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ACADEMIC OUTCOMES AMONG CHILDREN WITH CONGENITAL HEART DISEASE: A PAIRED SIBLING STUDY

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ABSTRACT

ACADEMIC OUTCOMES AMONG CHILDREN WITH CONGENITAL HEART DISEASE: A PAIRED SIBLING STUDY

By Penelope Strid

Objective. A better understanding of long-term development among children with congenital heart disease (CHD) is needed as survival rates have improved.
Population. A cohort of 208 adolescents born between 1998 - 2003, and surgically treated at Children's Healthcare of Atlanta for CHD and their similarly-aged siblings were recruited to assess long-term outcomes in children with CHD. Parents completed questionnaires about academic and social function of both children. Siblings with birth defects were excluded from the study and if more than one sibling was eligible, the one closest in age to the proband was selected.
Methods. The association between CHD and academic outcomes was assessed. Three characteristics of poor academic success were studied: ever having an individualized education plan (IEP), current eligibility for an accommodation, and ever repeating a grade since starting kindergarten. Using conditional logistic regression, models were adjusted for sex and current grade. To understand the observed associations better, the combined contribution of CHD, type of school attended and comorbidities were considered on the association with adverse educational outcomes.
Results. Among children with CHD, 71 (34.1%) experienced at least one of three adverse academic outcomes. In contrast, only 33 (15.9%) of the siblings had experienced an academic outcome of interest. From paired crude analysis, the odds of a child with CHD having one of the outcomes was approximately three times greater than the odds among siblings. When controlling for sex and current graded level, children with CHD were more likely to ever have an IEP than were their siblings (OR: 5.79, 95% confidence interval (CI): 2.06, 16.28). The odds of currently receiving an academic accommodation were 5.78 (95% CI: 2.15, 15.54) times the odds for siblings when controlling for current grade. The percentage of children with CHD who had repeated a grade was more than twice that of siblings. When controlling for grade level, the odds of repeating a grade were 4.20 (95% CI: 1.50, 11.70) times greater for children with CHD compared to their siblings.
Conclusions. Among adolescents, individuals with CHD were more likely to experience adverse academic outcomes and require academic assistance compared to their similarly-aged siblings.

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ABBREVIATIONS

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CHD	Congenital Heart Disease
CHOA	Children's Healthcare of Atlanta
CI	Confidence Interval
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Forth Education, Text Revisions
GED	General Equivalency Diploma
IDEA-2004	Individuals with Disabilities Education Improvement Act
IEP	Individualized Education Plan
OR	Odds Ratio
StICHD	Studying the Impact of Congenital Heart Disease
US	United States
VDS	Ventricle Septal Defect

BACKGROUND

Congenital heart disease (CHD) is a broad term describing heart defects present at birth (1, 2). In the United States (US) approximately 1% of live births have a congenital heart defect (3, 4). Across all ages, a 2016 study estimated about 2.4 million individuals are living with CHD in the US (3-5). From 2000-2005, the reported prevalence of CHD in Atlanta was 86.4 per 10,000 live births (6). This was a notable increase in prevalence of CHD since data from 1978-1983 suggested the prevalence was 50.3 per 10,000 live births (6). The increase in prevalence is suggested to be associated with improved echocardiography for diagnosis, and improved survival rates from better surgical procedures (7, 8). The mortality rate among individuals with CHD is greatest in the first year of life, and varies by the severity of the heart defect (9-11). Among all severities, the one-year survival rate has been improving, and more than 85% of those born with CHD now survive to adulthood (9, 11, 12). More than 60% of individuals currently living with CHD are adults (13). With increasing life expectancy, there is a need to better understand the impact of CHD on long-term development.

Given the breadth of defects described by CHD, further classification is used to distinguish defects by their severity and/or the type of surgical repair needed to treat the defect (14, 15). Various studies have suggested a tertiary classification of CHD by severity. Severe CHD includes cyanotic heart disease, the most common being tetralogy of Fallot (16-18). Moderate CHD captures cases with aortic incompetence, noncritical coarctation, large atrial septal defects, and complex ventricular septal defects (VSD) (16). The least severe disease states are considered mild CHD and includes small VSD, small patent ductus arteriosus, and mild pulmonic stenosis (16, 19, 20). Some defects may be

resolved over time, for example a small VSD may close itself as a child grows, however, many types of CHD require surgical intervention during infancy (7, 21).

The association between birth defects and comorbidities such as developmental, cognitive, and intellectual disabilities has been well reported (22-28). In general, more severe birth defects are associated with a higher risk of such comorbidities (24, 25). Additionally, the United States Institute of Medicine Committee on Social Security Cardiovascular Disability Criteria suggests that all individuals with CHD be evaluated for comorbidities, specifically mentioning a need for learning disability and cognitive impairment to be reported (1). Numerous studies have examined the association between congenital heart disease and neurodevelopment (29-35). In a study of 131 newborns and infants that were surgically treated for CHD, neurodevelopmental abnormalities were reported among more than 50% of the newborns, and 38% of the infants, with no significant difference in neurodevelopmental status after surgery (31). Furthermore, in this study, newborns with cyanotic heart disease (i.e. severe CHD) were more likely to have compromised neurodevelopment (31). Most studies assessing the neurodevelopment of individuals with CHD, have been focused on young populations, such as newborns, infants, and elementary-aged children (10, 34, 36, 37). Limited research has focused on the association between congenital heart disease and neurodevelopment among adolescents (28, 33).

Many factors contribute to compromised neurodevelopment in children with CHD, however the underlying causes are still unknown. Studies suggest inhibited brain maturation may cause neurodevelopment abnormalities; if blood flow is compromised, the brain may not receive enough oxygen (30, 32). Several proposed causes of

neurodevelopmental deficits such as preoperative acidosis and hypoxia, anesthetic technique used, and length of stay in the intensive care unit, are associated with the surgical procedure(s) many children with CHD have within their first year of life (29, 38-40). Other proposed causes of CHD neurodevelopmental deficits include: genetic factors, premature birth, and environmental impacts of socioeconomic status (29, 30, 33, 37, 41). This is concerning as neurodevelopment deficits, and developmental and cognitive disabilities present at a young age, can impact a child's long-term development, including academic performance (33, 42, 43).

Long-term developmental outcomes such as academic achievements are particularly important to study as education influences health, and social and economic development at both an individual and population level (44, 45). Among children with CHD, the odds of missing more than 10 days of school within a school year are three times higher compared to children without CHD (45). Most studies examining academic outcomes among children with CHD have only focused on standardized school-aged test performance and receipt of special education services as the education outcome of interest (29, 40, 41, 46-48). Remedial education services and policies vary by state and are impacted by funding, and state socio-economic attributes (49). Furthermore, defining and evaluating conditions that may require academic accommodations varies. For example, the definition and evaluation of autism spectrum disorder (ASD) was compared between three reference sources: state education agencies, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), and the Individuals with Disabilities Education Improvement Act (IDEA-2004) (50). The Department of Education for each state in the US is able to define special education eligibility categories, and as Pennington

et al. described, the definitions are inconsistent across the US (50, 51). The definition and evaluation method described in DSM-IV-TR is a standard developed by the American Psychiatric Association and is used by medical professionals to diagnose and classify conditions such as autism (52). Finally, IDEA-2004 is an amendment to the US special education law, and it changed autism to a disability category for education (50). This inconsistency among state and federal resources, provides motivation to further understand the effect CHD has on academic outcomes.

Generalizable studies will provide families and schools with evidence to take steps, such as providing developmental screening, to ensure children with CHD receive necessary assistance, even if they do not appear to have the specific case definition described by the state. Additionally, the study by Pennington et al. highlights the importance of including comorbidities such as ASD as mediators in models assessing the association between CHD and academic outcomes (50). Other common mediators in this relationship include attention deficit disorder (ADD)/ attention deficit hyperactive disorder (ADHA), intellectual disability, and learning disability (29, 45, 48). Furthermore, cardiovascular diseases have been linked to impaired executive function, memory, and language (53).

Various interventions have been associated with improved academic outcomes among children with birth defects and multiple disabilities. For example, an individualized education plan (IEP) can be established to address a student's academic and nonacademic/ behavioral needs (54). However, in order for a IEP to be discussed, a child must have a condition documented in IDEA-2004 (55). In contrast, accommodations such as receiving extra time to complete tasks, or given preferential

seating in the classroom can be established at the teacher's discretion, or by parent's request. Therefore, individuals with conditions not "severe" enough for an IEP, but still requires some academic assistance can be captured. Grade retention is a controversial academic outcome. Advocates of grade retention note benefits such as decreased hyperactivity, and increased behavioral engagement of students based on teacher ratings (56, 57). Negative effects of repeating a grade include poor social adjustment, and increased risk of not attaining a high school degree, which can have significant long-term implications (56-58). A study by Peterson and Hughes found children that were retained in first grade received fewer remedial education services compared to similarly achieving students that were promoted to the next grade (59). This suggests, grade retention should not be considered without also assessing academic accommodations.

Historically, research on CHD has focused on improving survival, however, as diagnostics techniques and medical interventions have been enhanced, the life expectancy of those with CHD has improved. Therefore, long-term developmental outcomes such as academic achievements, are particularly important for the present research. Congenital heart disease is associated with many comorbidities which are likely to affect educational outcomes, but are also associated with familial and environmental factors such as genetics and socioeconomic status which can be difficult to control for. Therefore, this study used a paired design where the child with CHD was matched to their similarly-aged sibling to assess a variety of academic outcomes.

METHODS

Study Population

Participants for this study were a subset of the Studying the Impact of Congenital Heart Disease (StICHD) study which included all children born between 1998 and 2003 who were treated at Children's Healthcare of Atlanta (CHOA) for CHD. As part of StICHD, a parent or guardian for 497 of 1,532 eligible children with CHD were successfully contacted and completed a questionnaire about the child's academics and comorbidities, and family demographics. Families also had the opportunity to complete a similar questionnaire for a sibling. Eligible siblings were a full sibling (i.e. have the same biologic parents), born between 1997 and 2004, had not lived in a different home than the child with CHD for more than a year, and did not have a birth defect. If more than one sibling was eligible, the questionnaire was to be completed on the one who was closest in age to the child with CHD. Data were available for 218 sibling pairs.

Data Collection & Variable Selection

This study utilized conditional logistic regression to model three academic outcomes including ever having an IEP, receiving any academic accommodation, and ever repeating a grade since kindergarten, among this paired cohort of children with CHD and their similarly-aged siblings. The exposure of interest, congenital heart disease, was established by CHOA electronic health records, and the sibling were considered free of the exposure. Data on the children's academics, comorbidities, and the family demographics were obtained from parent/ guardian completed questionnaires sent via mail in pre-stamped envelopes, and entered into REDCap for data storage. Any information denoted as current, suggest the information was current at the time the

questionnaires were completed. Covariates and mediators were identified *a priori* for inclusion in the models. It was hypothesized that sex and grade level would be confounders in the analysis of the academic outcomes among children with CHD compared to their siblings while type of school, and comorbidities would mediate the effect. Although grade level is not a true confounder, grade level serves as a proxy for age, and age is associated with survival outcomes. Therefore, grade level was added to the models as a confounder. A paired analysis allowed for control of confounding variables such as familial and economic factors.

Outcomes of interest in this study were dichotomized and include ever having an individualized education plan, currently receiving at least one academic accommodation, and ever repeating a grade. Ever having an IEP was the sum of individuals that previously had an IEP but do not currently have an IEP, and those with a current IEP. Current accommodation indicated the child was receiving at least one of the following accommodations: additional time to complete tasks/ take tests, allowed to take tests in a quiet area, given preferential seating in the classroom (e.g. near the teacher), and graded or assessed on a different standard than classmates. Finally, grade retention was measured as the participant repeated at least one grade since starting kindergarten.

Many studies report outcomes stratified, by severity of CHD. In this study CHD was classified into three levels of severity. Covariates in this study included sex, and current grade. At the time of the questionnaire, participants were in 5^{th} – 12^{th} grade, so current grade level was split into quartiles. Early middle school included 5^{th} and 6^{th} grade, late middle school included 7^{th} and 8^{th} grade, early high school included 9^{th} and 10^{th} grade, and late high school included 11^{th} and 12^{th} grade.

Mediators of interest included type of school and seven comorbidities. Type of school was categorized into public, private, and other, where other included homeschools, charters, and hybrid schools (i.e. homeschool and online). Additionally, the seven current comorbidities included: autism spectrum disorder (ASD), attention deficit disorder (ADD)/ attention deficit hyperactive disorder (ADHA), hearing problems, intellectual disability, learning disability, speech or language problems, and vision problems that cannot be corrected with standard glasses or contact lenses.

Data Analysis

Continuous variables such as age were compared using a paired t-test, nominal variables such as sex and comorbidities were compared using McNemar's test, and Wilcoxon signed rank tests were used to assess a difference in multilevel variables such as type of school and current grade level. A frequency plot was developed for the comorbidities and includes exact 95% confidence intervals based on the binomial distribution.

Initially, a crude model containing only the exposure, CHD, was developed for each of the three outcomes and a Mantel-Haenszel odds ratio was recorded. Interaction by severity of CHD type was assess. Then, fully adjusted models were ran using an initial set of covariates, sex and current grade. Multilevel variables such as current grade were added to the model as dummy variables. Modeling strategy was used to determine if reduced models could be used in place of the fully adjusted models, and to assess the incorporation of mediating factors such as type of school and comorbidities. Referent groups were consistent throughout the models, and included females, public school, and late high school.

All data analysis was performed in SAS 9.4 (Carey, NC). StICHD was approved by the IRB of Emory University and Children's Healthcare of Atlanta. Informed consent was provided by completion of the questionnaire.

RESULTS

This study was limited to 208 sibling pairs; pairs were eliminated if the sibling had been out of high school for more than a year (n=9) or the sibling's grade information was missing (n=1). The demographic characteristics of the families included in this study, and characteristics of the children with congenital heart disease are described in table 1. Majority (86.1%) of the surveys were completed by a biologic mother, and therefore, data were available on highest level of maternal education. Conditional logistic regression was used for analysis so familial characteristics were controlled for by design. Approximately half (46.6%) of the children with congenital heart disease in this study have non-critical CHD, the least severe form of CHD. Only 18.3% have critical single ventricle CHD, the most severe type. The distributions of age, sex, and pre-1st grade programming were not significantly different between children with CHD and siblings. As described in Table 2, the average age at the time of survey for children with CHD was 14 ±1.6 years, while siblings were on average 13.9 ±2.2 years, resulting in a mean difference of 0.13 (95% CI: -0.24, 0.50). The CHD group had more males (53.8%) than the sibling group (45.2%). Most of the children in the study attended public school, and the grade level distribution between groups was similar with most participants being in late middle school (i.e. 7th and 8th grade).

Among the 208 sibling pairs, 50% of the pairs had at least one sibling with one or more of the seven comorbidities. Figure 1 illustrates the frequency of comorbidities among children with CHD and the siblings. Overall, children with CHD have a greater frequency of all comorbidities studied; however hearing impairment and learning disabilities were the only disabilities that were significantly more common in adolescents

with CHD than in their siblings. For example, among children with CHD, the odds of having autism is 4.00 (95% CI: 0.85, 18.84) times higher than the odds among siblings.

The crude association between the academic outcomes examined in this study and CHD status is illustrated in model 1 of Table 3. Initially, a chunk test was used to assess interaction between CHD and CHD severity; no interaction was observed for any of the outcomes. The fully adjusted, and reduced models are described in model 2. Among the 208 children with CHD, only 18 had all three outcomes, 20 had two outcomes, and 33 had only one outcome. Of the 208 siblings, just 7 had all three outcomes, 9 had two outcomes, and 17 had only one outcome. From the crude association, the odds of ever having an IEP among children with CHD is 3.89 (95% CI: 1.87, 8.09) times the odds of ever having an IEP among the siblings. After controlling for sex and grade level, the observed association was stronger among adolescents with CHD having nearly 6-fold greater odds of having an IEP than their siblings (OR= 5.79, 95% CI: 2.06, 16.28). Similarly, children with CHD were more than three times more likely to have a current academic accommodation than their sibling (OR= 3.64, 95% CI: 1.87, 7.09). Again, this association was stronger after adjusting for sex and grade level (OR= 5.86, 95% CI: 2.15, 16.03). Using modeling strategy, a reduced model that eliminated sex and fell within 10% of the fully adjusted model and had slightly greater precision (OR= 5.78, 95% CI: 2.15, 15.54). All the children that received an accommodation also received an IEP or 504 plan at some point in their education. The crude OR for grade retention was 3.29 (95% CI: 1.41, 7.66), while the fully adjusted OR was 4.24 (95% CI: 1.50, 12.01). As with current accommodations, removing sex from the model did not change the OR by more than 10%, and increased precision (OR= 4.20, 95% CI: 1.50, 11.70).

After this initial stage of modeling, the grade level and comorbidities were added to each adjusted model to better understand the observed associations between CHD and adverse educational outcomes. Among children with CHD, 5 of the 17 that attend a non-public, non-private school (e.g. homeschool), repeated at least one grade since kindergarten. Of these 5 children, 3 had siblings that attended public school. There was inadequate power to run the models with each mediator. Therefore, 21 sibling pairs were eliminated from the sample as one or both had ASD and/or an intellectual disability, as these were the most severe comorbidities. A crude analysis was performed on this subset of the data, however, the ORs did not differ from the crude ORs for the full sample. This suggests the difference in academic outcomes among children with CHD and similarly-aged siblings persists even when the mediators ASD and intellectual disability are not included.

DISCUSSION

Congenital heart disease is a serious health condition that impacts the lives of the child with CHD, and their families (60). Individuals with CHD are not only burdened by the physical health implications of a heart defect, but many have other serious developmental and cognitive impairments (24, 25). These burdens are compounded and have been associated with reduced quality of life, increased unemployment, and negative economic implications (61-64). This study assessed academic outcomes because education is an important foundation for adulthood success (65). As more individuals born with CHD are surviving to adulthood, long-term outcomes are of interest (3, 5). The three academic outcomes examined in this study included ever having an IEP, current accommodation eligibility, and grade retention. These outcomes were selected as they describe a range of accommodations available to students. IEPs require a diagnosis of at least one condition outlined in IDEA-2004. Additionally, an IEP is typically developed with a team of teachers, and the child's family. In contrast, academic accommodations are less structured and can be established at the classroom level. This provides flexibility, and may capture more children with academic needs, even if the child does not meet a case definition to be eligible for an IEP. Finally, grade retention was studied as repeating a grade can have great consequences on a child's long-term academic outcomes (56, 59, 65). To assess the association between CHD and these outcomes, a paired sibling study was used to control for unmeasured familial and environmental factors.

In this study, children with CHD were more likely than their siblings to need academic support as illustrated by the increased crude odds in table 3. This association persisted even when serious conditions such as autism and intellectual disability were

removed. More participants with CHD were male. This is expected as cases of CHD that need to be surgically treated are more common among males, and this study's CHD population was derived from hospital records of children surgically treated for CHD (5, 66). The rate of disabilities among siblings was consistent with the average among school children in Georgia (67).

More children with CHD attended private school or another type of school such as homeschooling, in contrast to siblings. When school type was added to the fully adjusted/ reduced models, the OR increased, suggesting the effect of CHD on the academic outcomes is not mediated by school type. Temporal association cannot be determined between type of school attended and grade retention as data were only available on current school type. It is possible that because the child repeated a grade, they changed school type.

A study by Mulkey and colleagues assess standardized school-aged achievements test outcomes and receipt of special education services among 362 children that had a surgery for CHD before their first (28). The study participants all attended public school and scored significantly lower on the achievement tests than the general student population of the state, regardless of sex, gestational age, age at surgery, CHD diagnosis, and type and number of surgeries (28). Furthermore, the children with CHD were more likely to receive special education services. Among children with CHD receiving special education, achievement tests scores were significantly associated with reports of autism, intellectual disability, and multiple disabilities (i.e. significant cognitive impairment) (28). This is consistent with the outcomes observed in this study; children with CHD will require greater academic accommodations while in school.

The frequency of comorbidities in this study were determined from only conditions reported as current. The questionnaires provided to the parent/guardian asked if the child had *ever* been diagnosed with a condition, and if the child was *currently* diagnosed with that condition. Therefore, only current comorbidities were added to the analysis to account for successful interventions/ treatment and possible misdiagnosis. Children with CHD may have a greater opportunity to be diagnosed with comorbidities as CHD may require them to visit health care providers more frequently than siblings without CHD. The prevalence of all comorbidities was greater among the children with CHD, but these comorbidities are known to be more common among children with CHD in contrast to the general population, so over-diagnosis is not likely present (29, 45).

In the state of Georgia, kindergarten is not required, and therefore it was determined that such programming would not be included in the models (68). Since pre-school attendance has been associated with positive academic outcomes, there was an interest in understanding if access to such programming varied between children with CHD and siblings (69, 70). Attendance at Head Start, a federal program designed for children of low-income families from birth to 5 years, was explicitly asked in the StICHD questionnaires (71). Among the 60 total children that attended Head Start, 7 from each group, or 14 total children had a sibling that did not attend the program. Therefore, Head Start attendance illustrates siblings had similar access to pre-school programming.

CHD is referred to as a common birth defect, however it is only present in 1% of live births (3). However, the outcomes, IEP and academic accommodation are common. Therefore, the odds ratio is likely an overestimate of the prevalence ratio. On average among the crude analysis in this study, the proportion of students with an adverse

academic outcome is 3 times greater if the child has CHD (Table 3). This suggests there is a baseline difference in the incidence of each academic out among children with CHD and their similarly-aged siblings. The magnitude of this association is likely influenced by a combination of the various comorbidities commonly experienced by children with CHD.

Strengths and Weaknesses

The major strength of this study was that confounding from factors shared by the siblings was eliminated through the use of a paired analysis. Severity of CHD, annual household income, race, and ethnicity were reported for generalizability of the study. Unknown confounding is a common limitation of most studies assessing academic outcomes among children with CHD. Paired analysis is not without limitations however, as any non-shared confounding factors among matched pairs will contribute a greater bias when in a paired analysis compared to an unpaired analysis (72). This study also benefitted from having three common outcomes of interest, as most prior studies have been limited to assessing academic outcomes by standardized school-age testing. Additionally, the academic outcomes assessed illustrate the role of CHD during adolescence, an important developmental period, and a time that has not yet received much attention from the CHD research community. Also, this dataset included CHD patients that may not have required on-going treatment, so mild cases of CHD, and cases requiring minimal follow-up were still likely captured.

The primary weakness of this study was a limited sample size, resulting in inadequate statistical power for some analyses. Furthermore, as a retrospective study, data were limited to information obtained by the StICHD questionnaires. The models

included type of school currently attended, however no data was available on the type of classroom a child was in (i.e. special education). From the initial StICHD population of 1,532 eligible families, this study only had data on 208 sibling pairs, approximately 14% of the original population. Additionally, the study population was obtained from a healthcare facility, so individuals not treated surgically for CHD are missing from our sample. Selection bias may be present as a result of non-responders from the initial population, and non-response for sibling data. These data were self-reported by the parent or guardian of the child so the data likely captures the truth, however we cannot eliminate the possibility that recall bias may be present.

FUTURE DIRECTIONS

This study illustrated that children with CHD are likely to experience more academic outcome difficulties that could benefit from interventions compared to similarly-age siblings without CHD. This information can be used by parents and schools to establish an education plan that will best suit the child's needs. Many future directions are possible to further understand the association between CHD and academic outcomes. The role of demographic characteristics of the families such as annual household income, maternal education, and race and ethnicity, could be studied as each is known to be associated with academics and health outcomes. This study was limited by inadequate statistical power from a small sample size. Efforts could be made to obtain information from the families that did not initially report. Or, other, larger cohorts could be used to assess these factors. Future studies focusing on academic outcomes would benefit from a more detailed academic history of the study participants. For example, in this study more information on the child's school type, if it ever changed and knowing why (e.g. because child needed to repeat grade, family sought different environment) could be helpful in assessing the magnitude of effect for some covariates. Additionally, to better understand the current incidence and prevalence of CHD in the United States, an epidemiologic study should be conducted. Current resources reference data from the 2002 study by Hoffman and Kaplan, and a Reller et al. study published in 2008, that utilized data from 1998-2005 (4, 16). More recent prevalence estimates such as that by Gilboa et al. is based on extrapolations of data from Quebec, Canada (5). Although the United States and Canada are similar, the race, ethnic, and socioeconomic distributions differ (3, 5). To better understand long-term developmental outcomes among children with CHD, studies

of increased sample size should be used to explore the association of CHD and various academic outcomes, while also assessing the direct and indirect effect of mediators (i.e. comorbidities).

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Table 1. Demographic characteristics of study sample children with congenital heart disease and their family.

	Participants N=208
	n (%)
Type of CHD	
Critical Single Ventricle	38 (18.3)
Critical Double Ventricle	73 (35.1)
Non-Critical	97 (46.6)
Highest Level of Maternal Education	
Less than high school diploma/GED	25 (12.0)
High school diploma/ GED - some college	41 (19.7)
4 year college degree	67 (32.2)
More than 4 year college degree	46 (22.1)
missing	29
Annual Household Income	
Less than $25,000	17 (8.2)
$25,000 - $50,000	34 (16.3)
$50,001- $100,000	59 (28.4)
More than $100,001	92 (44.2)
missing	6
Survey Responder	
Biologic Mother	179 (86.1)
Biologic Father	23 (11.1)
Grandmother	3 (1.4)
[a]Other	3 (1.4)
Race & Ethnicity	
Non-Hispanic White	155 (74.5)
Non-Hispanic Black	32 (15.4)
Hispanic	10 (4.8)
[b]Other	11 (5.3)

a. Other responder includes adoptive mother (2), aunt (1)
b. Other race includes American Indian (2), Asian (7), and mixed races

Table 2. Characteristics of study sample children with congenital heart disease compared to study sample siblings.

	CHD N=208	**Sibling N=208**	
	Average (±SD)		Mean Difference (95% CI)
Age	14.0 (1.6)	13.9 (2.2)	0.13 (-0.24, 0.50)
Sex	n (%)		McNemar, p-value
Male	112 (53.8)	94 (45.2)	s(1)=3.38 p=0.07
Female	96 (46.2)	114 (54.8)	
Type of School Currently Attending			Kruskal-Wallis, p-value
[a]Public	165 (79.3)	175 (84.1)	χ^2 (2)= 1.67 p=0.43
Private	26 (12.5)	19 (9.1)	
[b]Other	17 (8.2)	14 (6.7)	
Current Grade Level			Kruskal-Wallis, p-value
Early Middle School (5th & 6th)	20 (9.6)	48 (23.1)	χ^2 (3)= 26.51 p<0.01
Late Middle School (7th & 8th)	92 (44.2)	56 (26.9)	
Early High School (9th & 10th)	63 (30.3)	53 (25.5)	
Late High School (11th & 12th)	30 (14.4)	51 (24.5)	
missing	3	0	
Before 1st Grade Programming			McNemar, p-value
Any pre 1st Grade	195 (93.8)	198 (95.2)	s(1)=1.29 p=0.26
Head Start	30 (14.4)	30 (14.4)	s(1)=0 p=1.00

a. Includes online public school
b. Includes homeschooling, charter, and hybrid (private & homeschool)

Table 3. School outcome characteristics among children with congenital heart disease compared to siblings.

	CHD N=208	**Sibling N=208**	**[a]Model 1**	**[b]Model 2**
	n (%)		OR (95% CI)	OR (95% CI)
IEP				
[c]Ever	49 (23.6)	23 (11.1)	3.89 (1.87, 8.09)	5.79 (2.06, 16.28)
Previous	17 (8.2)	8 (3.8)	2.80 (1.01, 7.77)	
Current	32 (15.4)	15 (7.2)	3.13 (1.41, 6.93)	
Current Accommodations				
At least 1 accommodation	48 (23.1)	29 (13.9)	3.64 (1.87, 7.09)	5.78 (2.15, 15.54)
Additional Time	42 (20.2)	17 (8.2)		
Test in Quiet Area	29 (13.9)	14 (6.7)		
Preferential Seating	28 (13.5)	15 (7.2)		
Different Scale	14 (6.7)	6 (2.9)		
Ever Repeated Grade	30 (14.4)	14 (6.7)	3.29 (1.41, 7.66)	4.20 (1.50, 11.70)

a. Crude, modeled with only exposure, CHD
b. Fully adjusted/ reduced models. IEP ever modeled with CHD, sex, and grade. Current accommodations and ever repeated grade modeled with CHD, and current grade.
Referent categories include: no CHD, female, and late high school.
c. IEP ever is sum of current and previous

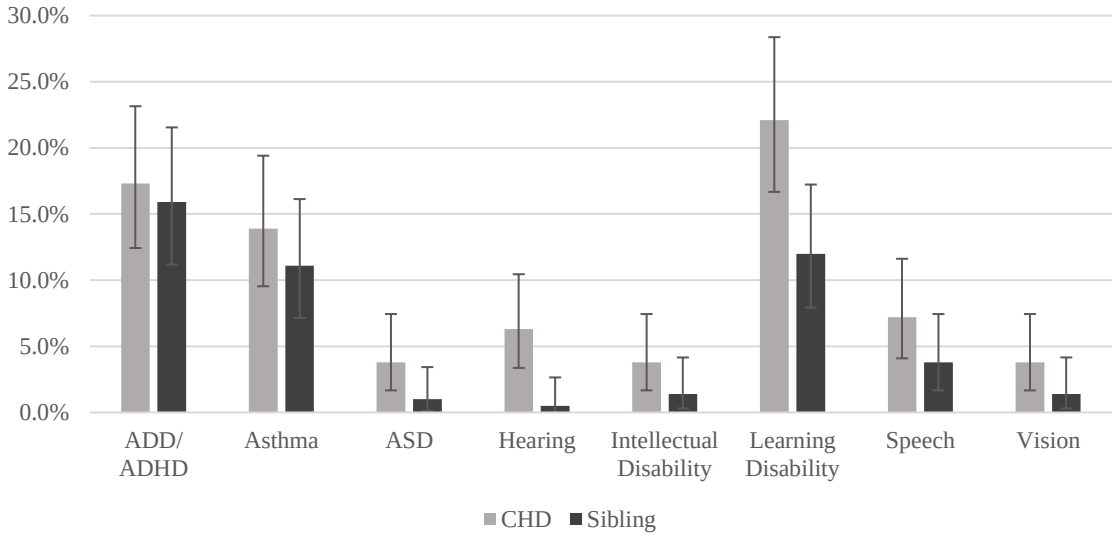

Figure 1. Frequency of other conditions among children with congenital heart disease and siblings with