School-Age Test Proficiency and Special Education After Congenital Heart Disease Surgery in Infancy

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Objective To evaluate test proficiency and the receipt of special education services in school-age children who had undergone surgery for congenital heart disease (CHD) at age <1 year.

Study design Data from Arkansas-born children who underwent surgery for CHD at Arkansas Children's Hospital at age <1 year between 1996 and 2004 were linked to state birth certificates and the Arkansas Department of Education longitudinal database containing achievement test scores in literacy and mathematics for grades 3-4 and special education codes. The primary negative outcome was not achieving grade-level proficiency on achievement tests. Logistic regression accounting for repeated measures was used to evaluate for associations between achieving proficiency and demographic data, maternal education, and clinical factors.

Results A total of 362 of 458 (79%) children who underwent surgery for CHD were matched to the Arkansas Department of Education database, 285 of whom had grade 3 and/or 4 achievement tests scores. Fewer students with CHD achieved proficiency in literacy and mathematics ($P < .05$) compared with grade-matched state students. Higher 5-minute Apgar score, shorter duration of hospitalization, and higher maternal education predicted proficiency in literacy ($P < .05$). White race, no cardiopulmonary bypass, and shorter hospitalization predicted proficiency in mathematics ($P < .05$). Sex, gestational age, age at surgery, CHD diagnosis, and type and number of surgeries did not predict test proficiency. Compared with all public school students, more children with CHD received special education services (26.9% vs 11.6%; $P < .001$).

Conclusion Children with CHD had poorer academic achievement and were more likely to receive special education services than all state students. Results from this study support the need for neurodevelopmental evaluations as standard practice in children with CHD. *(J Pediatr 2016;178:47-54).*

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Congenital heart disease (CHD) is associated with significant long-term neurocognitive effects. Risk factors for impaired cognitive outcomes in infants with CHD are multifactorial and include early structural brain immaturity and brain injury,[1-4] genetics,[5,6] timing of surgery,[7-9] age at surgery,[10] preoperative acidosis and hypoxemia,[11,12] type of CHD,[13] and anesthetic exposure.[14] We previously reported that children with CHD who underwent surgery during infancy had reduced academic proficiency at early school age owing to cognitive impairment.[7]

The poorer academic performance in children with CHD may be related to problems with early motor dysfunction,[15,16] impaired executive functioning,[17,18] and behavioral problems.[19] Children with CHD have a higher likelihood of receiving special education services at school age because of neurodevelopmental and learning disabilities.[7,19,20] Some major cardiac centers in the US have started neurodevelopmental cardiology clinics to perform standardized neurodevelopmental evaluations, make recommendations for therapy, and determine the need for special education services.[21,22]

The unique resources available in Arkansas have allowed us to study school-age outcomes of children with CHD. Arkansas Children's Hospital (ACH) cares for >95% of children born with CHD in the state and maintains a robust CHD surgery database. The Arkansas Department of Education (ADE) longitudinal

ACH	Arkansas Children's Hospital
ADE	Arkansas Department of Education
CHD	Congenital heart disease
dTGA	Dextro-transposition of the great arteries
HLHS	Hypoplastic left heart syndrome

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student database contains achievement test scores and special education codes. The Arkansas Reproductive Health Monitoring System database contains birth certificate data, including parental education, from all Arkansas-born infants. The matching of demographic, maternal education, birth and clinical CHD data, achievement test scores, school meal status, and special education codes from these 3 databases provided us a risk profile of school-age outcomes in children with CHD.

The objectives of this study were to examine achievement test proficiency at elementary school age from a cohort of children born over a 9-year period who required CHD surgery during infancy (3 additional birth years than our previous study),[7] to evaluate the impact of birth factors and maternal education on achievement test proficiency, and to determine the prevalence of special education services received by the cohort. By excluding matched children without grade 3 and 4 test scores from the proficiency predictive model, this study focused on a slightly healthier CHD cohort compared with our previous publication.[7] Based on previous studies, including our own,[7,20,23] we hypothesized that children who underwent CHD surgery during infancy would be less proficient on achievement tests and more likely to receive special education services compared with grade-matched Arkansas public school students, and that maternal education level would be an important predictor for the achievement of grade-level proficiency.

Methods

Following approval by the ACH Institutional Review Board, we performed a retrospective study of all children who underwent surgery for any type of CHD at ACH at age <1 year between January 1, 1996, and December 31, 2004. Children from these birth years were at least age 9-10 years old and would have undergone grade 3 and/or 4 achievement testing. Children were identified from the ACH Cardiac Surgery Outcomes and the Society for Thoracic Surgeons Congenital Heart Surgery databases. Children were excluded who had a birth weight <1500 g, had undergone only patent ductus arteriosus ligation, were born out-of-state or were not Arkansan, or had an identified genetic condition (eg, Down syndrome, 22q11.2 deletion syndrome, Turner syndrome) or neurologic condition (ie, documented stroke).[21] Children were verified as not having a mortality date in the CHD database and ACH medical record. The Arkansas Reproductive Health Monitoring System database verified mortality by state death certificate.

Demographic and clinical data collected from each child's medical record included date of birth, sex, race, social security number, mother's' name, date of admission for CHD surgery, CHD diagnosis, age and weight at surgery, type of CHD surgery, receipt (and duration) of cardiopulmonary bypass, duration of surgery, associated risk adjustment for congenital heart surgery 1 category,[24] and duration of hospitalization. The CHD diagnosis was recorded from the hospital surgery database and was confirmed by a review of cardiology and operative reports in the medical record.

Discrepancies in CHD diagnosis were resolved by review with a pediatric cardiac intensivist. CHD diagnoses were divided into 4 broad categories: left ventricular outflow tract obstruction (including hypoplastic left heart syndrome [HLHS]), right ventricular outflow tract obstruction, conotruncal defects (including dextro-transposition of the great arteries [dTGA]), and others,[25] as published previously.[7]

The Arkansas Reproductive Health Monitoring System database contains clinical and demographic information from Arkansan families with children affected with CHD. Data on birth weight, gestational age, Apgar scores, parental education, and birth hospital were available from the state birth certificate through this system. Insurance data were not available.

Arkansas Department of Education

The compiled dataset of surviving children with CHD was securely transmitted to the ADE's Arkansas Research Center. Social security number, date of birth, and mother's name were used to match infant data to student records.[7] The ADE database contains data for children that attend public schools in Arkansas. For each subject, the ADE provided scores on the Arkansas Augmented Benchmark Examinations (annual achievement tests taken by public school students, grades 3-8) and identified whether the child received special education services (and a reason code) based on established eligibility criteria.[26]

Grades 3 and 4 assessments were used to analyze early academic proficiency. Children born between 1996 and 2004 should have at least entered grade 3; however, the available grade data were dependent on the year(s) in which the child attended Arkansas public schools. The annual benchmark examination includes separate literacy and mathematics scores grouped into 4 levels: advanced, proficient, basic, and below basic. As a proxy for socioeconomic status,[27] the ADE provided data on meal status, designating whether or not the student received free or reduced-cost meals (indicating low socioeconomic status), or paid full price for lunch (indicating high socioeconomic status).

CHD Cohorts

All children who underwent surgery for CHD as infants and were matched to the longitudinal ADE database were classified as the total CHD cohort. The total CHD cohort included children who had at least one set of test scores, had any special education code, and/or had free/reduced/full-price lunch information at any time during grades 3-8. Subjects in the total CHD cohort were further classified into either the CHD test cohort when achievement tests scores were available from grades 3 and/or 4, or into the CHD partial data cohort when students only had other types of ADE data available (ie, special education codes, meal status, and/or grade achievement test scores not from grades 3 or 4). In general, up to 5% of children do not take the benchmark examinations for various reasons and so would be included in the CHD partial data cohort.

Statistical Analyses

Demographic and clinical variables were summarized separately for the CHD test cohort and the CHD partial data cohort.

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