than risk exposure. He shared frustrations during the beginning, his mindset of wanting to accept the challenge, and feeling excluded from activities his friends were able to participate in. G3 highlighted the impact of the pandemic on previously existing worries, sharing that she felt more worried during the pandemic because of the knowledge that it affected the heart and lungs and shared she was fearful it would have a stronger impact on the health of her brother's heart and lungs. G3 shared her fears that her brother would die or become hurt if he were to contract the virus. G5 shared that her family became more isolated during the start of the pandemic, as she and her sister both transitioned into online classes and did not resume engagement in activities until they had received information from medical providers that it was safe to do so. These findings contribute to the literature as there becomes an increased need to discuss the impacts of the pandemic, specifically on well-siblings. This study highlights the impact on already existing fears, new roles undertaken by well-siblings, extensions of pre-existing roles those well-siblings took on, and frustrations in having their sense of normal disrupted. Literature from previous pandemics suggests that the ways in which parents presented information regarding the swine flu pandemic influenced the fears reported by their children, indicating that there may also be a relationship between the level of health literacy amongst well-siblings and the frequency with which they report such fears (Remmerswaal & Muris, 2011).

Family Dynamics

Another theme to emerge from the data is well-siblings' perceptions of their family relationships. Previous literature has indicated that well-siblings report increased experiences of sibling jealousy and perceived parenting differences (Derouin & Jessee, 1996; Azhar et al.,

2016). Three participants shared perceived differences in ways their parents treated them in comparison to their siblings. These differences were largely characterized by levels of attention, with well-siblings feeling as if they received less from their parents; special privileges, such as their sibling with a CHD being able to miss school more frequently and receiving more gifts; and levels of household responsibilities, with participants reporting they feel like they take on more than their sibling living with a CHD. Additionally, literature regarding parental favoritism amongst children with multiple siblings suggests that younger siblings tend to identify as being the most favored by parents (Rohde et al., 2003). For the participants in this study, this finding was partially supported. Each participant was younger than their sibling living with a CHD, however three participants reported feeling as if their parents favored their older sibling and as if their sibling with a CHD received preferential treatment. For one participant, however, these feelings arose when her sister was receiving a heart transplant. She explained feeling overlooked as her sister was able to miss school, received gifts, and was given more attention from their parents and members of their various subsystems. One participant explained her parents favored her sister living with a CHD out of feelings of fear related to her sister's heart diagnosis. Future research should aim to explore levels of parental attention and perceived favoritism amongst well-children and their siblings living with a CHD, and how these may change during times of hospitalizations.

Despite being younger than their sibling living with a CHD, three participants reported feelings and responsibilities akin to that of an older sibling. This finding is documented in previous literature with studies suggesting that younger well-siblings typically undertake a caretaking role (Brennan et al., 2012; Lobato et al., 1988). Literature regarding the relationship between birth order and family roles suggests that older siblings tend to report taking on more

responsibility while younger siblings tend to identify as being the baby of the family (Pulakos, 1987). One participant explained differences in responsibilities and a feeling of being treated "more like an older sister than a younger sister." Two participants expressed a want to protect their sibling and feelings of guilt when they are unable to do so. These findings support previous literature and further confirm the distress experienced by well-siblings of children with a chronic illness.

Interestingly, when reporting on sibling relationships, three participants described their sibling living with a CHD as being either angry or mean. One participant reported feelings of anger, resentment, and jealousy towards her sister. Of these three participants, one reported a low level of health literacy, characterized by an inability to name her sibling's heart diagnosis, or provide a description about what the diagnosis meant. Three reported no involvement within support groups whereas two shared they had previously spoken with a child life specialist. Of the two participants who reported positive sibling relationships, both also reported involvement within support groups. These findings suggest that well-siblings would benefit from a combination of professional support, education, and close relationships with family and friends.

Understanding of Heart Diagnosis

Health Literacy

Prior research suggests parents are still not providing their well-children with the quality or quantity of information to counter adverse effects of having a sibling with a chronic illness (Lobato & Kao, 2005; Newton et al., 2005). These findings were partially supported, with three participants reporting not knowing the name of their sibling's heart diagnosis, one unable to provide a description, and one reporting an avoidance of ongoing conversations about it. Lobato and Kao (2005) found a correlation between the age of well-siblings and the information

provided, with more details being shared as the siblings became older. This study also supported their findings, with all participants reporting that conversations about their sibling's heart diagnosis have become more detailed with time. Two participants reported that they feel they have a better understanding of what their sibling has gone through as they are provided with more information. One participant reported feeling more informed during conversations about his brother's diagnosis as he has gotten older. These reported changes in conversation are developmentally appropriate and have been documented, with existing literature suggesting that while adolescents have limited health literacy, their ability to understand and process information improves with age and involvement in conversations related to health (Caldwell & Melton, 2020). This study further confirms the need to involve well-children in conversations regarding their sibling's diagnosis by providing them with age-appropriate information.

Fears about the Diagnosis

A study by van Riper (2003) found that well-siblings are most likely to report fears associated with loss and death. The findings of this study support these, with participants reporting worries about surgical complications and the possibility of death. Three participants reported that their fears are elevated when their sibling is staying in the hospital and euphemized fears that "something bad could happen." This study further highlights the need for well-children to be given age-appropriate information and to be involved with various support groups, as many stated they did not feel they could talk to anybody outside of the family about their fears and reported these fears were reduced when they were provided with information.

Well-Child's Support Champions

Family and Extended Family

The parent-child relationship has been found to serve as the largest source of support and protection for children (Gass, Jenkins, & Dunn, 2007). Congruent with this finding, all six participants reported their parents as being their primary source of support, with their mother as being the first person they go to in times of worry. Additionally, literature suggests that the quality of family relationships, specifically parent-child relationships, was indicative of children's ability to adjust in later adulthood (Dekovic & Buist, 2005). While the quality of parent-child relationships was not formally assessed in this study, participants were asked to describe the relationship each held with their parents. All participants reported feeling close with at least one parent, with three reporting they felt equally close with both and three reporting feeling closer with their mothers than their fathers. While this study seems to support the findings regarding the quality of the parent-child relationship and adjustment to adverse situations, more research is warranted as the level of parental involvement for each participant was affected by differing circumstances. For example, of the three participants who reported feeling closer to their mothers, one was homeschooled by her mother throughout her elementary school years; one participant's parents are divorced, and the participant resides primarily with her mother; and one participant experiences differential treatment from her father in comparison to her sister with a CHD. For these participants, there is no consistent pattern between their perceived parental closeness and mental health, indicating that professional support may be warranted to counteract the difficulties in adjusting to having a sibling with a CHD.

Friends

One theme to emerge from the data that contributes to present literature is the relationships well-siblings hold with their friends. Brennan and colleagues (2012) previously reported that many well-siblings develop strategies to compartmentalize their home life and

school life while maintaining a sense of normalcy. As previously discussed, the creation of a sense of normalcy was supported in this study. Regarding the process of compartmentalization, one participant reported wanting to not have mutual friends with their sibling with a CHD. Regarding her experience, she shared that she was homeschooled until middle school, during which time she and her sister had many friends in common. After having started at public school, however, she expressed relief about being able to "have friends that we don't share, and they don't know who she is." Additionally, four of the six participants shared a hesitancy in talking about their sibling's heart diagnosis with people outside of their family and close friends. Each of these participants expressed finding some security in not having to discuss their sibling's heart diagnosis with their friends at school, with one participant additionally expressing discomfort sharing information about her sister's diagnosis with others. G2 explained some of his hesitancy in speaking with friends about his brother's diagnosis is related to a feeling that members outside of his family system do not understand what it is like living with a sibling who has a CHD. He explained that his close friends know about his brother's heart diagnosis, but that he only shares this information with friends who are familiar and have a relationship with his family, especially his older brother who is living with a CHD. Considering well-siblings' want to maintain a sense of normalcy, participants shared some of their hesitations in sharing their sibling's diagnosis with friends as being because it is not something they feel their friends would understand or due to a fear that their friends would then treat them differently. G3 and G5 both explained that after sharing about their sibling's diagnosis with friends, they feel their friends have negative assumptions about their sibling's health or treat them differently by consistently asking how their sibling with a CHD is doing. Related to health literacy, all participants reported feeling as if they

have tools and language to engage in conversations about their sibling's heart diagnosis but elect not to.

Professionals and Support Groups

Literature indicates that the ability to adjust to the presence of a childhood chronic illness can be impacted by the severity of the diagnosis, socioeconomic status, and the level of outside support (Jackson et al., 2014; Williams et al., 1993). These findings were supported in the present study. Of the six participants, those who reported moderate levels of anxiety or moderate levels of depression also reported two levels of outside support, frequently a combination of parents and friends, with one reporting a combination of parents and a support group. The one participant who reported minimal levels of both anxiety and depression also reported a high socioeconomic status and a high level of support, mentioning family, friends, and a life-long involvement within support groups.

Previous findings in the literature have emphasized the influence of support programs on the experiences of well-siblings, calling upon child life specialists to better involve the well-child during times of their sibling's hospitalization (Gursky et al., 2007; Levick et al., 2010; Utens, 2018). In this present study, all six participants reported their sibling had previously been hospitalized at least once but only two had spoken with a child life specialist, per parent reports. All six participants, however, reported no memories of speaking with one. One reason for this is the ages of the participants. All participants were younger than their sibling with a CHD and reported that much of the cardiac care had happened before they were born or when they were under the age of five years. Given this, it may not have been feasible for these participants to speak with a child life specialist, nor would they have remembered the conversation, as indicated by parent reports of their well-children speaking with a child life specialist but the participants

not having memories of this conversation. One participant was able to accurately describe the role of one in the hospital and attributed his lack of interaction to only being one year of age at the time of his brother's hospitalization. He explained, however, that he would be open and willing to speak with one during his brother's upcoming surgery. Additionally, three participants reported a history of attending therapy, with two providing reasons directly related to their sibling with a CHD. Despite the need to better support well-siblings and the plethora of qualified professionals and organizations, it appears that many are still not having their needs for support met, as evidenced by a general lack of awareness amongst the participants regarding the role of a child life specialist and a lack of involvement in and awareness of local support groups.

Limitations

This study's findings should be considered in the context of its limitations. First, the sample consisted of participants all younger in age than their sibling living with a CHD. As highlighted in the literature, the experiences of younger siblings tend to be different than those of older siblings, thus limiting the application of findings to all well-siblings. As the participants in the present study were all younger than five years during the height of their sibling's cardiac care, they reported not knowing a life without the presence of their sibling's CHD. Including well-siblings who are older in age and can speak to how their daily routine changed when their sibling was born and diagnosed with a CHD would better generalize the findings across well-siblings. Second, all the siblings living with a CHD had significant additional diagnoses which were not explored in-depth through the interviews. It is unclear, then, the influence of these various diagnoses on the experiences of well-siblings and whether findings were related specifically to the presence of the heart diagnosis. Thirdly, all participants were white and came from families in which both parents were college-educated. This level of education may have

influenced how the parents relayed information about their child's heart defect to their well-children. Future research should aim to include a more diverse study population and one that is more representative of the general population. Fourth, four of the six participants identified as being female, further limiting the application of findings to all well-siblings. Finally, all recruitment and interviews took place virtually, thus excluding participants who may not have access to or may not be able to use technology.

Implications

Implications for Professionals

The findings from this study suggest implications for professionals, including child life specialists, medical providers, and mental health professionals. Child life specialists are essential in providing support to both children and their families during their time of hospitalization and beyond. The findings of Levic and colleagues (2010) suggest that there is a correlation between the visitation abilities of well-siblings and positive outcomes, with well-siblings who were able to visit their sibling in the hospital reporting increased knowledge and social support and decreased symptoms of anxiety. With their training in providing family centered care and developmentally appropriate information, child life specialists have adequate training and experience to provide psychoeducational support to well-siblings of children living with a CHD. There is a need to better involve well-siblings and their families with child life specialists to facilitate conversations regarding the sibling's diagnosis and provide information in developmentally appropriate ways.

Another implication for practice is the involvement of well-children during the treatment of their sibling by allowing them to be included in conversations with providers, visit their sibling during times of hospitalization, and education-based support groups. Tritt and Esses

(1988) suggest that the anxiety of well-siblings was reduced when they were involved in such ways, however the present study suggests that well-children are still frequently excluded as they do not attend continued cardiology appointments, and many are not aware of or involved in support groups. Providing information in a developmentally appropriate way and normalizing experiences may serve to lessen symptoms of anxiety as well-children are given adequate information and validation for their perception of normal. The creation and implementation of education-based support groups allows the opportunity for well-siblings to receive such information while building social support networks. Medical care providers, such as doctors, nurses, and child life specialists can serve to provide this developmentally appropriate information, lessening the stress on parents who may feel as if they must provide the right information in the right way.

Finally, mental health professionals play a valuable role in the support of well-siblings. Although not expected to have the same medical knowledge as a child life specialist, they serve to provide tools for coping and adjustment while validating the experiences of their clients. Mental health professionals are essential in guiding well-siblings to process their experiences and allow them to assign their own meaning. From a lens of systems theory, they can provide an understanding of the interaction between the well-sibling and their various interlocking systems, while highlighting discrepancies in healthy functioning. As all systems are interlocking and influence one other, mental health professionals may serve as a sense of security for well-siblings as oftentimes they will not interact with other members of the children's systems, allowing their clients to maintain healthy boundaries between their numerous systems. They can serve as a resource for well-siblings, allowing them a space to express their feelings and discuss their experiences without the presence of other family members. Finally, they provide a space for

well-children to feel safe and empowered, especially as many fears about their sibling may feel out of their control.

Implications for Parents

This study also has implications for parents, especially as they consider engaging in conversations regarding the diagnosis with their well-children. The parent-child relationship is documented in literature as being one of the most influential in the development of children. Parents are oftentimes children's most influential relationship, and such a relationship can influence all those in the future. The quality of parent-child relationships can affect children's formation of identity, both in adolescence and throughout adulthood. The presence of a child with a chronic illness can impact the parent-child relationship, as well-siblings report experiencing more frequent parental favoritism, less attention from parents, and sibling rivalry and jealousy. Oftentimes, however, parents may be unaware of the differential treatments. Understanding the phases of development is crucial for parents as children want continued attention from their parents as they grow and develop. Having a sibling living with a CHD can affect the level of attention well-children perceive they are receiving, which can further impact their development and well-being throughout their lifespan. It is essential that parents are aware of the impact a chronic illness can have on the experiences of their well-children and aim to treat all children within the home more equitably, explaining any perceived differences in developmentally appropriate terms.

Parents are also encouraged to share information with their well-child about their child's heart diagnosis. Previous literature has cited reasons for withholding information, such as a fear of overwhelming the well-child with information and not knowing which information is appropriate to provide and when (Kleiber et al., 1995; Lobato & Kao, 2005; Menke, 1987;

Newton et al., 2005). As demonstrated in these findings and supported by current literature, sharing information about the diagnosis with well-children can help reduce anxiety and improve adjustment not only in childhood but throughout various phases of development (Lobato & Kao, 2005). Involving well-siblings in conversations and allowing them to attend cardiology appointments, when appropriate, can be beneficial in their understanding of the diagnosis and the ways it may affect their daily lives and that of their sibling living with the CHD.

Implications for Research

Future research should explore the impact of the COVID-19 pandemic on the experiences of well-siblings of children living with a CHD. Literature is sparse regarding the implications on siblings of children with chronic illness in general, especially those living with a sibling with a CHD. This research could examine how the pandemic impacted well-siblings' daily lives, pre-existing fears about the well-being of their sibling and the mortality risk of living with a CHD, and the impacts on family relationships. Research from prior pandemics suggests the relationship between children's fears and information from parents regarding the pandemic. Thus, future research could explore the relationship between the COVID-19 pandemic, health literacy, and adjustment amongst well-siblings.

Participants also reported limited avenues for social support, with many only trusting members of their family with information and fears about their sibling's diagnosis. Future research could explore well-siblings' perceptions of their friendships and the role these friendships play in their lives. While friends are a major source of protection in adolescence, it appears well-children want to maintain a separation between life at school and life at home. Future research could also explore siblings' experiences in having conversations with friends

about their sibling's heart diagnosis, changes they observed afterwards, and the impact on their willingness to engage in future conversations.

To further the application of family systems theory, future research could utilize interviews with multiple members of the family system and compare perceptions of adjustment amongst parents, well-children, and children who have been diagnosed with a chronic illness. While literature from parental perceptions and sibling perceptions exist, studies comparing the two are sparse and fewer exist including the child with the chronic illness. Additionally, research could examine the adjustment and wellbeing of well-siblings who are involved with outside levels of support, such as support groups or therapy, with those who are not.

Another avenue for future research is the impact of having a sibling with a CHD on adult siblings. Literature on this population is sparse and would provide a deeper knowledge on the impacts as adults may be better able to speak on their childhood experiences. Young adults who have recently moved out of the house may be better able to identify differences in their childhoods as compared to their peers and may have more thoughtful insights about how their sibling's diagnosis has impacted them. As they gain these insights, they may be better able to speak about their previous roles in the family, their levels of responsibility within the home as compared to their sibling living with a CHD, and how their relationships with their family and friends changed overtime.

Finally, there is still a need for further research regarding the relationship between health literacy and adjustment. As many parents report discomfort in having these conversations, future research could examine the involvement of child life specialists, medical providers, and parents and ways to empower parents to speak with their well-children. Such professionals could be influential in providing information in lay terms for parents, helping them to improve their

understanding, and assisting them with sharing information with other members of their systems. Future research could further examine the needs of parents when engaging in these conversations, potentially examining the use of educational workshops and handouts. Finally, future research could further examine the impact of sibling-directed educational interventions on levels of health literacy and adjustment within childhood, adolescence, and adulthood.

Conclusion

This study contributes to the present literature by collecting data directly from well-siblings rather than from parental perceptions. As suggested in previous literature and supported by this study, the experiences of well-siblings are layered and complex. The experiences of well-siblings are affected by a multitude of factors, such as support from family and subsystems, socioeconomic status, and health literacy. Thus, the experience of one well-sibling may be similar but will not be identical to that of another. This study increased insight regarding well-siblings' perceptions of their relationships with their family, extended family, and friends as well as their current levels of support from professionals and support groups. This study also contributed to the literature regarding the impact of the COVID-19 pandemic on the experiences of well-siblings, especially as it relates to their sense of responsibility and want to protect their sibling living with a CHD. These findings highlight the importance of health literacy, the need for well-siblings to be involved in conversations regarding their sibling's diagnosis and speaks to how these conversations can change throughout various stages of development. As there continues to be a need to involve well-children during times of their sibling's hospitalization, the present study provides suggestions for health care professionals, mental health providers, and child life specialists to guide parents in speaking with their well-children and ways to better involve well-siblings. The present study also highlights the importance of support groups,

especially those that provide both education and social support, allowing well-siblings opportunities to interact with others who are in similar situations and build a sense of community with people they feel understand their experiences. In conjunction with future research, the findings of the present study can speak to the experiences of well-siblings, the need to be included in conversations regarding their sibling's heart diagnosis, and the creation and effects of sibling directed psychoeducational interventions.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
N-64 Brody Medical Sciences Building Mail Stop 682
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Notification of Initial Approval: Expedited

From: Social/Behavioral IRB

To: Annalise Bernardino

CC: Priti Desai

Date: 1/24/2022

UMCIRB 21-002739

Re: Experiences of School-Aged Siblings of Children with Complex Congenital Heart Defects

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) occurred on 1/24/2022. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

The approval includes the following items:

Name	Description
A. Bernardino Assent Form.docx	Consent Forms
A. Bernardino Bracketing Statement.docx	Study Protocol or Grant Application
A. Bernardino Camp Braveheart Director Recruitment Letter.docx	Recruitment Documents/Scripts
A. Bernardino Chief of Pediatric Cardiology Recruitment Letter.docx	Recruitment Documents/Scripts
A. Bernardino Debriefing Email.docx	Additional Items
A. Bernardino Demographic Questionnaire.docx	Surveys and Questionnaires

A. Bernardino Demographic Questionnaire.docx	Data Collection Sheet
A. Bernardino GAD-7.docx	Surveys and Questionnaires
A. Bernardino Health Literacy Questionnaire.docx	Surveys and Questionnaires
A. Bernardino Informed Consent Form.docx	Consent Forms
A. Bernardino Interview Schedule.docx	Interview/Focus Group Scripts/Questions
A. Bernardino Phone Script.docx	Recruitment Documents/Scripts
A. Bernardino PHQ-8.docx	Surveys and Questionnaires
A. Bernardino Recruitment Flier.docx	Recruitment Documents/Scripts
A. Bernardino Thesis Chapters.docx	Study Protocol or Grant Application

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: BRACKETING STATEMENT

When a child is diagnosed with a chronic illness, it affects every member of the family and the systems with which they interact. Parents are placed under extreme amounts of stress, both personally and financially as they adjust to increased medical bills, more frequent doctors' appointments, and an increased need for medications and medical equipment. Many parents experience feelings of blame or guilt surrounding the diagnosis and experience divorce or separation at an increased rate. Siblings may experience increased feelings of sibling rivalry or jealousy, perceived parenting differences or favoritisms, and exclusion from not being able to participate in the same activities as their peers.

I grew up in Atlanta with a younger sister diagnosed with five complex, congenital heart defects. She has since received eight open heart surgeries and undergone countless procedures. To this date, she requires ongoing care and frequent appointments with her providers. There are three years between my youngest sister and me as well as another sister sandwiched in between. Because the three of us are so close in age, I do not remember a life that has not been defined by medical challenges. We all grew up in the home together, raised by two parents who did everything in their power to give us a "normal" life in the midst of countless abnormalities. When my sister was in Texas receiving surgery, my other sister and I would bounce between our grandparents' house, or aunt's house, and neighbors who offered to provide extra care.

Growing up in a household defined by congenital heart defects, I experienced many of these same things. While I was fortunate to have parents who rose above the challenge, there were moments of rivalry between my sister and me and feelings that she was subject to special treatment and existed under a different set of rules. I also experienced extreme feelings of isolation and exclusion. While many programs existed to provide support for my parents and for my sister with the diagnosis, there was very little focusing exclusively on the needs of siblings. I often felt as if there were very few people in my life, outside of my family, who really understood what life was like on a daily basis, which contributed heavily to the feelings of isolation I experienced on a daily basis. I often struggled between feeling protective over my sister and wanting so badly to lead a "normal" life as my peers in school seemed to.

My experiences coupled with feelings of isolation and disconnect from my peers have been the basis of my desire to complete this research. I hope to speak with school-aged siblings who are being raised in similar situations as the one I was and learn more about their present experiences, their perceived levels of support, and how hospitalizations and health literacy affect their experiences. I predict I will find themes of sibling rivalry, parental favoritism, isolation, and exclusion. Related to support, I predict that well-siblings will feel largely excluded from many support groups and report that many times their peers and community lack understanding about their family situation.

Understanding that I have lived through this experience, I am aware that I cannot be completely objective. I also understand that my experience may not be the same across the board and thus it is crucial that I do not bring my own lived experiences in the midst of my present work. I will not impose my ideas and biases on participants. I will strive to analyze data based on their reported experiences and to listen objectively, understanding that the experiences of my participants may be drastically different than mine. I will also never disclose to my participants my identity as a sibling of an individual with a complex congenital heart defect. Finally, I will not offer therapy to my participants but will instead listen objectively and empathetically to their reports and offer resources for extra support. Through this research, I hope to understand more the experiences of other children facing similar situations to the one I was raised in. I hope this

research is the beginning of a much larger project, one that serves to increase the support for siblings of children with chronic illness and serves to provide education, community, and a sense of belonging.

APPENDIX C: INFORMED CONSENT FORM

Parental/Guardian Permission to Allow Your Child to Take Part in Research

Information to consider before allowing your child to take part in research that has no more than minimal risk.

Title of Research Study: Experiences of School-Aged Siblings of Children with Complex Congenital Heart Defects
Principal Investigator: Annalise Bernardino (Person in Charge of this Study)
Institution, Department or Division: Human Development and Family Science
Address: 1000 East 5th St. ECU Building 112W Greenville, NC 27858
Telephone #: 252-328-4630

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems, and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why is my child being invited to take part in this research?

The purpose of this research is to explore the experiences of school-aged children currently living or have lived in the home with a sibling with a complex congenital heart defect. Your child is being invited to take part in this research because they have been identified as currently living or have living in the home with a sibling with a complex congenital heart defect. The decision for your child to take part in this research will also depend upon whether your child without a complex congenital heart defect wants to participate and your approval of their participation. By doing this research, we hope to learn about how living with a sibling with a complex congenital heart defect may impact the experiences of school-aged siblings.
If you and your child agree for him/her to volunteer for this research, your child will be one of about 20 people to do so.

Are there reasons my child should not take part in this research?

Your child should not take part in this research if they do not currently live or have not lived in the past with a brother or sister with a complex congenital heart defect. They should also not take part in this research if they are not between the ages of 12 and 17 years. They should not participate if they are unable to read, write, or speak in English.

What other choices do I have if my child does not take part in this research?

Your child can choose not to participate in this research. You do not need to make any other choices.

Where is the research going to take place and how long will it last?

The research will be conducted virtually from East Carolina University's Marriage and Family Therapy Clinic utilizing an online meeting video platform called WebEx. Your child will need to have means to access this, either through a personal computer, smart phone, or tablet. Interviews will take place either one or two times, depending on the need for a follow-up interview. The

total amount of time your child will be asked to volunteer for this study is between 20 minutes to 1 hour for each interview.

What will my child and I be asked to do?
You will be asked to do the following: read the study information, discuss any questions about the study with me or my thesis director, and talk to your child about this study. If you and your child agree to participate, then you will be asked to read and sign the consent form and mail it in the postage paid envelope. Along with the consent form, you will be asked to complete the demographic questionnaire, which can either be mailed along with the signed consent form or over the phone. The demographic questionnaire is to gather basic information about you, your child with a complex congenital heart defect, your other children living in the home, and your family makeup. Finally, you will schedule a time for your child to complete a virtual interview. Your child will be asked to do the following: read and sign the assent form, complete a health literacy questionnaire, complete two standardized mental health assessments, and work with you to schedule a time to participate in a virtual interview. Your child will be asked to participate in one or two virtual interviews. The interview questions that I will be asking are about your children's personal experiences of living with a brother or sister with a complex congenital heart defect. These experiences are largely focused on home, school, and community.

What might I experience if I take part in the research?
We do not know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. There is a small possibility answering some of the interview questions presented in the interview tool may cause your child to become upset due to the nature of the questions. We will send a follow-up email regarding resources for support, if needed. The information gained by doing this research may help you and other families living with a child with a complex congenital heart defect.

Will my child be paid for taking part in this research?
We will be able to compensate and appreciate your child for the time they volunteer while being in this study. Each participant will receive a gift card in the amount of $10 to Target. This gift card will be mailed addressed to you after the completion of their interview(s).

Will it cost me anything for my child to take part in this research?
It will not cost you any money to be part of the research. Your child will need to be able to access the Internet and complete a virtual interview, using either a computer, smartphone, or tablet.

Who will know that I took part in this research and learn personal information about me?
The research team associated with this study may know that your child took part in this research and may see information about your child that is normally kept private. The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your child's welfare during this research and may need to see research records that identify your child. All participants and their families will be deidentified using a unique identifier code and information shared during this study will not be able to be linked back to you or to your child.

All the information you and your child share will be kept confidential, except for disclosures regarding child abuse, elder abuse, abuse towards a person with a disability, or threat to harm self or others. The PI is a court-mandated reporter and is legally obligated to disclose information of this nature to the proper entities, if such information is disclosed.

How will you keep the information you collect about my child secure? How long will you keep it?
There will be two pieces of data generated from this study: audio/visual interview data and a printed transcript. Electronic data will be stored in a password-protected Pirate Drive that is accessible through a password-protected computer. This will help ensure no breach in confidentiality occurs. The deidentified printed transcript will be kept in a secure, locked cabined in a locked office at East Carolina University and will be kept following University guidelines.

What if my child decides he/she doesn't want to continue in this research?
Your child can stop his/her participation at any time after the interview has already started. There will be no consequences if he/she stops, and he/she will not be criticized. Your child will not lose any benefits that he/she would normally receive. If the interview is ended without adequate data for analysis, however, we will be unable to compensate your child for their time.

Who should I contact if I have questions?
The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator via email at bernardinoa20@students.ecu.edu or her researcher chair's office at 252-328-2866 or email at desaip.ecu.edu.
If you have questions about your child's rights as someone taking part in research, you may call the University and Medical Center Institutional Review Board (UMCIRB) at phone number 252744-2914 (days, 8:00 am-5:00 pm).
If you would like to report a complaint or concern about this research study, you may call the Director for Human Research Protections, at 252-744-2914.

Is there anything else I should know?
Your child's information collected as part of the research, even if identifiers are removed, will not be used or distributed for future studies.

I have decided my child can take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that my child can stop taking part in this study at any time.
- By signing this informed consent form, my child is not giving up any of his/her rights.
- I have been given a copy of this consent document, and it is mine to keep.

Thank you for your time and consideration.

Parent or Guardian's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT) **Signature** **Date**

APPENDIX D: ASSENT FORM

Assent Form

Things You Should Know Before You Agree To Take Part in this Research

IRB Study #21-002739
Title of Study: Experiences of school-Aged Siblings of Children with Complex Congenital Heart Defects
Person in charge of study: Annalise Bernardino
Where they work: East Carolina University
Other people who work on the study: Dr. Priti Desai
Study contact phone number: 252-328-2866
Study contact email address: bernardinoa20@students.ecu.edu; desaip@ecu.edu

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People at East Carolina University study ways to make people's lives better. These studies are called research. This research is trying to find out more about the experiences of children who have a brother or sister with a complex congenital heart defect.

Your parent(s) need to give permission for you to be in this research. You do not have to be in this research if you don't want to, even if your parent(s) has already given permission.
You may stop being in the study at any time. If you decide to stop, no one will be upset with you.

Why are you doing this research study?
The reason for doing this research is to learn more about the experiences of children (12-17 years old) who have a brother or sister who has a complex congenital heart defect.

Why am I being asked to be in this research study?
We are asking you to take part in this research because you have been identified as somebody currently living with or has lived with a brother or sister who has a complex congenital heart defect.

How many people will take part in this study?
If you decide to be in this research, you will be one of about 20 children taking part in it.

What will happen during this study?
If you decide that you want to be in this research study, this is what will happen:
Your mom or dad will:

1. Complete a form giving their permission for you to participate.
2. Complete a questionnaire about your family.

You will:

1. Complete a form stating that you wish to be a part of this research.

2. Complete a questionnaire about your current knowledge of your brother or sister's heart defect.
3. Complete two short questionnaires about your mental health.
4. Work with your mom or dad to schedule a time for you to complete one or two virtual interviews. During these interviews, you will answer questions such as about yourself; your family; your home and school life; and how you feel when your brother or sister is staying in the hospital.
   Your interviews will be recorded. At any time, you may ask to take a break, skip a question you do not wish to answer or to come back to, or to be done with the interview. If you do not wish to keep talking at a certain point, you also have the option to reschedule your interview.

These interviews will take place virtually through a platform called Webex. You will need to have access to the Internet as well as a computer, smartphone, or tablet to complete this interview. Each interview will last approximately 20 to 60 minutes.

Who will be told the things we learn about you in the study?

The things that we learn about you in this study will only be shared with the research team. In case you tell me about an adult currently or previously hurting you; if you tell me about an adult hurting an elder; if you tell me about an adult hurting a person with a disability; or if you tell me about any threat or intention to hurt yourself or somebody else, this information will have to be told to your parents as well as professionals who can get you the right kind of help.

What are the good things that might happen?

Good things may happen to people who take part in research. These are called "benefits." The benefits to you of being in this study may be having a chance to talk about your experiences; having the opportunity to provide information about how you can be better supported; and having the opportunity to use your voice to help us understand how to better help you and other children in similar situations to yours.

What are the bad things that might happen?

Things we may not like may happen to people in research studies. These are called "risks." For you, when discussing your experiences, you may have feelings, such as sadness, anger, or guilt. You may or may not have these feelings. If you experience any of these feelings, please let me know as well as your parents. We can help find a professional for you to talk to about your feelings.

What if you or your parents don't want you to be in this study?

If you or your parents don't want you to be this study, you do not have to participate in this study.

Will you get any money or gifts for being in this research study?

You will receive a $10 Target gift card for being in this study. This gift card will be mailed to your parents to give to you after you have completed your interview(s).

Who should you ask if you have any questions?

If you have any questions about the research, you should ask the people listed on the first page of this form. If you have other questions about your rights while you are in this research study, you may call the Institutional Review Board at 252-744-2914.

If you decide to take part in this research, you should sign and print your name below. It means that you agree to take part in this research study. Your parents will mail this form to the researchers. Thank you for your time and consideration.

_____ _____

Sign your name here if you want to be in the study Date

_____

Print your name here if you want to be in the study

_____ _____

Signature of Person Obtaining Assent Date

_____

Printed Name of Person Obtaining Assent

Department of Pediatrics
Brody School of Medicine | 3E-142 Brody Medical Sciences Building | Mail Stop 632
East Carolina University | Greenville, NC 27834-4354
252-744-2540 office | 252-744-1376 fax

APPENDIX E: LETTER OF SUPPORT FROM CHIEF OF PEDIATRIC CARDIOLOGY

To Whom It May Concern:

Ms. Annalise Bernardino is conducting a master's Thesis exploring the experiences of school aged children living with a sibling with a complex congenital heart defect. Camp WholeHeart will participate in the study by sending the study flier and letter from the Camp Director to parents of our campers, both past and present. Parents of interested participants will be asked to contact Ms. Bernardino or Dr. Desai via email or phone. Further contact will be made by Ms. Bernardino or her thesis advisor, Dr. Desai, who will contact the parents of interested participants by phone to clarify their questions about the study and to confirm their interest to send the online questionnaire links and to schedule an interview. We hope that this research will provide valuable information regarding lived experiences of this population and better ways to support them.

I fully support Ms. Bernardino in pursuing this important research study.

Please contact me if you require more information.

Sincerely,

Charlie J. Sang, Jr., M.D., FAAP, FACC, FSC
Section of Pediatric Cardiology
Brody School of Medicine

APPENDIX F: LETTER OF SUPPORT FROM CAMP BRAVEHEART DIRECTOR

To Whom It May Concern:

Ms. Annalise Bernardino is conducting a master's Thesis exploring the experiences of school-aged children living with a sibling with a complex congenital heart defect. Camp Braveheart will participate in the study by sending the study flier and letter from the Camp Director to parents of our campers dating back to the year 2017. Parents of interested participants will be asked to contact Ms. Bernardino or Dr. Desai via email or phone. Further contact will be made by Ms. Bernardino or her thesis advisor, Dr. Desai, who will contact the parents of interested participants by phone to clarify their questions about the study and to confirm their interest in order to mail the study tools and to schedule an interview. After the completion of the interviews, if siblings need a local support resource, our camp child life specialists can be available. We hope that this research will provide valuable information regarding lived experiences of this population and better ways to support them.

I fully support Ms. Bernardino in pursuing this important research study.

Please contact me if you require more information.

Sincerely,

Shannon Antinarella

Shannon Antinarella
Manager, Camp and Auxiliary Programs
shannon.antinarella@choa.org
404-785-6735

1575 Northeast Expressway
Atlanta, GA 30329
shannon.antinarella@choa.org
p: 404-785-6735

Department of Pediatrics
Brody School of Medicine | 3E-142 Brody Medical Sciences Building | Mail Stop 632
East Carolina University | Greenville, NC 27834-4354
252-744-2540 office | 252-744-1376 fax

APPENDIX G: LETTER FROM CHIEF OF PEDIATRIC CARDIOLOGY

Dear Parent or Caregiver,

I invite you to consider participating in a research study, which may improve knowledge regarding the lived experiences of siblings of children with complex congenital heart defects. Your participation may also provide insight for other families with well-siblings of children with complex congenital heart defects.

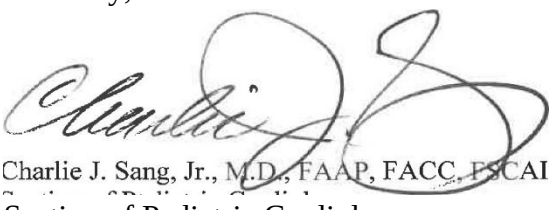
Annalise Bernardino is a master's student in the Human Development and Family Science Department at East Carolina University and will be conducting this research. She will be working under the guidance of Priti P. Desai, PhD, MPH, CCLS, Associate Professor in the department.

Annalise will be recruiting well-siblings between the ages of 12 to 17 years of campers from Camp WholeHeart to serve as participants. If you agree to have your child participate in this study, they will be asked to engage in one or two in-depth interviews to share their lived experiences living with a brother or sister diagnosed with a complex congenital heart defect. Interviews will be scheduled on a first come, first serve basis until the necessary data are collected. Please see the enclosed flier regarding study details as well as contact information for the thesis team.

Please consider allowing your child to participate in this upcoming study, which will hopefully generate valuable information regarding the lived experiences of well-siblings of children with complex congenital heart defects. The study has been Institutional Review Board (IRB) approved. If you are interested in participating, please contact Annalise or Dr. Desai; their contact information is provided on the attached study flier. They will also be happy to provide more detailed information regarding the study.

Our camp team wholeheartedly supports this research project. Please contact Annalise at bernardinoa20_a_students.ecu.edu or Dr. Priti Desai at desaip@ecu.edu or by phone at 252-3282866 if you have further questions about this study

Sincerely,



Charlie J. Sang, Jr., M.D., FAAP, FACC, FSCAI
Section of Pediatric Cardiology

APPENDIX H: LETTER FROM CAMP BRAVEHEART DIRECTOR

Children's Healthcare of Atlanta

Dear Parent or Caregiver,

I invite you to consider participating in a research study, which may improve knowledge regarding the lived experiences of siblings of children with complex congenital heart defects. Your participation may also provide insight for other families with well-siblings of children with complex congenital heart defects.

Annalise Bernardino is a Master's student in the Human Development and Family Science Department at East Carolina University and will be conducting this research. She will be working under the guidance of Priti P. Desai, PhD, MPH, CCLS, Associate Professor in the department.

Annalise will be recruiting well-siblings between the ages of 12 to 17 years of campers from Camp Braveheart to serve as participants. If you agree to have your child participate in this study, they will be asked to engage in one or two in-depth interviews to share their lived experiences living with a brother or sister diagnosed with a complex congenital heart defect. Interviews will be scheduled on a first come, first serve basis until the necessary data are collected. Please see the enclosed flier regarding study details as well as contact information for the thesis team.

Please consider allowing your child to participate in this upcoming study, which will hopefully generate valuable information regarding the lived experiences of well-siblings of children with complex congenital heart defects. The study has been Institutional Review Board (IRB) approved. If you are interested in participating, please contact Annalise or Dr. Desai; their contact information is provided on the attached study flier. They will also be happy to provide more detailed information regarding the study.

Our camp team wholeheartedly supports this research project. Please contact Annalise at bernardinoa20@students.ecu.edu or Dr. Priti Desai at desaip@ecu.edu or by phone at 252-328-2866 if you have further questions about this study.

Sincerely,

Shannon Antinarella

Shannon Antinarella
Manager, Camp and Auxiliary Programs

1575 Northeast Expressway
Atlanta, GA 30329
shannon.antinarella@choa.org
p: 404-785-6735

APPENDIX I: RECRUITMENT FLIER

Are you the parent or guardian of an individual living with a complex congenital heart defect? Do you have other children living in the home?

We need YOUR help for a research study!

We are seeking your help in a graduate-level research study being conducted at East Carolina University aiming to understand the experiences of children between the ages of 12 to 17 years who have a brother or sister with a complex congenital heart condition. This experience is unique compared to other children. Your child's participation in this study may help to increase knowledge regarding these experiences and learn about ways to provide better support to brothers and sisters of a person with a heart condition. All participants will be appreciated for their time with a $10 Target gift card.

If you consent to your well-child participating, you will be asked to:

1. Sign a consent form stating you give permission for your child to participate in this study
2. Complete a questionnaire about your family demographics. This includes questions such as who lives in the home, education and income, and your child's heart diagnosis.

Your well-child will be asked to:

1. Sign an assent form stating they wish to participate in this study
2. Complete a health literacy questionnaire regarding their knowledge of their brother or sister's heart diagnosis as well as two standardized mental health screeners
3. Complete one or two virtual interviews that will last approximately 20-60 minutes using WebEx, an online meeting space.
   All interviews will be recorded. The research team will follow all research ethics to protect each participant's identity, and their identity will never be revealed during the reporting of findings.

Your well-child is eligible to participate if:

1. They have a brother or sister with a complex congenital heart defect who currently attends or has attended Camp Braveheart or Camp WholeHeart
2. They are between the ages of 12 years and 17 years old
3. They have access to the Internet and a computer to participate in a virtual video interview
4. They speak, read, and write in English

For more information, contact Annalise Bernardino at bernardinoa20@students.ecu.edu or Dr. Priti Desai at desaip@ecu.edu or at 252-328-2866. Annalise Bernardino is a current student and Dr. Desai is a faculty member at East Carolina University.

Thank you for your consideration to participate in this important study!

APPENDIX J: PHONE CALL SCRIPT

Hello! My name is Annalise Bernardino, and I am a current Masters' student at East Carolina University. I would like to speak with the parent or guardian of *(child's name)*. I am following up regarding information that you received from your camp director *(either Shannon or Dr. Desai)*.

As you read in the recruitment information, I am currently conducting a research study about how living with a brother or sister with a complex congenital heart defects affects school-aged siblings also living in the home. I have received permission from your child's camp director and my university's research regulatory team for this study. First, I would like to thank you for expressing interest in allowing your child to participate in this study and answer any questions you may have.

Before we continue, I want to verify if your child is eligible to participate in the study. To do this, I will ask you a few questions.

1. Do you have a child with a complex congenital heart defect?
2. Does this child currently attend, or have they previously attended, Camp *(Braveheart or WholeHeart)*?
3. Do you have other well-children living in the home?
4. Are these children between the ages of 12 years and 17 years?
5. Do you have access to the Internet and a computer, smartphone, or tablet to complete virtual video interviews?
6. Does your child speak, read, and write in English?

If the answer to any of the screening questions is "no":

Thank you for your time. Unfortunately, part of the criteria for my study is *(insert reasoning based on answer to question*). Since *(reason)*, we no longer need your participation in this study. I appreciate you taking this call and speaking with me and hope you enjoy the rest of your day.

If the answer to all of the screening questions is "yes":

I am calling to provide information about the study and answer any questions you may have. I hope you and your family will consider participating in the study by completing a demographic surgery and virtual video interviews on a date and time that works well for you. I would like to give you some more information about the study. Do you have a few minutes for me to discuss this with you?

If the answer is "yes":

I would like to learn more about the experiences of school-aged children living with a brother or sister with a complex congenital heart defect. I am interested in learning about these daily experiences as well as how these experiences may change when their brother or sister is in the hospital or receiving surgery. Additionally, I am interested in learning more about the perceived support of your children who do not have a heart defect.

There is no financial cost for participating. Your child's interviews will take place using a virtual video system called WebEx. During these interviews, I am hoping to speak with your child about their brother or sister's heart defects and conversations around this, their daily routine, and how their experiences change when their brother or sister is staying in the hospital or receiving surgery. Do you have access to the Internet and a computer, smartphone, or tablet to complete this interview?

I will be sending you more detailed information about the study, but at this time, do you have any questions regarding this study?

Do you think you might still be interested in allowing your child to participate in this study? After this phone call, I will be mailing you a study packet. This packet will include the consent and assent forms, the demographic questionnaire, the health literacy questionnaire, and two mental health screeners. The demographic questionnaire will ask questions about your household makeup and some general questions about your child's heart diagnosis.

The *consent form* and *demographic questionnaire* are **yours** to complete; the *assent form, health literacy questionnaire, and mental health screeners* are **your child's** to complete. The health literacy questionnaire will ask for information regarding their brother or sister's heart diagnosis as well as their experiences in having these conversations. The mental health screeners are standardized and will screen for the severity of anxiety and depression symptoms. Before we can complete an interview, I will need to have these returned using the postage-paid envelope. What is the best mailing address for you to receive these?

Would you and your child prefer to complete these over the phone or by mail?

(if by phone): Great! Is there a date and time that works for the both of you for us to schedule a follow-up phone call? This will likely take between 30-45 minutes.

(if by mail-in): Great! I will be sending these tools in the mail along with a pre-paid postage envelope for these to be mailed back.

I will also email you my availability so that we can schedule a date and time for an interview.

If you and your children decide to participate, you are still able to drop out of the study at any point in time.

I appreciate your time. Please let me know if you have any questions regarding the study, either now or at any point of time in the future. You can reach my thesis advisor, Dr. Priti Desai, at 252-328-2866, or you may email me directly at bernardinoa20@students.ecu.edu. All of this contact information is also available on the flier that was sent via email.

Thank you so much for your time today!

APPENDIX K: FAMILY DEMOGRAPHIC QUESTIONNAIRE

For researcher and team use only	
Participant Code: _____	Date Received: _____
Final Participant: Yes No	Date of Analysis: _____

This questionnaire is designed to better understand your family makeup and demographics. It consists of four sections: household makeup; parental information; child with complex congenital heart defect information; and well-sibling information. Each section will provide instructions for how to complete it. If for any question, you do not wish to answer, please mark or write "prefer not to state."

Section I: Household Makeup

a. Household

This section is aimed to better understand your current household makeup. Please write a number on the blank provided to represent the number of people living in your home falling under each category.

_____ People Living in the Home

_____ Adults (18+ years of age)

The following questions will ask about specific relationships between people living in the home. Please refer to relationships as they pertain to your child with a complex congenital heart defect. Please identify how many people falling under each category currently live in your home by writing a number on the blank provided. If the answer is zero, you may either write "0" or leave blank.

_____ Biological Parents
_____ Stepparents
_____ Aunts/Uncles
_____ Siblings
_____ Biological Grandparents
_____ Step-grandparents
_____ Cousins

_____ Children (less than 18 years of age)

_____ Siblings of Child with Complex Congenital Heart Defect

_____ Stepsiblings
_____ Half-siblings
_____ Full siblings

The following questions are to better understand where your children currently reside. Please write the answer for each on the blank provided.

b. With whom does your child with a heart defect currently live?

_____

c. With whom do your child with a heart defect's siblings currently live?

_____

The following questions are to better understand the current ages of your children. Please write the answer for each on the blank provided.

d. What is the current age of your child with a complex congenital heart defect *(in years)*?

_____

e. What are the current ages of their siblings *(in years)*?

_____

The following question is to better understand your current household income. Please place a check or "X" on the line next to the answer that best represents your annual household income.

f. What is your annual household income?

_____ less than $20,000
_____ $20,000-$34,999
_____ $35,000-$49,999
_____ $50,000-$74,999
_____ $75,000-$99,999
_____ $100,000-$149,999
_____ greater than $149,999
_____ Prefer not to Answer

Section II: Parent/Guardian Information

*The following section is to gather parent/guardian demographic information. For the following questions, please report as information applies to **yourself**. If for any question, you do not wish to answer, please mark or write "prefer not to state."*

a. What is your age (in years)? Please write the number on the blank provided. _____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is your gender?

_____ Male
_____ Female
_____ Gender Non-Binary
_____ Transgender Male
_____ Transgender Female
_____ Other/Prefer not to State

c. What is your race/ethnicity?

_____ White
_____ Hispanic or Latino
_____ Asian/Pacific Islander
_____ Native American
_____ African American
_____ Multiracial
_____ Biracial
_____ Other/Prefer not to State

d. What is the highest level of education you have completed?

_____ Some High School; No Diploma
_____ High School Graduate
_____ Some College Credit; No Degree
_____ Trade Training
_____ Other/Prefer not to State
_____ Associate Degree
_____ Bachelor's Degree
_____ Master's Degree
_____ Doctorate Degree

e. What is your current occupation?

_____ Protective Service Occupations
_____ Business and Financial Operations Occupations
_____ Healthcare Support Occupations
_____ Education, Training, and Library Occupations
_____ Computer and Mathematical Occupations
_____ Management Occupations
_____ Food Preparation and Serving Related Occupations
_____ Farming, Fishing, and Forestry Occupations
_____ Homemaker/Unemployed
_____ Other

*The following section is to gather parent/guardian demographic information. For the following questions, please report as information applies to **your partner**. If for any question, you do not*

wish to answer, please mark or write "prefer not to state." If there is only one parent/guardian in your home, please mark here (_____) and move on to the next section.

a. What is your partner's age (in years)? Please write the number on the blank provided.

_____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is your partner's gender?

_____ Male
_____ Female
_____ Gender Non-Binary
_____ Transgender Male
_____ Transgender Female
_____ Other/Prefer not to State

c. What is your partner's race/ethnicity?

_____ White
_____ Hispanic or Latino
_____ Asian/Pacific Islander
_____ Native American
_____ African American
_____ Multiracial
_____ Biracial
_____ Other/Prefer not to State

d. What is your partner's highest level of education completed?

_____ Some High School; No Diploma
_____ High School Graduate
_____ Some College Credit; No Degree
_____ Trade Training
_____ Other/Prefer not to State
_____ Associate Degree
_____ Bachelor's Degree
_____ Master's Degree
_____ Doctorate Degree

e. What is your partner's current occupation?

_____ Protective Service Occupations
_____ Business and Financial Operations Occupations
_____ Healthcare Support Occupations
_____ Education, Training, and Library Occupations
_____ Computer and Mathematical Occupations
_____ Management Occupations
_____ Food Preparation and Serving Related Occupations
_____ Farming, Fishing, and Forestry Occupations
_____ Homemaker/Unemployed
_____ Other

Section III: Information of Child with Complex Congenital Heart Defect

The following section is to gather demographic information about your child with a complex congenital heart defect. For the following questions, please report as information applies to ***this child****. If for any question, you do not wish to answer, please mark or write "prefer not to state."*

a. What is this person's age *(in years)*? Please write the number on the blank provided.

_____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is this person's gender?

_____ Male
_____ Female
_____ Gender Non-Binary
_____ Transgender Male
_____ Transgender Female
_____ Other/Prefer not to State

c. What is this person's race/ethnicity?

_____ White
_____ Hispanic or Latino
_____ Asian/Pacific Islander
_____ Native American
_____ African American
_____ Multiracial
_____ Biracial
_____ Other/Prefer not to State

The following questions are to understand more about your child's heart defect and your experiences in discussing this with your other children.

d. What is the name of their complex congenital heart defect(s)? Please write your answer on the blank provided.

_____
_____
_____

e. Do they have any other health diagnoses? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any other health diagnoses on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____
_____
_____

f. How many heart-related surgeries have they had? Please write a number on the blank provided. _____

When was their most recent heart-related surgery? Please write your answer on the blank provided in **month-year** format. _____

g. What have you told your other child(ren) about their heart diagnosis?

_____
_____
_____
_____

What prompted this conversation?

_____
_____
_____
_____

What was your experience in having this conversation?

_____
_____
_____
_____

How has this conversation changed over time, if at all, as your children have gotten older?

_____
_____
_____
_____

Section IV: Information of Well-Siblings

This section is to gather information about the well-children living in your home. Each will be given their own section for you to report on. For the following questions, please report as information applies to ***the oldest well-sibling****. If for any question, you do not wish to answer, please mark or write "prefer not to state."*

a. What is this person's age *(in years)*? Please write the number on the blank provided.

_____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is this person's gender?

_____ Male
_____ Female
_____ Gender Non-Binary
_____ Transgender Male
_____ Transgender Female
_____ Other/Prefer not to State

c. What is this person's race/ethnicity?

_____ White
_____ Hispanic or Latino
_____ Asian/Pacific Islander
_____ Native American
_____ African American
_____ Multiracial
_____ Biracial
_____ Other/Prefer not to State

d. Does this person have any health diagnoses *(such as asthma, epilepsy, or allergies)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any other health diagnoses on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____
_____
_____

e. Does this person have any mental health diagnoses *(such as anxiety, depression, or obsessive-compulsive disorder)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any mental health diagnoses on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____
_____
_____

h. Therapy is a way to help support people who may be struggling with a mental diagnosis. It can help to eliminate or control symptoms so they can better cope and to increase their well-being. Does this person currently attend any type of therapy *(such as individual, group, or family)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing which type of therapy on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____

_____

_____

f. Has this person ever visited your child with a complex congenital heart defect while they were staying in the hospital? Please place a check or "X" on the blank corresponding with your answer.

_____ Yes _____ No

g. A certified child life specialist is a professional who works with children staying in the hospital and their families. These professionals help with coping with being in the hospital as well as having an illness. Has this person ever spoken with a child life specialist? Please place a check or "X" on the blank corresponding with your answer.

_____ Yes _____ No

*For the following questions, please report as information applies to **the second oldest well-sibling**. If there are no more well-siblings living in your home, please mark here (_____). If for any question, you do not wish to answer, please mark or write "prefer not to state."*

a. What is this person's age *(in years)*? Please write the number on the blank provided.

_____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is this person's gender?

_____ Male _____ Transgender Male

_____ Female _____ Transgender Female

_____ Gender Non-Binary _____ Other/Prefer not to State

c. What is this person's race/ethnicity?

_____ White _____ African American

_____ Hispanic or Latino _____ Multiracial

_____ Asian/Pacific Islander _____ Biracial

_____ Native American _____ Other/Prefer not to State

d. Does this person have any health diagnoses *(such as asthma, epilepsy, or allergies)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any other health diagnoses on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____

_____
_____

e. Does this person have any mental health diagnoses *(such as anxiety, depression, or obsessive-compulsive disorder)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any mental health diagnoses on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____
_____
_____

i. Therapy is a way to help support people who may be struggling with a mental diagnosis. It can help to eliminate or control symptoms so they can better cope and to increase their well-being. Does this person currently attend any type of therapy *(such as individual, group, or family)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing which type of therapy on the blanks provided.

_____ Yes _____ No

If yes, please specify:

_____
_____
_____

f. Has this person ever visited your child with a complex congenital heart defect while they were staying in the hospital? Please place a check or "X" on the blank corresponding with your answer.

_____ Yes _____ No

g. A certified child life specialist is a professional who works with children staying in the hospital and their families. These professionals help with coping with being in the hospital as well as having an illness. Has this person ever spoken with a child life specialist? Please place a check or "X" on the blank corresponding with your answer.

_____ Yes _____ No

*For the following questions, please report as information applies to **the third oldest well-sibling**. If there are no more well-siblings living in your home, please mark here (_____). If for any question, you do not wish to answer, please mark or write "prefer not to state."*

a. What is this person's age *(in years)*? Please write the number on the blank provided.

_____

For the following questions, please place a checkmark or an "X" on the blank that best corresponds with your answer. If for any question you do not wish to answer, please mark the line corresponding with "prefer not to state."

b. What is this person's gender?

_____ Male _____ Transgender Male
_____ Female _____ Transgender Female
_____ Gender Non-Binary _____ Other/Prefer not to State

c. What is this person's race/ethnicity?

_____ White _____ African American
_____ Hispanic or Latino _____ Multiracial
_____ Asian/Pacific Islander _____ Biracial
_____ Native American _____ Other/Prefer not to State

d. Does this person have any health diagnoses *(such as asthma, epilepsy, or allergies)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any other health diagnoses on the blanks provided.
_____ Yes _____ No
If yes, please specify:
_____
_____
_____

e. Does this person have any mental health diagnoses *(such as anxiety, depression, or obsessive-compulsive disorder)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing any mental health diagnoses on the blanks provided.
_____ Yes _____ No
If yes, please specify:
_____
_____
_____

j. Therapy is a way to help support people who may be struggling with a mental diagnosis. It can help to eliminate or control symptoms so they can better cope and to increase their well-being. Does this person currently attend any type of therapy *(such as individual, group, or family)*? Please place a check or "X" on the blank corresponding with your answer. If you select "yes," please specify by writing which type of therapy on the blanks provided.
_____ Yes _____ No
If yes, please specify:
_____
_____
_____

f. Has this person ever visited your child with a complex congenital heart defect while they were staying in the hospital? Please place a check or "X" on the blank corresponding with your answer.
_____ Yes _____ No

g. A certified child life specialist is a professional who works with children staying in the hospital and their families. These professionals help with coping with being in the hospital as well as having an illness. Has this person ever spoken with a child life specialist? Please place a check or "X" on the blank corresponding with your answer.
_____ Yes _____ No

Thank you so much for your time in completing this questionnaire! If you have additional children living in your home, please report on them by attaching a separate sheet of paper to this questionnaire and mailing it along with your signed consent and assent forms.

APPENDIX L: HEALTH LITERACY QUESTIONNAIRE

For researcher's use only	
Participant Code: _____	Date Received: _____
Final Participant: Yes No	Date of Analysis: _____

A health literacy survey is designed to see how much you know about your brother or sister's heart diagnosis. It is okay to not know some of the answers to these questions. Please answer as best as you can. Please complete this form by yourself (without help from anybody else) by writing your answers in the blank for each question. If you do not know an answer, it is okay to write "I don't know." If you need more space, you may write the number of the question on the back of this paper or attach another page.

1. What is the name of your brother or sister's heart diagnosis?

_____

_____

2. What do you know about their heart diagnosis/condition?

_____

_____

_____

_____

_____

_____

3. Who first told you about their heart diagnosis?

_____

_____

4. If you have questions about their heart diagnosis or treatment, who do you ask?

_____

_____

_____

5. What was your initial experience in talking with your parents or guardians about your brother or sister's diagnosis? What information did they tell you? How did you feel when having this conversation?

6. How has this experience of talking with your parents or guardians about your brother or sister's diagnosis changed as you have gotten older and had ongoing conversations?

7. Do you feel like you have enough information about your brother or sister's heart diagnosis? If no, what do you wish you still knew?

8. Is there anybody else (besides your parents or guardians) you talk to about your brother or sister's diagnosis? If yes, what has been your experience with this?

_____

_____

_____

_____

_____

_____

APPENDIX M: PATIENT HEALTH QUESTIONNAIRE-8 (PHQ-8)

Depression is a mental health diagnosis experienced by many people. It is defined as a consistent feeling of sadness and loss of interest in everyday activities. Some common symptoms include sadness, difficulty sleeping, and changes in appetite. The following questions are designed to measure your symptoms of depression. For each, please report on the frequency with which you have experienced each symptom ***over the past two weeks****. Circle the number that corresponds with your answer choice.*

	Not at all	Several Days	More than half the days	Nearly every day
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3
Trouble falling or staying asleep, or sleeping too much	0	1	2	3
Feeling tired or having little energy	0	1	2	3
Poor appetite or overeating	0	1	2	3
Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
Trouble concentrating on things, such as reading or watching television	0	1	2	3
Moving or speaking so slowly that other people could have noticed; or, the opposite – being so fidgety and restless that you have been moving around a lot more than usual	0	1	2	3

APPENDIX N: GENERALIZED ANXIETY DISORDER-7 (GAD-7)

Anxiety is a mental health diagnosis experienced by many people. It is defined as intense and persistent worry and fear about everyday situations. Some common symptoms include increased heart rate, rapid breathing, and sweating. The following questions are designed to measure your symptoms of anxiety. For each, please report on the frequency with which you have experienced each symptom ***over the past two weeks****. Circle the number that corresponds with your answer choice.*

	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious, or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Worrying too much about different things	0	1	2	3
Trouble relaxing	0	1	2	3
Being so restless that it's hard to sit still	0	1	2	3
Becoming easily annoyed or irritable	0	1	2	3
Feeling afraid as if something awful might happen	0	1	2	3

APPENDIX O: PARTICIPANT INTERVIEW SCHEDULE

Participant Code: _____ Date of Interview: _____

Thank you for agreeing to participate in this study. Before we move forward with the interview, I would like to provide you with a brief introduction and explanation of this study.

I am interested in talking with brothers and sisters of children with complex congenital heart defects in an effort to learn and understand more about your experiences, daily lives, and perceived social support. I am wanting to learn about your ways of coping with your brother or sister's diagnosis and the impact, if any, that it has had on your life. I am also interested in talking with you about your mental health and how, if at all, this has been impacted by your brother or sister's diagnosis. Finally, I am wanting to see if you have any suggestions for how you can be better supported or involved with your brother or sister's care. I will be recording your interview so that I can have notes and remember all of the information that you share; however, all of your responses will be kept confidential and will not be shared with anybody that is not directly involved within this study. The exceptions to this are if you tell me about an adult currently or previously hurting you; if you tell me about an adult hurting an elder; if you tell me about an adult hurting a person with a disability; or if you tell me about any threat or intention to hurt yourself or somebody else.

You have control over this interview and do not have to share anything you are not comfortable with. You also have the right to stop this interview at any time – just let me know if or when this is the case. I also want to be sensitive to the fact that discussing some of these topics may bring up some memories and difficult feelings. If this is the case for you, please let me know at any time so I can provide you and your family with some resources to help manage these. To protect your identity and maintain your confidentiality, any names of people or places that you share during this interview will be removed when it is transcribed. Additionally, your name and identity will never be used during transcription and data analysis. Do you have any questions before continuing? Are you ready to begin?

(start meeting and recording on WebEx)
This is ____ *(participant's code)*.

follow-up questions for each research question will vary based on each participant's answers and their birth-order

1. What is it like for you to have a brother or a sister with a heart defect?
    a. What aspect of your daily life do you find to be the most difficult about having a brother or a sister with a heart defect?
    b. What are the most helpful and positive aspects?
    c. What kinds of things worry you about having a brother or a sister with a heart defect?
    d. Who can you talk to when you feel worried?
    e. Have you found other ways of coping with feelings of being worried?
        i. What are some of these ways?

2. What is it like for you when your brother or sister with a heart defect is staying in the hospital?
    a. Did your brother or sister with a heart defect get surgery in the same state in which you live or a different one?
    b. What do you remember about this time?
    c. As far as you can remember, have you ever talked with a child-life specialist about your brother or sister's heart diagnosis?
        i. What was this experience like for you?
    d. How does your daily routine change when you brother or sister with a heart defect is staying in the hospital? Are these changes positive or negative?
    e. What kinds of things worry you about having a brother or sister with a heart defect when they are at the doctor or staying in the hospital?
        i. Do you feel as if you are able to control it?
        ii. Are there people you feel like you can talk to that help you manage your worry?
        iii. Have you found other ways of coping with feelings of being worried? *If yes, what are some of these ways?*
    f. Who do you feel you can talk to when your brother or sister with a heart defect is at the doctor or staying at the hospital and you feel worried?
3. Who do you identify as being members of your support system?
    a. Are you or your family currently involved with any type of support group?
        i. What has been your experience participating in these?
        ii. Do you feel included in the activities?
        iii. Do you feel as if these groups meet your needs for support?
        iv. Is there anything you would like for these programs to add that would improve your experience?
    b. What was it like for you when your brother or sister went to camp?
        i. How included or not did you feel?
    c. Do you currently attend any type of therapy?
        i. How long have you been attending therapy?
        ii. What happened for you to decide to start going to therapy?
        iii. How has this experience been for you?
4. What is it like to be a member of your family?
    a. Are there differences in the way your parents treat you in comparison to your brother or sister with a heart defect?
        i. What kinds of differences do you notice?
        ii. Are these positive or negative?
    b. What are your responsibilities within your family?
        i. Are these the same or different from your other brothers and sisters, specifically your brother or sister with a heart defect?
    c. Describe your relationship with your parents.
        i. Is this the same or different as you think it is for your brother and sisters?
    d. What is your relationship like with each of your brothers and sisters?
5. Tell me a little bit about your relationships with people outside of your immediate family. These people can be anybody, including your friends, teachers, neighbors, and extended family.

a. How do people outside of your immediate family treat you?
    i. Is this the same or different from how they treat your brother or sister with a heart defect?
    ii. Are these differences positive or negative?
b. Tell me about your friends at school.
    i. What kinds of things do you enjoy doing together?
    ii. Do you spend time together outside of school?
        1. Are they able to come to your house?
        2. What is the process of inviting a friend over?
        3. Are there any limitations or rules your parents have about inviting friends over?
c. What do you enjoy doing outside of school?
    i. Are you a member of any teams or clubs?
        1. What has been your experience participating in these?
        2. What is the most positive aspect?
        3. What is the most negative?
    ii. Have the activities you are involved in ever changed?
        1. When did these changes happen?
        2. What occurred that made these changes happen?
d. Are there things your friends are able participate in or do that you cannot?
    i. Why do you think this is?
    ii. What has this been like for you?
e. Are there other people outside of your immediate family you enjoy spending time with?

Open-Ended

6. If you could offer advice to another child in a similar situation, what would you want to say?
7. Is there anything else you would like to add?
8. How are you feeling right now?

I want to thank you so much for your time today and for being willing to talk with me. I know some of these questions are not easy to discuss, especially virtually with a person that you have never met before. I appreciate your time and your honesty. I encourage you to talk with your parents at any time if you feel you would like to speak with a professional in the field of mental health (also known as a therapist), or with a child life specialist. I would like to let you and your parents know that more questions may come up in the future and encourage you to have conversations about these. I will be sending your parents some information about how to facilitate these conversations as well as resources if, at any point, you decide it would be beneficial to attend therapy. Do you have any questions or anything else you would like to add at this point? (if no) Thank you so much for your time. I enjoyed speaking with you today.

Some of the questions in this interview guide have been adapted from a previous study by Menke (1987).

APPENDIX P: PARENT DEBRIEFING EMAIL

Dear parent or caregiver,

Thank you again for allowing your child to be a part of this study. It provided valuable information as to how well-siblings experience living with a brother or sister with a complex congenital heart defect. I want to reiterate that some of the topics discussed in our interview may have been difficult for your child and may have brought up a mix of feelings including pride, sadness, happiness, protectiveness, or anger. Many of these feelings are extremely normal and may continue to present themselves as your child continues to process and relieve previous experiences.

Your child may be asking more questions about their brother or sister's diagnosis, about rules that have been created in your family, and what happens when their brother or sister is at the doctor or in the hospital. They may also be discussing their personal experiences more and sharing what their experience so far has been like for them. Again, all of this is normal as they begin to process through information they may not have previously considered.

Your child has been encouraged to share any large feelings with you and to alert you if they begin to feel overwhelmed or start to need additional support. Should you need referrals to resources in your area, please contact your camp director for information for their camp child life specialist. They will be able to point you in the right direction and help make sure your child feels seen, heard, and validated. If your child needs to debrief within a couple of weeks of their interview and further discuss some topics that may have come up, please contact Dr. Priti Desai, a certified child life specialist (desaip@ecu.edu or 252-328-2866) or Dr. Andrew Brimhall, a licensed Marriage and Family Therapist (brimhalla@ecu.edu or 252-737-2076).

Again, thank you for allowing your child to participate in this study.

Sincerely,

Annalise Bernardino