



Executive Functioning and School Performance among Pediatric Survivors of Complex Congenital Heart Disease

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Objective To investigate the presence and severity of real-world impairments in executive functioning—responsible for children’s regulatory skills (metacognition, behavioral regulation)—and its potential impact on school performance among pediatric survivors of complex congenital heart disease (CHD).

Study design Survivors of complex CHD aged 8-16 years (n = 143) and their parents/guardians from a regional CHD survivor registry participated (81% participation rate). Parents completed proxy measures of executive functioning, school competency, and school-related quality of life (QOL). Patients also completed a measure of school QOL and underwent IQ testing. Patients were categorized into 2 groups based on heart lesion complexity: 2-ventricle or single-ventricle.

Results Survivors of complex CHD performed significantly worse than norms for executive functioning, IQ, school competency, and school QOL. Metacognition was more severely affected than behavioral regulation, and metacognitive deficits were more often present in older children. Even after taking into account demographic factors, disease severity, and IQ, metacognition uniquely and strongly predicted poorer school performance. In exploratory analyses, patients with single-ventricle lesions were rated as having lower school competency and school QOL, and patients with 2-ventricle lesions were rated as having poorer behavioral regulation.

Conclusions Survivors of complex CHD experience greater executive functioning difficulties than healthy peers, with metacognition particularly impacted and particularly relevant for day-to-day school performance. Especially in older children, clinicians should watch for metacognitive deficits, such as problems with organization, planning, self-monitoring, and follow-through on tasks. (*J Pediatr* 2016;173:154-9).

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Congenital heart disease (CHD) is the most common congenital structural defect, occurring in 9 out of 1000 live births,¹ with one-third having complex CHD requiring intervention during the neonatal period.² At one time, rapid deterioration and death were the expected outcomes for complex CHD, but medical advances have improved 20-year survival rates to around 80%.³ Unfortunately, survivors often suffer neurodevelopmental morbidity because of prenatal factors (eg, reduced brain volume) as well as chronic or intermittent hypoxia, hypoperfusion, reperfusion, or ischemia related to their circulatory abnormalities and associated medical interventions.⁴⁻⁷ Accordingly, children with CHD are at higher risk of cognitive deficits and poorer school outcomes than their healthy counterparts,⁸⁻¹¹ with many requiring special educational services.^{12,13} In one large multicenter study, 35% of children with CHD required some form of special education.¹⁴

To better address scholastic concerns, it is important to understand the underlying contributors. Intelligence is a key factor, but IQ accounts for only 25% of variance in school performance for survivors of CHD.⁹ Beyond IQ, executive functioning has emerged as an important predictor of school performance in healthy children.¹⁵⁻¹⁷

Executive functioning broadly encompasses 2 main components: behavior regulation (control of emotional and behavioral impulses) and metacognition (planning, organization, self-monitoring, initiation, and follow-through).¹⁸ These executive skills are integral to a child’s cognitive, emotional, and social development.

Among pediatric survivors of complex CHD, few studies have examined deficits on structured tests of executive functioning or its real-world implications.

BRIEF	Behavior Rating Inventory of Executive Function
CBCL	Child Behavior Checklist
CCHMC	Cincinnati Children’s Hospital Medical Center
CHD	Congenital heart disease
Peds-QL	Pediatric Quality of Life Inventory
QOL	Quality of life

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Most studies indicate roughly one-quarter to one-half of survivors score abnormally low,^{8,19,20} although one study found rates as high as three-quarters of survivors.²¹ However, these studies generally failed to include patients' self-report or parent proxy measures of executive functioning. Because structured tests can fail to appreciate executive functioning deficits that are evident in real-world settings (eg, trouble starting homework, overreacting to minor infractions),¹⁸ actual rates of impairment may be even greater. In light of growing numbers of survivors of CHD and the potential for long-term morbidity, it is important to understand the risks for real-world executive functioning deficits as well as their impact on what is arguably the most important "job" of school-age children: school performance.

The current study had 2 main aims. The first aim was to investigate whether executive functioning deficits in daily life (per parent report) are differentially present in pediatric survivors of complex CHD surgery and, concurrently, to confirm the presence of lower intellectual functioning and greater school problems. We hypothesized that survivors would have significantly worse group scores and have higher rates of impairment, than published norms across measures of executive functioning, intelligence, and school functioning. Exploratory analyses also examined whether the behavior regulation vs metacognitive aspects of executive functioning were differentially affected and whether effects varied by age or heart lesion complexity (1- vs 2-ventricle disease). Patients with single-ventricle lesions often have many more medical complications because of the complexity of their disease and required treatments. They require multiple operations during their lifetime and have a much higher use of medical care utilization including, the need for cardiac catheterization, multiple hospitalizations, the requirement of multiple medications, and many doctor visits annually. The second aim was to clarify the scholastic implications of executive functioning morbidity in survivors of complex CHD surgery. We hypothesized that poor executive functioning would be associated with worse school functioning, over and above associations with demographic characteristics, intelligence, and heart lesion complexity.

Methods

This cross-sectional study was approved by the Institutional Review Board at Cincinnati Children's Hospital Medical Center (CCHMC). English-speaking survivors of CHD surgery aged 8-16 years were recruited via mailings and phone calls from 2008 and 2010 to a regional registry of children who had all undergone cardiac surgery in the neonatal period (28 days or less) or infancy (1 month to 1 year). Survivors were eligible to participate if they had a primary diagnosis of complex 2-ventricle CHD transposition of the great arteries or tetralogy of Fallot or single-ventricle CHD requiring Fontan palliation, and had undergone cardiac surgery at CCHMC or were followed at CCHMC or Dayton Children's Hospital. Survivors were excluded for other significant med-

ical diseases (eg, cancer); comorbid genetic syndrome contributing to developmental delay; pregnancy; or an unrelated major life event within the past 6 months (eg, serious illness of a family member, parental divorce) that may impact quality of life (QOL). Parents provided written consent, and children provided verbal or written assent. As part of a larger study on neurodevelopmental outcomes, children underwent neuropsychological evaluation while parents completed questionnaires. Demographic information and medical history were obtained via parent report and review of the medical record.

The parent-report version of the Behavior Rating Inventory of Executive Function (BRIEF)¹⁸ is a 86-item questionnaire designed to assess the various facets of executive functioning in an everyday environment in school-aged children aged 5-18 years. The BRIEF has 2 summary indices: metacognition and behavioral regulation. Metacognition encompasses abilities involved in working memory; initiating, planning, and organizing tasks; and monitoring performance. Behavioral regulation is defined as the ability to shift mindset and regulate and control emotions and behavior. Both indices have excellent internal consistency and test-retest reliability¹⁸ and have been shown to be sensitive to executive functioning deficits in patients with surgically corrected CHD.¹¹ Age- and sex-normed scores are expressed in T-score units, with higher scores indicating worse difficulties.

School performance can be difficult to measure. Grading schemes vary, and academic knowledge (assessed via formal tests) is only indirectly related to day-to-day functioning.²² With the goal of assessing day-to-day performance at school, we measured the overlapping constructs of school competency and school-related QOL. School competency was assessed by the Child Behavior Checklist (CBCL), which queries parents on the child's typical grades (using a standardized metric) and the need for educational supports.²³ The CBCL is highly reliable and valid, and the School Competency Index is sensitive to adverse effects of CHD.¹¹ School-related QOL was assessed by the school functioning subscale of the Pediatric Quality of Life Inventory (Peds-QL) version 4.0,²⁴ a generic health-related QOL measure with scores that are highly reliable, valid, and generalizable²⁵ and has been used previously in pediatric cardiovascular populations.¹⁰ The Peds-QL school subscale inquires about day-to-day classroom-relevant functional skills (eg, keeping up with schoolwork). Both measures were age- and sex-normed to T-scores, with higher scores indicating better functioning.

The Wechsler Intelligence Scale for Children-Fourth Edition is a widely used, reliable, and valid instrument that assesses intelligence in children aged 6-16 years. To minimize burden, an 8-subtest short form of the Wechsler Intelligence Scale for Children-Fourth Edition was used to yield a prorated full scale IQ.²⁶

Demographic covariates included age, sex, race (recoded as white/nonwhite), and yearly family income (dichotomized at \$51 000, the US median income level for 2012). The

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