Long-Term Outcomes in Children with Congenital Heart Disease: National Health Interview Survey

Hilda Razzaghi, PhD, MSPH[1,2], Matthew Oster, MD, MPH[1,3], and Jennita Reefhuis, PhD[1]

Objective To assess the extent of long-term morbidity in children with congenital heart disease (CHD).
Study design We used data from the 1997-2011 National Health Interview Survey to study long-term outcomes in children aged 0-17 years with CHD. Parents were asked whether their child was diagnosed with CHD. We assessed for comorbidities, including autism/autism spectrum disorders; healthcare utilization, including number of emergency room visits; and daily life aspects, including number of days of school missed. These outcomes were compared between children with and without reported CHD using ORs and χ^2 statistics.
Results The study included 420 children with reported CHD and 180 048 children without CHD, with no significant between-group differences in age and sex. The odds of reporting worse health and more than 10 days of school/daycare missed in the previous year were 3 times higher for the children with CHD compared with those without CHD. Children aged 2-17 with CHD were more likely than those without CHD to have had a diagnosis of autism spectrum disorder (crude OR, 4.6; 95% CI, 1.9-11.0) or intellectual disability (crude OR, 9.1; 95% CI, 5.4-15.4). The rates of emergency room, home, and doctors' office visits were significantly higher in the children with CHD.
Conclusion Reported adverse outcomes were more prevalent in the children with CHD. Our findings, particularly those regarding neurodevelopmental outcomes, may be helpful for parents, healthcare providers, and others in assessing the specific needs of children and teenagers with CHD. *(J Pediatr 2015;166:119-24)*.

Congenital heart disease (CHD) includes both structural and nonstructural anomalies present at birth. Structural anomalies of the heart, or congenital heart defects, are the most common type of birth defect in the US,[1,2] and the leading cause of infant mortality associated with birth defects.[3] With new surgical techniques and medical therapies, mortality rates have decreased for children with congenital heart defects[4,5]; an estimated 85% of these children survive into adulthood.[6,7] An estimated 650 000 to 1.3 million US adults were living with a congenital heart defect in 2002.[1] These survivors are at increased risk for physical and developmental disabilities.[8-11] The prevalence and severity of comorbidities increase with the complexity of the defect.[12] Given the increases in survival, there are more adults living with CHD who have comorbidities and higher hospital admission rates than the general population.[13-16] In addition, recent literature shows increased risks of neurodevelopmental outcomes including difficulties with language, attention, academic achievement, fine and gross motor skills, and psychosocial factors for children of various ages with CHD.[17-20]

The National Health Interview Survey (NHIS), a cross-sectional study, includes a representative sample of children aged 0-17 years and has included a question about a diagnosis of a CHD for many years. The purpose of the present study was to assess social and daily life, comorbidities, neurodevelopmental outcomes, and healthcare utilization among children with CHD using a nationally representative sample, to collect data on CHD in children that are useful for policy and public health/planning purposes.

Methods

We used data from the NHIS for 1997-2011. The NHIS is an annual multistage probability sample survey of the civilian, noninstitutionalized US population conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention. The survey consists of computer-assisted personal interviews with 3 main components: the family core, sample adult core, and sample child core. In addition to these main components, supplemental sets of questions are added each year, which can differ from one year to the next. The family core is completed by an adult from the family, who responds to the questionnaire as a

ADHD	Attention deficit/hyperactivity disorder
ADD	Attention deficit disorder
CHD	Congenital heart disease
NHIS	National Health Interview Survey
SC	Sample child

From the [1]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA; [2]Oak Ridge Institute for Science and Education, Oak Ridge, TN; and [3]Children's Healthcare of Atlanta, Emory University School of Medicine, Atlanta, GA

H.R. was supported by an appointment to the Research Participation program for the Centers for Disease Control and Prevention administered by the Oak Ridge Institute for Science and Education through an agreement between the Department of Energy and Centers for Disease Control and Prevention. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of Centers for Disease Control and Prevention. The authors declare no conflicts of interest.

http://dx.doi.org/10.1016/j.jpeds.2014.09.006

proxy for the entire family. The family core includes questions on health status, income and assets, limitations, injuries, and more. The sample adult core is completed by a random adult (aged ≥18 years or older) from the family, and the sample child core is based on a random sample child (SC) from the family (aged ≤17 years), about whom a knowledgeable adult in the family answers the questions. Questions covering health status, limitations, injuries, healthcare access and utilization, and health insurance are similar in the sample adult core and sample child core; however, questions regarding health conditions are different and specific to each core. A new sample design for the NHIS was implemented in 2006, with a fundamental structure very similar to the previous design (1995-2005) (http://www.cdc.gov/nchs/nhis/about_nhis.htm). The National Center for Health Statistics Research Ethics Review Board approved the NHIS protocol.

The present study includes information collected on all children aged 0-17 years from the sample child core component from 1997 to 2011. Children with Down syndrome (n = 298), 21 of whom also had CHD, were excluded from our analysis. Information regarding other birth defects or genetic syndromes is not available in the NHIS. We evaluated only those questions that were relevant to our study objective and were included in the years 1997-2011; the questions examined for this analysis are included in the **Appendix** (available at www.jpeds.com).

One of the questions asked in the sample child core component of NHIS is "Has a doctor or other health professional ever told you that the sample child has congenital heart disease?" A total of 441 children had a reported CHD diagnosis (cases), and 180 325 did not have a reported CHD diagnosis (controls).

Demographic information, including age, sex, and race/ethnicity of the SC, were reported at the time of the interview. Race/ethnicity was classified as non-Hispanic white, non-Hispanic black, Hispanic, and other. For children with and without CHD, we assessed the following: whether health was better, worse, or about the same in the last year; days of school (or daycare) missed in the last year; need for special equipment; impairment or health problem limiting physical activity; and whether the SC has had a problem that requires a prescription medication for more than 3 months. We also reported on comorbidities, including cerebral palsy, sickle cell anemia, asthma, allergies, and ear infections. Neurodevelopmental outcomes assessed were autism/autism spectrum disorder, attention deficit/hyperactivity disorder (ADHD), attention deficit disorder (ADD), and intellectual disability. Various elements to assess healthcare utilization were examined, including number of emergency room visits, home care visits, and healthcare provider visits in the last year.

Statistical Analyses

Analyses were conducted using SAS version 9.3 (SAS Institute, Cary, North Carolina). Survey sample weights and the appropriate sample design variables were used in the analyses to account for the complex survey design, oversampling, and differential nonresponse and noncoverage, to ensure a nationally representative estimate of the US civilian noninstitutionalized population. The Taylor series linearization method was used to calculate 95% CIs for the estimated prevalences, and χ^2 statistics were used to compare cases with controls.

Results

Between 1997 and 2011, we analyzed data on 180 468 children aged 0-17 years with completed NHIS interviews, including 420 children with reported CHD and 180 048 children without CHD. Age and sex distributions were not significantly different between the 2 groups ($P = .99$ for those with CHD and $P = .54$ for those without CHD); the majority of both cases and controls were non-Hispanic white (**Table I**). When comparing aspects of daily life, cases were 3 times more likely than controls to report worse health in the last year (OR, 3.3; 95% CI, 1.8-6.0) and were also 3 times more likely to have missed more than 10 days of school/daycare (OR, 2.9; 95% CI, 2.1-4.1) (**Table II**). The need for special equipment and an impairment limiting crawling, walking, and running were reported more frequently among cases compared with controls (**Table II**). Of those children with impaired crawling, walking, and running ability, 98% had an impairment that had lasted or would last more than 12 months.

A study of other conditions and comorbidities examined in the NHIS revealed higher rates of asthma, ear infections, and neurodevelopmental issues in cases compared with controls (**Tables II** and **III**). For children aged 2 years and younger cases were more than twice as likely as controls to have reported 3 or more ear infections in the last year (OR, 2.4; 95% CI, 1.2-5.2) (**Table II**). Among neurodevelopmental outcomes in children aged 2-17 years, cases had higher odds of autism spectrum disorder (OR, 4.6; 95% CI, 1.9-11.0), ADHD/ADD (OR, 1.6; 95% CI, 1.1-2.4), and intellectual disability (OR, 9.1; 95% CI, 5.4-15.4) compared with controls (**Table III**).

We also examined healthcare utilization patterns (**Table III**). Cases were twice as likely as controls to have seen a healthcare professional who treated a variety of illnesses in the last year (OR, 1.9; 95% CI, 1.3-2.7). There

Table I. Characteristics of US children aged 0-17 years with and without CHD, 1997-2011

Variables	CHD (n = 420)	No CHD (n = 180 048)	*P* value*
Age, n (%)			.99
0-5 y	144 (33.4)	61 916 (33.2)	
6-11 y	127 (33.1)	55 487 (33.3)	
12-17 y	149 (33.4)	62 645 (33.5)	
Sex, n (%)			.54
Male	216 (49.4)	92 518 (51.1)	
Female	204 (50.6)	87 530 (48.9)	
Race/ethnicity, n (%)			.05
Non-Hispanic white	252 (68.1)	87 993 (59.8)	
Non-Hispanic black	42 (10.4)	28 055 (14.5)	
Hispanic	97 (15.1)	51 601 (19.1)	
Other	27 (6.3)	11 792 (6.4)	

Data source: NHIS. Percentages do not correspond with raw numbers because of the weighting used in the NHIS.
*χ^2 test.