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Parenting stress is associated with executive functioning in preschool-age children with congenital heart disease

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Introduction/Study Question: Children with complex congenital heart disease (CHD) are at high risk of significant cognitive impairments. Due to the burden of their child's precarious condition, the parents are also at risk of high levels of anxiety and stress. Among other factors, parenting stress has been identified as a predictor of executive functioning at school entry in healthy children. This cohort study aimed to investigate the association between parenting stress and executive functioning in 5-year-olds with complex CHD. We hypothesized that higher levels of parenting stress will be associated with poorer performance in executive tasks and higher rates of parent-reported executive deficits.
Methods: Fifty-eight children with complex CHD followed at the CHU Sainte-Justine neurocardiac clinic were recruited (mean age = 5.55 years; standard deviation, SD = 0.26). They all underwent at least one cardiac surgery. Children performed standardized executive function assessment of their planning abilities (Tower subtest of the NEPSY) as well as their inhibition and selective attention skills (K-CPT-2). Parents completed standardized questionnaires on the executive functioning of their child (BRIEF-P) and parenting stress (PSI-4-SF). A bivariate Pearson correlation matrix was computed and corrected for multiple comparisons (Benjamini FDR set to 25% for executive tasks and 5% for questionnaire scores).
Results: A significant part of our cohort had impairements in planning abilities (13%), inhibition (44%) and selective attention (58%) when completing executive functioning tasks. Questionnaire scores revealed that 33% of the parents reported significant deficits in at least one sphere of executive function. Only 8% of the parents reported above-normal parenting stress levels. Bivariate Pearson correlations revealed a significant negative association between parenting stress and planning abilities (Tower subtest; p=.034) and a significant positive association between the K-CPT-2 measures of impulsivity (Commissions; p=.016) and selective attention (Detectability; p=.049) and parenting stress. Similarly, the results revealed a significant positive association between parenting stress and the five core subscales of the BRIEF-P (Inhibition: p<.001; Flexibility: p=.015; Emotional Control: p<.001; Working Memory: p<.001; Planning and Organizing: p=.003).
Discussion: Higher parenting stress is associated to worse planning abilities and better inhibition and selective attention in 5-year-old children and more parent-reported executive dysfunction. Since parents tend to pass on their anxiety to their child, we hypothesize that a better impulse control might reflect a fearful approach to novelty transmitted by the parents, making the child less prone to commit to an answer. We also hypothesize that the better ability to distinguish targets from non-targets (selective attention) might result from heightened vigilance, also passed on by the parents as they are more alert to potential threats. Our results underline the interplay between parenting stress and executive functioning at school entry contrasting with results we obtained in school-age children whose objective executive performance was not associated with their parents' stress levels.

Caregiver Perspectives on Family Centered Follow-up After Pediatric ECMO

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Intro: Most pediatric patients requiring extracorporeal membrane oxygenation (ECMO) survive to hospital discharge. However, survivors are at increased risk of physical, cognitive, and emotional health impairments. The Extracorporeal Life Support Organization recommends neurodevelopmental assessment and support for recovery. Evidence reporting families' priorities in follow-up are limited. The aim of this study was to elicit caregivers' perspectives regarding vital components of and challenges to participating in post-ECMO follow-up care.
Methods: An electronic survey was completed by consented caregivers of pediatric ECMO survivors who were <18 years of age at the time of ECMO and admitted to the neonatal, pediatric or

cardiac ICU at the UPMC Children's Hospital of Pittsburgh between 2015-2020. Caregivers were contacted by email with up to four reminders sent to non-responders every 3 days. Demographic, hospital, and ECMO details were extracted from both a local ECMO database and the electronic health records and linked with survey respondents. Descriptive data were presented as median (interquartile range). Free text comments were qualitatively analyzed into themes.
Results: Fifty of the 121 eligible families (41%) responded. 59% of pediatric ECMO survivors were male, with a median age of 3 months and ECMO duration of 97 hours. Forty-two percent of caregivers categorized their child's overall health as "fair" or "poor" after ECMO therapy. More specifically, caregivers reported impairments in speech and language (58%), attention/concentration (38%), behavior (25%), motor (40%), memory (21%), hearing (6%) and vision (19%) domains. Eleven percent of children received home care nursing prior to ECMO versus 53% after ECMO. Similarly, 9% of children received special accommodations or extra learning support in school prior to ECMO versus 44% after ECMO. The majority of families found their child's primary care providers and subspecialty providers "very helpful" or "somewhat helpful" in aiding their child's recovery. A majority of respondents were either "extremely likely" or "somewhat likely" to come to either an in-person or virtual multidisciplinary ECMO follow-up clinic (66% and 77%, respectively). Qualitatively, caregivers spoke to the medical, developmental, social and emotional aspects of their child's recovery. Caregivers noted personal emotional challenges and changed bonds between siblings. Resources provided during hospitalization and post discharge were noted to be helpful although additional resources for coping, such as in-hospital patient and family mental health support, peer support groups, and neurodevelopmental support, were mentioned. Finally, caregivers positively commented on the support they received from their medical team but also lamented on the many appointments after discharge and the frustrations with coordination of appointments, home nursing, supplies, and medications.
Discussion: Caregivers of children who survived ECMO hospitalization identified specific unmet needs, including improving parent and child emotional support, appreciation for organized neurodevelopmental follow-up, and coordination of care post hospital discharge. These findings suggest an urgent need to include caregivers and patients in the development of a structured multidisciplinary ECMO follow up clinic.

The association between overprotective parenting and the growth and development of children with congenital heart disease: a systematic review

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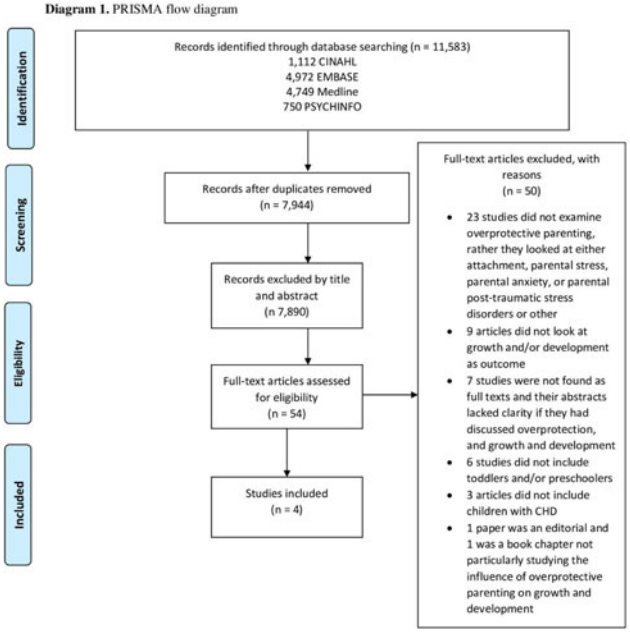
Introduction: Congenital Heart Disease (CHD) is the most common birth defect of childhood. Over recent years, advances in the treatments significantly improved the preoperative and perioperative outcomes of children with CHD, with 90% surviving into adulthood. However, the disease still marks these children with residual sequelae after surgical interventions. One of the main health problems that persist even after surgical intervention is the growth and developmental delay. Even with the recent improvements in the management of CHD, neurodevelopmental outcomes after cardiac surgery have improved only modestly over time. Parents are primarily responsible for the care of the child with CHD after hospitalization. However, the demands of such a chronic illness place these parents under high levels of stress, which in turn impact the parent-child relationship. Because of the child's long-term illness process, some parents tend to perceive the child as highly vulnerable and become overprotective, further limiting the developmental opportunities and subsequently influencing their growth and development. Overprotective parenting was found to affect healthy and chronically ill children's psychological and behavioral outcomes negatively. However, studies on the association between overprotective parenting practices and the growth and development of children with CHD are seldom investigated. Therefore, this study aimed to answer the following research question, whether there was an association between overprotective parenting and the growth and development of children with congenital heart disease.
Methods: This study used a systematic review methodology and included CINAHL, EMBASE, MEDLINE and PsycINFO databases. The GRADE guidelines were followed to assess the risk of bias.
Results: PRISMA reporting guidelines were employed. Of the 11,583 abstracts screened, 56 full-text articles were retrieved and four met the pre-determined criteria for the narrative analysis. There was no reporting found on the association between parental overprotectiveness and the growth of children with CHD. However, regarding development, studies suggested that maternal overprotectiveness was significantly higher in children with CHD than in healthy controls and appeared to be associated with some of the domains of child development.
Discussion: Targeting parenting approaches remain important to enhance the development of children with CHD, since overprotective parenting appeared to be associated with some of the domains of development. However, more research is needed given the limitations of the studies reviewed.



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Single Ventricle Patients: Determining the Need for Neuropsychological Evaluation through In-Clinic Consultation and Screening

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The Children's Health Fontan Clinic (FC) is a multidisciplinary collaboration intended to assess, treat, and support single ventricle patients who have undergone staged palliation. The FC prioritizes equitable access to neuropsychological services for English- and Spanish-speaking families through the inclusion of language-proficient providers. This quality improvement project aimed to investigate the most common concerns endorsed on a neurodevelopmental symptom checklist for FC patients, as well as the most common diagnoses and recommendations provided post-evaluation for single ventricle patients. Patient demographics can be found in Table 1.

The Neurodevelopmental Symptoms Checklist (NSC) is an unpublished screening tool created to efficiently identify patient neurocognitive and behavioral needs during FC appointments. Initial NSC screening of patients ages 5 to 25 years of age were analyzed using weighted scores for symptom clusters (Table 2). Descriptive data on diagnoses and recommendations following evaluations for patients within the same age range were also gathered (Table 3).

To date, 61 consultations have been completed. Of those, 47 received the NSC. Both the NSC and consultation were used to determine the need for evaluation. Approximately 56 evaluations have been completed. The most common NSC concerns included emotional difficulties, executive dysfunction, and attention problems. The most common diagnoses provided following neuropsychological evaluation were AD/HD, Internalizing Disorder, and Learning Disability. The most common recommendations included educational support, psychotherapy, and medication consultation.

The NSC symptoms, diagnoses, and recommendations are comparable to what has been identified in the congenital heart disease literature.[1] Future goals include increasing access to in-clinic consultations and consistent monitoring through screens and evaluations to improve outcomes among single ventricle patients, as well as modifying and validating the NSC for potential use across pediatric medical centers.

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Implementation of a Dedicated Cardiac Neurodevelopmental Program

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Introduction: Children with congenital heart disease (CHD) are at risk for neurodevelopmental deficits and require developmental care to maximize their potential. Prior to 2020, the developmental care of Stanford Children's CHD patients was fragmented. Inpatient developmental care for patients in the Cardiovascular Intensive Care Unit (CVICU) was limited to interventions performed by physical and occupational therapists with little nurse, physician, or parent involvement. Outpatient clinics served a subset of children with CHD, ended at age 3 years, and lacked recommended, routine standardized developmental screening. Our goal was to establish a Cardiac Neurodevelopmental Program (CNP) providing neuroprotective and developmentally supportive inpatient and outpatient care for CHD patients.

Methods: We reviewed characteristics of established US cardiac center programs including funding sources, program personnel and composition, and neurodevelopmental screening schedules and assessments. A needs assessment of nursing knowledge of inpatient developmental care among critically ill patients was completed. Key stakeholders from cardiology, developmental-behavioral pediatrics, neonatology, inpatient rehabilitation, and nursing convened to design a dedicated CNP. Consensus criteria established patients at highest risk for developmental deficits, catchment area was defined, and predicted clinic volume was estimated. Methods of inpatient identification and referral pathways were established.

Results: Inpatient needs assessment revealed that frontline staff were unfamiliar with basic principles of CVICU neurodevelopmental care (e.g., noise prevention, cycled lighting, positioning). A CVICU specific developmental pathway was adapted from the NICU to teach bedside providers and parents to implement developmental care at all stages of illness. Twice monthly bedside CNP rounds educate parents and staff, document care plans, and summarize neurological, audiological and genetic findings, rehabilitation status, and social/emotional support. At hospital discharge we found that children meeting California Children's Services High Risk Infant Follow Up medical eligibility were seen in the Stanford Children's Infant Development Specialty Program (IDSP) until age 3. Many patients eligible for follow up by American Heart Association (AHA) criteria and those over 3 years were excluded. A shared list in the electronic medical record was created to track patients referred from CNP rounds and through outreach to Stanford cardiologists. Inpatient to outpatient transition is ensured by pre-discharge scheduling of IDSP or CNP appointment and rehab therapies, and/or obtaining consent for Early Intervention. All high-risk cardiac patients as defined by the AHA are seen in IDSP until age 3 and then in CNP clinic for ongoing care.

Discussion: We leveraged the success and infrastructure of existing programs to promote infant and child development. The Stanford CNP is improving the continuum of developmental care for children with CHD through multidisciplinary collaboration, educational modules, clinical rounds, and the CNP clinic. Future work includes social determinants of health assessment, refinement of referral and clinical protocols, and establishing a research program.

The provision and impact of rehabilitation provided by Physiotherapists in children with congenital heart disease following cardiac surgery: A scoping review

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Introduction: Children with congenital heart disease (CHD) are at risk of delayed motor development with increased risk for those requiring cardiac surgical intervention. We conducted a scoping review to identify the provision and impact of physiotherapy-delivered rehabilitation in children with CHD following cardiac surgery

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Methods: CINAHL, EMBASE, PUBMED, AHMED, EMCARE, Cochrane Database of Systematic Reviews, NHS Evidence databases were searched (2000-2022). Included studies were published in full, in English and reported the use of physiotherapy in CHD (participants 0-18 years) post-surgical procedure Articles were screened by title and abstract and through full-text review with results structured in accordance with the PAGER framework and PRISMA- ScR checklist.
Results: 5747 papers were screened, with seven full-text peer-reviewed papers published 2014-2021 identified. Included papers were predominantly from non-randomised cohort studies with sample size between 1-247. Study participants ranged from 0-16 years, with a variety of cyanotic and acyanotic congenital heart defects and surgical procedures. There was wide variation in duration, frequency, length and type of physiotherapeutic interventions and lack of standardised assessment of impact. Few adverse events were reported, however assessment of stability prior and during interventions varied significantly.
Discussion: Assessing the impact and provision of physiotherapy in CHD post-surgical intervention is challenging due to low sample sizes, lack of control groups, heterogeneous demographics and variable intervention and formats delivered. Further research is required to identify optimum format of physiotherapy provision, establish potential impact of physiotherapy delivered rehabilitation on motor function and development and establish recommendations regarding measures of stability pre and during intervention.

Fetal hemodynamics are associated with survival and short-term neurodevelopmental outcomes in patients with cyanotic congenital heart disease

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Introduction: Neurodevelopmental delay is common in patients with cyanotic congenital heart disease (CHD). We previously demonstrated correlations between *in utero* cerebral oxygenation and brain growth in fetuses with CHD using fetal cardiovascular magnetic resonance (CMR).[1] However, fetal cardiovascular magnetic resonance (CMR) measures of fetal circulatory physiology have not previously been compared with survival or neurodevelopmental outcomes.
Objective: Our objective was to determine the relationship between late gestational *in utero* hemodynamics, survival and neurodevelopmental outcome at 18 months of age in the setting of cyanotic CHD.
Methods: Blood flow was measured in the major fetal vessels of 161 late-gestational human fetuses with cyanotic CHD using cine phase contrast CMR. In a subgroup of subjects, major vessel oxygen saturations and hemoglobin were measured using MR relaxometry. Fetal cerebral oxygen delivery (CDO_2) was calculated using a combination of superior vena caval (SVC) flow, ascending aortic oxygen saturation and fetal hemoglobin concentration, and indexed to fetal weight (kg). The corrected Bayley Scales of Infant and Toddler Development Assessment III was employed to determine cognitive, language, and motor composite scores in a subgroup of 74 patients at 18 months of age, 28 of which had CDO_2 measured. Unpaired comparison tests, correlation analyses, and multivariable linear regressions were used to assess relationships between fetal hemodynamics and outcomes.
Results: Subjects underwent fetal CMR at 36.1 gestational weeks (IQR: 35.3, 37.0): mean combined ventricular output (CVO) was 437.4±116.2 ml/kg/min, SVC flow was 137.0±45.6 ml/kg/min, CDO_2 was 13.3±4.7 ml/kg/min. Neurodevelopment was assessed at 18.6 months (IQR: 18.2,19.4): mean cognitive composite was 100 (IQR: 95, 110), language composite was 94 (IQR: 89, 103), and motor composite was 100 (IQR: 91, 107). The mortality rate prior to 18 months was 14.3% (23/161) and was inversely related to fetal CVO (446 vs. 383 ml/kg/min, p=0.02). SVC flow was positively associated with cognitive composite (r=0.33, p=0.004), language composite (r=0.27, p=0.02), and motor composite scores (r=0.26, p=0.03). Adjustment of diagnosis in the multivariable linear regression model revealed SVC flow was positively associated with cognitive composite (r=0.44, p=0.001) and language composite (r=0.38, p=0.01), but not motor composite scores. Specific diagnoses were a significant predictor of Bayley outcome. CDO_2 was positively associated with cognitive composite (r=0.56, p=0.001), language composite (r=0.39, p=0.04) and motor composite scores (r=0.46, p=0.01).
Discussion: Fetal hemodynamic parameters are associated with survival and 18-month neurodevelopmental assessment outcomes in patients with cyanotic CHD, even when adjusted for diagnosis. While a range of postnatal risk factors for adverse neurodevelopmental outcomes have previously been identified, our results emphasize possible links between fetal circulatory physiology and neurodevelopmental outcomes in patients with cyanotic CHD.

Impact of a systematic developmental follow-up program on the neurodevelopment of school-aged children with complex congenital heart disease: preliminary results

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Introduction: Congenital heart diseases (CHD) are the most common type of congenital anomalies. Children born with complex CHD usually require cardiac surgery in their first year of life and have a higher risk of developing cognitive and functional difficulties. As of 2012, the American Heart Association recommends early systematic follow-ups for children born with CHD. Consequently, the Clinique d'Investigation NeuroCardiaque (CINC) was founded at the Sainte-Justine hospital. The purpose of the CINC is to systematically assess children born with CHD and provide individualized interventions through a multidisciplinary team. In a previous study in three-year-old children, we have shown that those part of the CINC had fewer developmental delays than children born before the opening of the CINC in

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2013, who thus received standard clinical care. With increased academic demands, several developmental issues arise in school-aged children with CHD. The aim of the current study is thus to evaluate the benefit of the CINC program in school-aged children (8 to 11 years old). We hypothesize that the benefits from our developmental program will be greater at that age.
Methods: To date, 47 children with complex CHD were recruited: 10 children (3 boys; mean age = 9 years, SD= 0.49 years) enrolled in a systematic follow-up program (CINC group) and 37 children (24 boys; mean age = 9 years, SD = 1.5 years) who received standard care before the opening of the CINC (control group). All patients had at least one cardiac surgery in the first year of life. Children completed standardized neuropsychological tasks assessing intellectual functioning, attention and impulsivity, cognitive flexibility, planification and organization skills, visuoconstructive abilities, reading accuracy, mathematical skills and verbal memory. Preliminary data were compared with norms as well as between groups with independent sample t tests.
Results: Preliminary data reveal a significant difference in attention, planification and organization skills in both the CINC and control groups as compared to the norms ($p < 0.05$). Comparisons between groups reveal significantly better visuo-constructive abilities ($p = 0.02$) and a tendency of better cognitive flexibility ($p = 0.09$) and reading accuracy ($p = 0.06$) in the CINC group compared to the control group. However, the controls exhibit better mathematical skills compared to the CINC patients ($p < 0.001$).
Discussion: In 8-to-11-year-olds with CHD, children who benefited from the follow-up program at the CINC and those who received standard health care show cognitive deficits related to attention, planification and organization. Children in the CINC group showed better visuoconstructive abilities, and a tendency for better executive functioning and reading skills while children in the control group showed better mathematical abilities. It is noteworthy that the measure of mathematical skills has the highest rate of missing data (almost 30%). Because of the current very small sample size of the CINC group, it is difficult to interpret these results and further data is required in order to assess the impact of our systematic developmental follow-up program on the neurodevelopment of children with complex CHD.

The association between parenting stress and executive functioning in school-aged children with congenital heart disease

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Introduction/Study Question: The survival rate of children born with congenital heart disease (CHD) is increasing due to the advancement of medical knowledge and the refinement of surgical techniques. With a longer lifespan, a plethora of neurodevelopmental sequelae, notably lower executive functioning, is observed in this population. Due to the burden of their children's precarious condition in the first years of life, parents of these children are also at a risk of higher stress levels. Among other factors, parenting stress has been identified as a predictor of executive functioning in healthy children. The current study aimed to investigate the association between parenting stress and executive functioning in 8 to 11-year-old children with complex CHD. We hypothesized that higher levels of parenting stress are associated with poorer performances in executive functioning and higher rates of parent-reported executive deficits.
Methods: To date, 37 children with complex CHD were recruited (24 boys; mean age = 9 years, 11 months, SD = 1.5 years). All patients had at least one cardiac surgery in the first year of life. Children completed standardized executive function tasks assessing cognitive flexibility (D-KEFS-Trails Making Test), working memory (WISC-V- Digit Span Backwards), and planification and organization skills (Rey-Osterrieth complex figure- copy condition). Parents completed standardized questionnaires on their children's executive functioning (BRIEF-P) and on parenting stress (PSI). A bivariate Pearson correlation matrix was applied and corrected for multiple comparisons (Benjamini FDR set to 25% for executive tasks and 5% for questionnaire scores).
Results: Bivariate Pearson correlations revealed no significant associations between parenting stress and all child-measured executive functions scores. However, all seven indexes of parent-reported executive functioning showed moderate or strong positive associations with parenting stress: Inhibit ($p<.001$), Shift ($p<.001$), Emotional Control ($p<.001$), Initiate ($p<.001$), Planning and Organizing ($p<.002$), Organizing of materials ($p<.012$), and Monitor ($p<.001$).
Discussion: In 8-to-11-year-olds with CHD, parenting stress is positively associated with parental reported children's executive dysfunction, but not with directly child-measured executive functions. However, parenting stress seems to influence the parents' perception of their children's executive functioning. These results are in contrast with other findings from our laboratory showing an association between parenting stress and directly measured executive functions in younger children (preschoolers). Overall, these results suggest that executive functioning in school-aged children is not associated with parental factors anymore and might be more associated with other psychosocial factors, notably the school environment and peers, whereas at preschool-age, executive functioning is strongly influenced by parental factors. This study underlines the subtle interplay between parenting stress and parent-perceived and measured executive functioning at school-age.

Standardized School Screening to Identify Educational Needs and Link Supports to Children with Heart Disease

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Introduction: Children with heart disease are at-risk for an array of neuropsychological deficits that may affect development,

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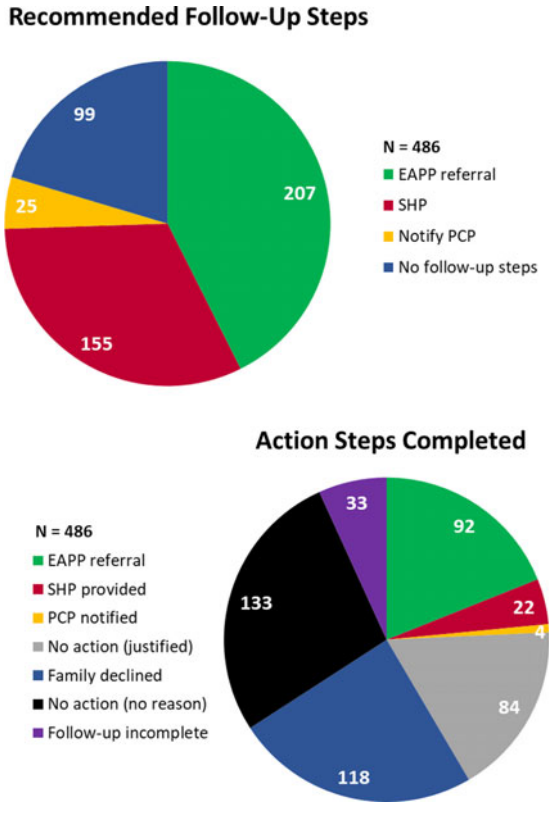
psychosocial skills and academic attainment. While some medical centers offer school liaison services, cardiology clinicians may lack a consistent approach to identify school concerns and determine applicable support services, reflecting an urgent need to develop these resources. The aim of this quality improvement project was to create and seamlessly integrate a school screening system into outpatient cardiology clinic workflow and screen ≥80% of eligible children for school concerns.

Methods: The project team at a single center developed a 5-question School Screener EPIC flowsheet where clinic staff indicate whether the child's cardiac condition is chronic and the parent/guardian identifies developmental, psychosocial and academic concerns or other school support needs. Based on responses to these questions, 1 of 4 action steps are automatically recommended for follow-up: Educational Achievement Partnership Program (EAPP) referral, notify primary care provider (PCP), school health plan (SHP) or no action step needed. Best practice advisory alerts with links to forms allow clinic staff to complete follow-up steps immediately and record the action taken at the bottom of the flowsheet. Following clinic-wide roll out and training, 23 cardiology nurses administered the School Screener to children meeting screening criteria: 3.0-17.9 years old, a cardiology office visit at the main campus, and qualifying department types (9 total) and visit types (9 total). Exclusion criteria were children with a diagnosis of "normal heart" and those previously screened within the past 11 months.

Results: During the 4th quarter of 2021, 672 children met screening criteria and 486 (72.3%) were screened for school concerns. Screening rates peaked at 82.0% in September and gradually decreased throughout the end of the year. The pool of eligible children and the cohort screened were demographically consistent in age and gender (mean age 10.0 years, range 3.75 – 17.98 years, and 58% male), but ethnically divergent: 15.3% Hispanic in the pool and 8.7% in the screened cohort. 47.7% of children had ≥1 school concern in the 3 areas screened: 28.0% had developmental concerns, 32.1% academic and 37.2% psychosocial. The distribution of follow-up step recommendations was largely as expected: 42.6% EAPP, 31.9% SHP, 5.1% PCP, and 20.4% with no follow-up step needed; however, there was a larger than expected variance between the recommended follow-up steps and the action step actually completed (see figure).



Discussion: The School Screener successfully integrated into clinic workflow and additional optimizations may boost screening rates consistently ≥80%. Follow-through on EAPP referral recommendations far exceeded SHPs and PCPs. Further investigation is needed to determine utility of and adaptations for SHP and PCP follow-up steps.

White Matter Microstructure and Self-Reported Neuropsychological Functioning in Youth Born with Congenital Heart Disease

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Introduction: Adolescents born with congenital heart disease (CHD) frequently present with impairments in executive and psychological functioning, the neural correlates of which remain poorly understood. We have previously used multicomponent driven equilibrium single pulse observation of T_1 and T_2 (mcDESPOT) and neurite orientation dispersion and density imaging (NODDI) to detect lower myelination and axon density, with relatively preserved axon orientation, in youth born with CHD in many association white matter tracts. Association tracts are known to play a critical role in higher-order cognitive functioning and emotional regulation. Therefore, this study aimed to determine if myelination and axonal density and orientation alterations within association tracts are related to executive and psychological functioning in youth born with CHD.

Methods: Youth aged 16 to 24 years born with complex CHD who underwent open-heart surgery before two years of age completed a brain MRI including T1-weighted, high angular resolution diffusion imaging, and mcDESPOT acquisitions. Participants also completed three self-report questionnaires: the Behavior Rating Inventory of Executive Function - Adult Version (BRIEF-A) to assess various domains of behavioural regulation and metacognition; the Flourishing Scale to assess social-psychological prosperity; and the Resilience Scale to assess self-perceived resilience. Linear or logistic regression models were used to examine the associations of myelin water fraction (MWF), neurite density index (NDI), and orientation dispersion index (ODI) values in 8 bilateral association tracts with continuous outcome scores or presence of significant impairments, respectively. All models controlled for age, sex,

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and maternal education. The false discovery rate correction for multiple comparisons was applied.
Results: MWF in several association tracts was negatively associated with T-scores on the Self-Monitor and Working Memory scales of the BRIEF-A (where higher T-scores indicate poorer functioning). Higher NDI in several association tracts was associated with lower odds of a clinically-significant impairment (T-score ≥ 65) on the Self-Monitor scale of the BRIEF-A. No significant associations were found for the Flourishing Scale or Resilience Scale.

Improving Early Mobility and Parental Holding in the Nemours Cardiac Intensive Care Unit (CICU)

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Objectives: To increase the proportion of newborns (NBs) held by their parents by 24 hours of life (HOL) to 50% in 6 months and decrease the amount of time until a baby is held 50% in 6 months; to increase the proportion of non NBs mobilized out of bed (OOB) by 24 hours to 50% and decrease the median time to OOB by 50% in 6 months.
Population/Sample: All newly admitted patients to the CICU.
Methods: Members from the cardiac interdisciplinary team reviewed current early mobility guidelines and barriers to success. An updated evidence based early mobility and holding guideline was created and reviewed by the CICU medical team, nursing management/staff, and the therapy team in accordance with available best practices. An electronic medical record flowsheet was generated to allow nursing and medical staff to discuss and document guidelines daily using patient rounds checklist. Data illustrating the holding and mobilization of CICU patients were collected. This data was analyzed to reflect the impact of newly implemented standards of care on patient mobilization and early NB holding using standard quality improvement methodology.
Results: For the 2 years prior to Plan/Do/Study/Act (PDSA) cycle 1, the mean proportion of NBs held by 24 HOL was 17%, and the median time to hold was 72.5 hrs. In 5/24 months, 0 NBs were held by 24 HOL. During PDSA cycle 1, every month the proportion of NBs held was above the previous trend line (Fig 2A), while every data point for median time to hold was below the previous trend line, both indicating an improvement (Fig 3A). Prior to PDSA cycle 1 the mean proportion of non-NBs OOB by 24 hours was 30% and the median time to first OOB was 28.1 hrs. During PDSA cycle 1 there was no consistent change in the proportion of non-NBs mobilized OOB within 24 hours (Fig 2B) nor the median time to first mobilization (Fig 3B).
Discussion: Following the implementation of the holding guidelines a consistent increase in the number of NBs held by their parents within 24 HOL along with a decrease in the amount of time from birth to first hold by parents/family. We did not achieve the same improvement in children >30 days old. PDSA cycle 2 will include an analysis of the most common barriers to early holding and mobility from PDSA cycle 1.

Early Mobility / Holding Guidelines in CICU

Low Risk for Early Mobility Discuss with CICU attending	Higher Risk for Early Mobility Discuss with CICU attending	Absolute contraindications No Early Mobility at this time
• Continuous EEG	• POD #0	• Open chest
• Fragile bones precautions without fractures	• Fragile bones precautions with fracture	• Life threatening pulmonary hypertension
• Chest tube (capped pigtail catheter, mediastinal or pleural drain)	• Intubated- nasal and oral (with 2 providers at b/s)	• Critical airway with endotracheal tube present
• Pacer wires- not in use	• Externally paced with hemodynamically stable underlying rhythm	• Externally paced without an underlying rhythm
• Chest tube	• VV ECMO	• Central VA ECMO
• Umbilical lines positioned centrally and appropriately secured	• VA ECMO with tunneled central cannula or peripheral cannula	• UV line- low lying with prostaglandins running
• Tracheostomy- 4 weeks after first trach change	• Para corporeal LVAD or BiVAD	• Tracheostomy- prior to first trach change
• Arterial line	• Hemodynamic instability-need for cardioactive or vasopressor infusion other than Milrinone	• Intracardiac lines
• Central lines and/or PICC lines	• Tracheostomy- up to 4 weeks after 1st trach change	

Figure 1: Holding and mobility guidelines currently in use at Nemours Cardiac Center

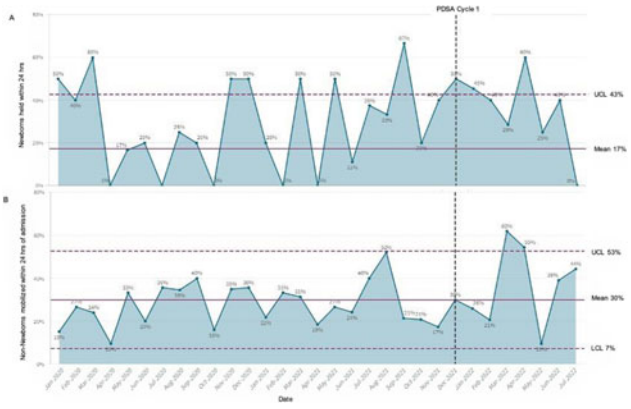

Figure 2: A) Proportion of newborns (<30 days) held by their parents within 24 hours of life. B) Proportion of non-newborns mobilized out of bed by 24 hours of admission the cardiac intensive care unit. UCL: Upper confidence limit, LCL: Lower confidence limit

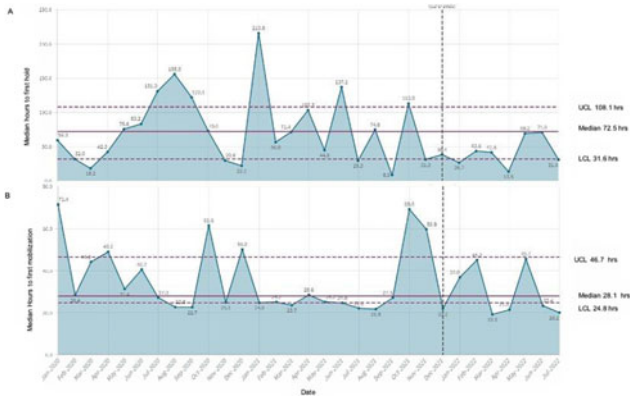

Figure 3: A) Median time to first hold of newborns by parents. B) Median time to mobilization of non-newborns out of bed. UCL: Upper confidence limit, LCL: Lower confidence limit.

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Psychosocial Outcomes of Emerging Adults with Congenital Heart Defect

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Introduction: A congenital heart defect (CHD) is the most common neonatal birth defect affecting approximately 8 in 1000 live births.[1] Individuals born with a complex CHD often experience neurodevelopmental and psychosocial deficits throughout their lifespan.[2,3] Additionally, executive function (EF) deficits have been consistently observed in the CHD population, and are associated with poorer academic achievement and a higher incidence of psychiatric disorders.[4] The transition from adolescence to adulthood is known to be a critical period for self-determination during which autonomy and psychosocial wellbeing are expected to flourish. However, little is known about the psychosocial functioning of youth with CHD during this period specifically. Therefore, this study aims to characterize the psychosocial wellbeing and autonomy of emerging adults with CHD and explore the potentially modifiable factors associated with optimal outcomes to orient the care offered in cardiac transition programs.
Methods: Adolescents and young adults 16-26 years of age born with a CHD requiring open-heart surgery utilizing cardiopulmonary bypass during the first two years of life were enrolled to complete a series of questionnaires assessing psychosocial functioning, as measured by resilience and psychological wellbeing, as well as EF and age-appropriate indicators of autonomy. Healthy age- and sex-matched participants were also recruited. Group differences were assessed using two-sample t-tests, Pearson χ^2, Fisher exact tests, or analysis of covariance as appropriate. Associations between individual or clinical variables and outcomes were assessed using multiple linear regression and analysis of covariance.
Results: A total of 58 emerging adults with CHD and 57 healthy youth participated in this study. Emerging adults with CHD had lower educational attainment and were more likely to still be living with their parents when compared to controls. Controlling for maternal education, psychosocial functioning did not significantly differ between the two groups; however, emerging adults with CHD had significantly lower EF than their healthy peers. Worse EF was associated with worse psychosocial functioning in both the CHD and the control groups. Longer total bypass time and total aortic clamp time were associated with worse EF.
Discussion: In this present study, we identified that EF deficits present in emerging adults with CHD are associated with worse psychosocial wellbeing. While our finding of EF deficits is consistent with prior literature in individuals with CHD, the lack of psychosocial deficits is not. These results support the need for further research into the challenges experienced by individuals with CHD across the lifespan in order to develop an optimal support program for a successful transition to adult care.

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Prevalence of torticollis following congenital heart disease repair

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Introduction and study question: The Herma Heart Institute of Children's Wisconsin established a routine congenital heart disease neurodevelopmental follow up program in 2007. During routine follow up of these cardiac patients it appeared that there were a significant number of patients that were diagnosed with torticollis. It is known that if torticollis is left untreated it may lead to plagiocephaly, facial asymmetry, visual and motor disturbances. (1, 2, 3) To date there is not any literature that identifies the prevalence of this finding in this population. Our goal was to determine the prevalence of torticollis in infants who underwent cardiac surgery in infancy in order to intervene and prevent known sequelae.
Study design: A retrospective chart review was completed of all patients seen in the Herma Heart Institute Developmental Follow-up clinic from September 2014 through May 2018. All patients met high risk criteria established by the American Heart Association for developmental follow up and had undergone complex congenital heart surgery in the first year of life. Physical examination by one of two physicians and standardized developmental evaluation utilizing the Bayley Scales of Infant Toddler Development, 3rd edition by a physical therapist were completed. A diagnosis of torticollis was included if made at the initial follow up clinic visit. The prevalence rate was calculated based on the time of the first clinic visit.
Result: 555 patients were seen during the data collection period. 185 patients exhibited torticollis for an overall prevalence rate of 33.3%. Of those with torticollis, 55.7% were male (103/185), and 78.9% had undergone a two ventricle repairs (146/185). 56.2% of patients with torticollis also demonstrated at least one delay on the Bayley Scales of Infant Toddler development. Of those patients with more than one visit (146), 23.3% (34/146) had persistence of their torticollis at a subsequent visit.
Discussion: The prevalence of torticollis in the congenital heart disease population has never been reported. This study provides initial evidence of a significant burden of disease in the congenital heart disease population, as over half the patients with torticollis also had at least one area of developmental delay. Further exploration of the progression/resolution of disease and further characterization of the impact of torticollis is warranted.

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An Investigation of Developmental Screening Outcomes in the Congenital and Heart Transplant Population

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Developmental screenings are useful to assist in evaluation and management of children with congenital heart disease (CHD)[1]. This quality improvement project aimed to investigate developmental domains between surgical intervention groups via the Ages and Stages Questionnaire (ASQ-3)[2].

Retrospective chart review was employed to examine pediatric cardiology patients' ASQ-3 results completed during outpatient cardiology appointments between 03/2016 and 04/2022. Initial ASQ-3 of patients (n=166) ages 4-12 months of age were analyzed (Table 1). The following surgical groups were examined: shunt dependent (SD), shunt dependent + aortic arch reconstruction (SD/AA), and heart transplant (HT). Chi square test of independence was used to examine categorical data. Independent samples t-test and analysis of variance evaluated mean differences between groups with Tukey's HSD test implemented for post-hoc examination.

There were no significant differences in development based on demographic variables. A greater percentage of HT patients were categorized as "delayed" in communication and fine motor skills than SD and SD/AA patients (Table 2). HT patients also demonstrated poorer communication mean scores than both the SD (p = .001, 95% C.I. = -16.80, -3.45) and SD/AA groups (p = .04, 95% C.I. = -14.31, -.30) (Table 3). HT patients demonstrated significantly worse mean scores for gross motor (p = .01, 95% C.I. = -17.71, -1.94), fine motor (p = .02, 95% C.I. = -16.71, -1.49), and personal social skills (p = .01, 95% C.I. = -16.82, -1.94) than the SD group. There were no significant differences in development between congenital and acquired heart disease patients within the HT group.

Developmental differences were observed within complex pediatric cardiac surgical procedure groups in the current sample with HT patients evidencing greater delayed screenings. Potential reasons for these outcomes include increased illness severity of patients awaiting heart transplant. The provision of developmental intervention and neurodevelopmental support prior to discharge is recommended.

Table 1.
Demographics

	Shunt Dependent (n = 70)	Shunt Dependent + Arch Reconstruction (n = 55)	Heart Transplant (n = 41)	Total (n = 166)	ANOVA p-value
Age at screening in months	8.0 (6.0 - 12.0)	6.0 (4.0 – 12.0)	7.0 (4.0 – 12.0)	7.0 (4.0 – 12.0)	≤0.01
	Shunt Dependent (n = 70)	Shunt Dependent + Arch Reconstruction (n = 55)	Heart Transplant (n = 41)	Total (n = 166)	X^2 p-value
Gender, Male	36 (51%)	37 (67%)	20 (49%)	93 (56%)	0.12
Ethnicity					
Non-Hispanic or Latino	36 (51%)	30 (55%)	26 (63%)	92 (55%)	0.47
Race					
White	58 (83%)	45 (82%)	32 (78%)	135 (81%)	0.78
Black	9 (13%)	7 (13%)	8 (20%)	24 (14%)	
Asian	1 (1%)	0 (0%)	0 (0%)	1 (0.6%)	
Other	2 (3%)	3 (6%)	1 (2%)	6 (4%)	
Language, English	56 (80%)	44 (80%)	34 (83%)	134 (81%)	0.92
Congenital Heart Disease	–	–	24 (59%)	–	

All continuous variables shown as median (IQR)
All categorical variables shown as n (%)

Table 2.
ASQ-3 Classification by Domain

	Shunt Dependent (n = 70)	Shunt Dependent + Arch Reconstruction (n = 55)	Heart Transplant (n = 41)	Total (n = 166)	X^2 p-value
Communication					0.02
Age Appropriate	52 (74.3%)	35 (63.6%)	19 (46.3%)	106 (63.9%)	
At Risk	11 (15.7%)	11 (20.0%)	8 (19.5%)	30 (18.1%)	
Delayed	7 (10.0%)	9 (16.4%)	14 (34.1%)	30 (18.1%)	
Gross Motor					0.10
Age Appropriate	19 (27.1%)	10 (18.2%)	5 (12.2%)	34 (20.5%)	
At Risk	15 (21.4%)	7 (12.7%)	5 (12.2%)	27 (16.3%)	
Delayed	36 (51.4%)	38 (69.1%)	31 (75.6%)	105 (63.3%)	
Fine Motor					≤0.01
Age Appropriate	42 (60.0%)	22 (40.0%)	17 (41.5%)	81 (48.8%)	
At Risk	5 (7.1%)	19 (34.5%)	6 (14.6%)	30 (18.1%)	
Delayed	23 (32.8%)	14 (25.5%)	18 (43.9%)	55 (33.1%)	
Problem-Solving					0.82
Age Appropriate	42 (60.0%)	32 (58.2%)	20 (48.8%)	94 (56.6%)	
At Risk	11 (15.7%)	8 (19.5%)	8 (19.5%)	27 (16.3%)	
Delayed	17 (24.3%)	15 (27.3%)	13 (31.7%)	45 (27.1%)	
Personal-Social					0.08
Age Appropriate	37 (52.9%)	21 (38.2%)	12 (29.3%)	70 (42.2%)	
At Risk	17 (24.3%)	13 (23.6%)	10 (24.4%)	40 (24.1%)	
Delayed	16 (22.9%)	21 (38.2%)	19 (46.3%)	56 (33.7%)	

All categorical variables shown as n (%)

Table 3.
Analyses of Variance Between Surgical Group and ASQ-3 Screening Results Following Surgical Intervention

ASQ Domain		N	M(SD)	F	η^2
Communication				6.51**	.07
	Shunt dependent	70	45.00(13.96)		
	Shunt dependent + aortic arch	55	42.18(12.90)		
	Transplant	41	34.88(16.68)		
Gross Motor				4.54*	.05
	Shunt dependent	70	25.07(17.74)		
	Shunt dependent + aortic arch	55	23.18(17.44)		
	Transplant	41	15.24(17.75)		
Fine Motor				4.53*	.05
	Shunt dependent	70	43.86(16.62)		
	Shunt dependent + aortic arch	55	37.73(14.43)		
	Transplant	41	34.76(18.27)		
Problem-Solving				0.50	.01
	Shunt dependent	70	41.00(17.06)		
	Shunt dependent + aortic arch	55	39.58(15.16)		
	Transplant	41	37.68(18.94)		
Personal-Social				4.46*	.05
	Shunt dependent	70	38.29(15.51)		
	Shunt dependent + aortic arch	55	34.55(14.41)		
	Transplant	41	28.90(18.63)		

Note. *p<0.05, **<0.01

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Associations among screen time, sleep hours, social functioning, executive functioning, and disruptive behaviors in pediatric heart disease

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Introduction and Study Question: Children who have had cardiac surgery are more likely to develop learning and cognitive deficits that negatively impact their academic, social, vocational, and community functioning.[2] Quality sleep and limited screen time are associated with improved health-related quality of life and child behavior.[4] This study explored links between screen time and sleep

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duration and children's social, behavioral, and executive functioning in a congenital and acquired heart disease sample.
Method: We obtained parent report of children's screen time sleep duration via single items and parent report of children's social skills (SRS-2), behavior problems (BASC-3), and executive functioning (BRIEF-P) via standardized measures. We examined whether meeting age-normed sleep and screen time recommendations were linked with children's social, behavioral, and/or executive functioning. Due to study novelty, we conducted multiple *t*-tests to avoid type II error in multivariate tests.
Results: Descriptive data is summarized in Table 1. Children who did not meet minimum sleep recommendations evidenced greater hyperactivity and atypical behaviors, and worse expressive social communication, modulating emotional responses, and flexibly transitioning in tasks/situations. Children who had more than recommended screen time evidenced greater inattention, internalizing symptoms, and atypical behaviors and worse adaptability, social awareness, social cognition, and social communication (Table 2).
Discussion: Average sleep duration was below AAP recommendations.[3] Average screen time was above AAP recommendations.[1] Sleep and screen time predicted differences in social skills, behavior symptoms, and executive functioning. Findings suggest the importance of closely monitoring cardiac patient screen time/sleep duration and providing caregiver education/intervention as needed.

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Table 1
Demographics with sleep and screen time descriptives

Variable	*n*	M(SD)
Age in months	10	32.36(17.24)
	2	
Daily sleep hours	10	9.84(1.33)
	2	
Daily screen time hours	10	1.90(1.57)
	2	

Variable	*n* (%)
Gender	
Male	57(55.9%)
Ethnicity	
Non-Hispanic/Latino	74(72.5%)
Race	
Caucasian	55(53.9%)
Black	15(14.7%)
Asian	1(1.0%)
Other, biracial	3(2.9%)
Language	
English	89(87.3%)
Met minimum sleep recommendations	62(60.8%)
At or below recommended screen time	40(39.2%)

Table 2. Links among child functioning, sleep, and screen time

	Less than recommended sleep hours M(SD)	More or equal to recommended sleep hours M(SD)	*t*	*df*	*p*-value
Measures					
BASC-3 Hyperactivity	58.39(12.45)	51.32(11.74)	2.22	58	0.03*
BASC-3 Atypicality	57.78(12.46)	50.68(9.75)	2.47	58	0.02*
SRS-2 Social Communication	61.18(10.68)	53.60(10.06)	2.34	40	0.02*
BRIEF-P Emotional Control	59.44(13.59)	50.57(13.55)	2.05	40	0.04*
BRIEF-P Flexibility Index	59.81(15.52)	50.15(11.63)	2.30	40	0.03*

	Over recommended screen time M(SD)	Under or equal to recommended screen time M(SD)	*t*	*df*	p-value
Measures					
BASC-3 Attention	56.40(10.53)	49.07(7.55)	-2.49	58	0.02*
BASC-3 Atypicality	55.49(11.94)	47.13(5.93)	-2.59	58	0.01**
BASC-3 Internalizing Index	52.80(1033)	45.73(6.19)	-2.50	58	0.02*
BASC-3 Adaptability	45.33(11.15)	54.27(11.96)	2.64	58	0.01**
SRS-2 Social Awareness	61.63(10.58)	52.22(5.93)	-2.55	40	0.02*
SRS-2 Social Cognition	60.88(13.22)	49.00(6.56)	-2.59	40	0.01**
SRS-2 Social Communication	58.55(11.16)	49.78(6.20)	-2.25	40	0.03*

*≤ .05, ** ≤ .01

Nursing Education of Neurodevelopmentally Appropriate Cue-Based Cares of Infants with Critical Congenital Heart Disease

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Introduction/Objective: Pediatric patients with complex congenital heart disease have delays in several key areas of neurodevelopment, notably motor skills, cognition, communication and language skills, visual/motor and visual/spatial integration, and executive functioning. Cardiac critical care unit (CCU) environmental factors, including monitor alarms, sleep interruptions, and diminished stimulation with sedation and paralysis, may contribute to these delays. We describe a nursing education model with a correlative case study integrating a neurodevelopmental model into routine medical care thereby improving neurodevelopment.
Methods: Forty-one registered nurses (RNs) in our cardiac center underwent a 30-minute lecture and simulation session focusing on cue-based and four-handed cares. The education curriculum was developed utilizing a literature review of best practices for developmental care models in NICUs (Neonatal Integrative Care Model or IDC), as well as current and emerging practices on CVICUs (Individualized Family-Centered Developmental Care Model or IFDC) in addition to proprietary unit-specific recommendations based on therapists' discretion and observation. A locally developed pre- and post-lecture survey was administered to the CCU nursing staff to assess nursing awareness and comfort in providing the described cares. We continue to monitor how utilizing this model impacts various CCU environmental factors. For example, one patient with complex single ventricle congenital heart disease who required Berlin EXCOR ventricular assist device support was evaluated utilizing the practices communicated between the therapy and nursing staff.
Results: Pre-test average scores were 72% while post-test scores were 88%, showing a 16% improvement in nursing comfort with cue-based and four-handed cares (Table 1). As an example of clinical correlate, a long-term patient before implementation had severe hyperactive delirium that required 75.2 morphine milligram equivalents (MME), daily exposure to 13 mg midazolam and 6 mg lorazepam, daily exposure to 302 mcg dexmedetomidine and 72 mcg clonidine, haloperidol, risperidone, and ketamine for

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Variable	Score
Pre-Test Score	72%
Post-Test Score	88%
Improvement	16%

Table 1. Scores of locally derived assessments of nursing comfort and understanding of cue-based and four-handed cares.

Medicine	Before	After
Morphine Milligram Equivalent (MME)	75.2	53.2
Midazolam (mg)	13	0
Lorazepam (mg)	6	8
Dexmedetomidine (mcg)	302	130
Clonidine (mcg)	72	130

Table 2. Medication dose of case received before and after nursing staff had undergone education of cue-based and four-handed cares for case correlate.

baseline safety of the patient and cooperation with life-sustaining medical equipment as well as additional periodic exposure to opioids and ketamine for cares, dressing changes and wound vacuum changes. After implementation this exposure decreased to 53.2 MME, daily exposure to 8 mg lorazepam, and daily exposure to 130 mcg dexmedetomidine and 200 mcg clonidine at baseline with no additional requirements for cares, dressing changes nor wound vacuum changes (Table 2). This case study, while not directly causative, shows the correlative improvements in administering neurodevelopmentally appropriate cares can have on exposure to sedation medications.

Conclusions: Nursing education on cue-based and four-handed cares rooted in theories from both the Neonatal Integrative Care Model (IDC) and the Individualized Family-Centered Developmental Care Model (IFDC) is an effective way to increase nursing understanding and comfort. While further research is warranted, it can also potentially contribute to a correlative decrease in the required amount of sedation medications utilized for pediatric patients with congenital heart disease.

Left ventricular dimensions and function by three-dimensional echocardiography are associated with brain injury in neonatal encephalopathy

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Background: Despite therapeutic hypothermia (TH), many neonates with neonatal encephalopathy (NE) develop brain injury. These neonates often present with cardiac dysfunction in the first days of life.

Objective: To evaluate the association between brain injury on magnetic resonance imaging (MRI) and cardiac function of neonates with NE treated with TH, using bi-dimensional (2D) and three-dimensional echocardiography (3D-ECHO).

Design: Single-center prospective study of neonates with moderate to severe NE treated with TH between 2019 and 2021. 3D-ECHOs were performed on day of life (DOL) 2 (during TH). Left ventricular (LV) metrics were measured by Simpson's biplane and 3D-Speckle Tracking Echocardiography. Cardiac function of neonates with vs. without brain injury were compared.

Results: We included 16 infants; ten had injury on brain magnetic resonance imaging and six did not. Demographic/clinical characteristics were similar between groups. Neonates with brain injury had higher left ventricle end-diastolic volume (LVEDV) 4.6 [1.2] vs 3.4 [0.9] mL; p = 0.04. They also had higher 3D-derived stroke volume (1.8 [0.5] vs 2.5 [0.7] mL; p=0.047) and higher peak global circumferential strain (-26.6 [3.6] vs –21.3 [4.0] %; p=0.01). 2D echocardiography also showed a higher LVEDV (7.1 [1.6] vs 5.4 [1.2] mL; p=0.047) and stroke volume (4.5 [3.7] vs 3.2 [0.9] mL; p=0.02) in neonates with brain injury, but did not show a higher peak circumferential strain.

Conclusion: Neonates with moderate to severe NE developing brain injury despite TH had differences on their 3D-ECHO LV markers compared neonates without injury. An enhanced understanding of their cardiac alterations may help improve their management and outcomes.

Starting School Strong: Providing 1:1 education to caregivers of children with CHD to increase knowledge of and advocacy within the early childhood special education system

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Introduction & Study Question: Children with congenital heart disease (CHD) are at higher risk for developmental delays affecting cognitive, linguistic, and motor abilities. These delays may qualify patients for early childhood special education (ECSE) services in the public school system; however, caregivers of children with CHD may be unaware of how to access these services or how to transition from Early Intervention (EI) to ECSE, leading to gaps in care. We hypothesized that providing 1:1 caregiver education about the benefits of participation in ECSE, how to access services, and caregiver rights and responsibilities within the public

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education system could improve caregiver comfort navigating the system and advocating for necessary services.
Methods: Children with CHD aged 24-48 months previously referred for EI developmental therapy services through the Illinois Department of Human Services were identified through our cardiac neurodevelopmental clinic. Their caregivers were invited to participate in a 1:1 virtual information session about ECSE services conducted by the clinic's Education Liaison via telemedicine. Pre- and post-intervention surveys measured caregiver understanding of the differences between EI and ECSE, the transition process from EI to ECSE, and interest in accessing ECSE services. The post-intervention survey also evaluated whether the caregiver had taken steps toward requesting an ECSE evaluation.
Results: A total of 7 caregivers participated in this pilot study with children ranging in age from 30-36 months at baseline data collection. Pre-intervention, 3 children (43%) were still receiving EI services and 3 children (43%) had recently aged out of the program. None of the caregivers reported participation in a transition planning conference with the EI and ECSE teams. Six of 7 caregivers (86%) reported being interested in pursuing ECSE services for their child.
Post-intervention, 6 caregivers (86%) reported understanding the differences between EI and ECSE services (vs. 4 caregivers (57%) pre-intervention), and 100% of caregivers reported knowing the next steps required to complete the transition to ECSE services (vs. 2 caregivers (29%) pre-intervention). At study conclusion, 5 caregivers (71%) had taken steps to request an ECSE evaluation, and 1 patient (14%) had been placed in a Head Start Program with specialized services.
Discussion: Difficulty navigating the transition between EI and ECSE can lead to gaps in care. In this pilot study, provision of 1:1 caregiver education facilitated better caregiver understanding and advocacy for necessary services but was labor intensive. Cardiac neurodevelopmental clinics may be well-positioned to support caregivers through this transition but would require appropriate dedication of resources to the effort.

Association of Reading Exposure and Maternal Education Level with Developmental Outcomes in Infants with Congenital Heart Disease

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Introduction: Early childhood literacy programs (ECLP) to facilitate reading exposure are recommended by the American Academy of Pediatrics for cognitive and language development. In 02/2021, we launched Books@Heart, a novel inpatient ECLP, for all infants with congenital heart disease (CHD) admitted to the Texas Children's Hospital (TCH) Heart Center. We aimed to analyze the impact of inpatient and outpatient reading exposure on developmental outcomes in children with CHD, including the interaction of reading exposure with maternal education level.
Methods: Infants <1 year of age who received ECLP services through Books@Heart and were followed in the TCH Cardiac Developmental Outcomes Program clinic with completion of the Survey of Well-Being of Young Children (SWYC) were included. The SWYC is a parent-completed developmental-behavioral screening tool for children that assesses risk for developmental disorders and family/social determinants of toxic stress. For this study, the answer to the question, "During the past week, how many days did you or other family members read to your child?" was recorded. During the visit, standardized cognitive scores were assessed with Capute Scales (Cognitive Adaptive Test (CAT), and Clinical Linguistic and Auditory Milestone Scale (CLAMS)) and overall developmental quotient (DQ) was calculated. Demographics including maternal education were abstracted.
Results: Forty-four patients and families met inclusion criteria - 52% female, 11% born at gestation <36weeks, and race/ethnicity distribution as follows: 30% non-Hispanic White, 43% Hispanic, 11% non-Hispanic Black, and 16% Others. Eighteen percent of mothers had not graduated high school (2% <middle school, 2% middle school, 14% some high-school), while 82% were high school graduates or higher (14% high school, 11% some college, 7% trade school, 32% college, and 18% graduate).
The median outpatient reported weekly reading frequency in the first 2 years of life was 4 (IQR 2 - 7). There was a significant correlation between the maternal education level and reported reading frequency ($r = 0.349$, $p = 0.024$).
The median inpatient reported weekly reading frequency was 1 (IQR 0 - 3). We did not find an association of inpatient reported reading frequency with maternal education level ($p = 0.226$).
CAT /CLAMS developmental data at 6 months of age were available for 28 patients. Median CAT DQ was 102 (2 - 117) and median CLAMS DQ was 95 (85 - 102). We did not find a significant correlation between inpatient reported reading frequency or level of maternal education with CAT ($p = 0.336$ and 0.937, respectively) or CLAMS DQ scores ($p = 0.128$ and 0.830, respectively). However outpatient reported reading frequency had a positive correlation with the CLAMS DQ ($r = 0.430$, $p = 0.028$).
CONCLUSIONS: Higher maternal education level is associated with increased early childhood reading exposure in children with CHD. Outpatient reported reading frequency was associated with higher CLAMS DQ, suggesting that interventions targeting reading exposure and book access may improve developmental outcomes in these patients. Larger prospective studies are needed to assess the impact of inpatient ECLP on neurodevelopmental outcomes.

Positive Impact of Inpatient Childhood Literacy Program on Developmental Care and Family Experience

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Introduction and Study Question: Early childhood literacy programs (ECLP) to distribute books as well as anticipatory guidance about reading during primary care clinic visits is recommended by the American Academy of Pediatrics (AAP) to promote cognitive and language development. To incorporate this into the inpatient developmental care of children with congenital heart disease, we launched Books@Heart, a novel inpatient ECLP at Texas Children's Hospital Heart Center in 02/2021. The aim of this study was to report the impact of Books@Heart on inpatient caregiver reading practices and family experience.
Methods: Through Books@Heart, each patient age <1year and their family receives a book, guidance about reading to infants, and a calendar for self-tracking reading frequency at admission as well as at ages corresponding to recommended well-child checks. At least 2 weeks after receiving the first book, feedback was solicited from all families receiving services from Books@Heart using a QR-code based electronic survey. Paired samples t-tests were used to compare reading practices and access to books pre- and post- Books@Heart.

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Results: We received 60 feedback surveys, and the responses are summarized in the attached table. 98% (59/60) of respondents reported being very satisfied or satisfied with the information and books received through Books@Heart, and 98% (40/41) strongly agreed or agreed that reading helped them feel more connected/involved in their child's care. 92% (24/26) of respondents felt that Books@Heart improved their experience at the hospital. A majority of parents did not identify any barriers to reading to their child in the hospital (68%, 28/41). Of note, 12% (5/41) reported that they did not know they are allowed to read to their child and 5% (2/41) were worried that by reading they are in the way of medical care.
Compared to the reported reading frequency prior to introduction to Books@Heart, caregivers reported a significantly higher reading frequency after learning about Books@Heart (p = 0.002), with the proportion of caregivers reading to their child daily increasing from 35% (17/49) to 64% (23/36). There was also a trend towards improvement in access to books with 18% (14/38) parents reporting no books at home prior to Books@Heart, which decreased to 11% (14/49) after learning about Books@Heart (p = 0.071).
CONCLUSIONS: Based on caregiver report, we conclude that an inpatient ECLP in a heart center is effective in improving reading exposure for infants with heart disease. We also report positive impacts on access to books, and family engagement and experience. Next steps include addressing the barriers to reading to infants in the hospital as well as caregiver and medical provider education about the benefits of early childhood reading. Larger prospective studies are needed to assess the impact of inpatient ECLP on long- term literacy attitudes and behaviors, as well as neurodevelopmental outcomes.

Table. Caregiver Feedback on Satisfaction, Patient Experience, and Reading Practices after Books@Heart

QUESTION	NUMBER OF RESPONSES	RESPONSES					
Do you prefer Spanish or English?	n = 41	English 88% (36/41)	Spanish 12 (5/41)				
Are you satisfied with the type of books and information you received through Books@Heart?[2]	n = 60	91% (55/60) Very Satisfied	7% (4/60) Somewhat satisfied	2% (1/60) Unsure			
Have there been any barriers to reading to your child in the hospital?[2]	n = 41	68% (28/41) No Barriers	5% (2/41) I'm worried I'm in the way of medical care	2.5% (1/41) I'm worried I will stress the child	12% (5/41) Didn't know I was allowed to read	10% (4/41) I don't have books to read to them	2.5% (1/41) There is never enough time
Do you agree with the following statements?[3]		Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	
Reading to my child helps me feel more connected and involved in their care	n = 41	80% (35/41)	12% (5/41)	0	2% (1/41)	0	
Books@Heart has improved the patient experience at Texas Children's Hospital	n = 26	58% (15/26)	34% (9/26)	8% (2/26)	0	0	
On average, how many times did you read to your child?[1]	NUMBER OF RESPONSES	Never	1-2 times per week or a few times a month	3-5 times a week	Daily		
Before Books@Heart	n = 49	10% (5/49)	29% (14/49)	26% (13/49)	35% (17/49)	P = 0.002	
After Books@Heart	n = 36	0% (0/36)	19% (7/36)	17% (3/36)	64% (23/36)		
How many books did you have for your child at home/in the hospital?[1]	NUMBER OF RESPONSES	None	1-5 books	5-10 books	Too many to count		
Before Books@Heart	n = 49	18% (9/49)	26.5% (13/49)	26.5% (13/49)	29% (14/49)	P = 0.071	
After Books@Heart	n = 38	11% (4/38)	26% (10/38)	26% (10/38)	37% (14/38)		

1. Questions included in first edition of feedback questionnaire
2. Questions added in second edition of feedback questionnaire
3. Questions added in third edition of feedback questionnaire

Neurodevelopmental impact of antenatal diagnosis in children with transposition of great arteries

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Introduction and Study Question: Infants with congenital heart disease (CHD), including those with transposition of the great arteries (TGA), are at risk for poor brain growth, which has been linked to neurodevelopmental impairments. It is unknown whether antenatal diagnosis can affect brain growth and neurodevelopmental outcomes. Our objectives were to determine whether (1) antenatal diagnosis of TGA is associated with pre- and post-operative brain weight and (2) associations between pre- and post-operative brain weights and 18-month neurodevelopmental outcomes are modified by antenatal diagnosis.
Methods: Pre- and post-operative clinical characteristics were collected in a retrospective cohort of 143 infants with TGA (80 antenatally diagnosed [56%]). We assessed brain maturation by calculating brain weights on pre- (n=107, median post-menstrual age [PMA] 39.7 weeks, IQR 38.3-41.1) and post-operative (n=122, PMA 42 weeks, IQR 39.6-44.4) MRIs. 18-month cognitive, language and motor outcomes were assessed in 101 children using Bayley Scales of Infant Development, 3rd edition (BSID-3). General estimating equations (GEEs) were used to assess the association between antenatal diagnosis with pre- and post-operative brain weights. GEEs with an interaction term were used to determine whether antenatal diagnosis modified the association between brain weights with BSID-3 scores; all models accounted for PMA at MRI, brain injury, and ventricular septal defect (VSD).
Results: Infants with antenatal diagnosis were younger at birth compared to those diagnosed postnatally (39 weeks vs 39.3 weeks postnatally, p=0.024) with no other significant differences. Antenatal diagnosis was not associated with greater postnatal brain weights (Coef=6.44, 95%CI [-6.29,19.17]). The interaction between antenatal diagnosis and postnatal brain weight significantly predicted BSID-3 cognitive (p=0.0007) and language (p=0.048), but not motor outcomes. Specifically, in postnatally diagnosed infants, smaller brain weights are associated with lower cognitive and language scores; this association was attenuated in those diagnosed antenatally (Figure 1). VSD was a significant

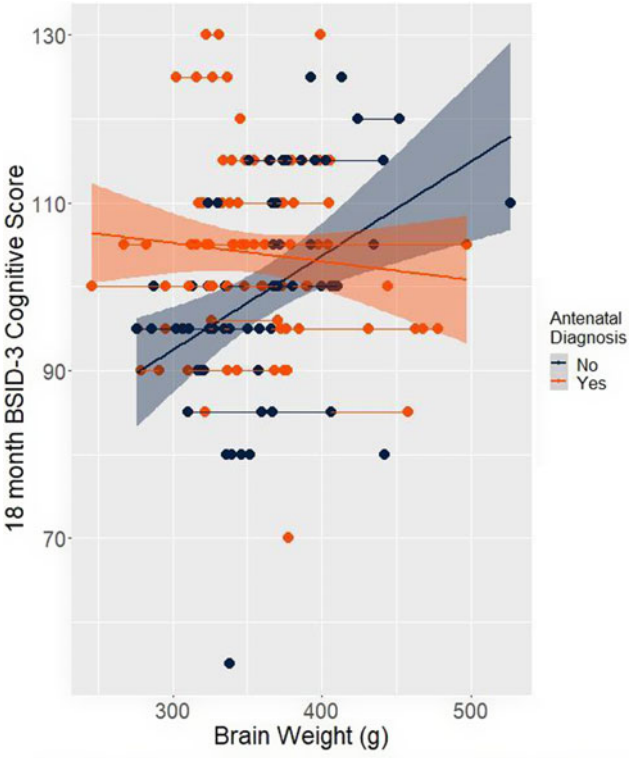

Figure 1. BSID-3 cognitive scores by pre- and post-operative brain weights stratified by antenatal diagnosis (p=0.0007)

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predictor (Coef=-5.31, 95%CI [-10.39,-0.23], p=0.04) of cognitive outcomes.
Discussion: Antenatal diagnosis interacts with neonatal brain weight to predict 18-month cognitive and language outcomes in infants with TGA. Specifically, smaller brain weight is associated with lower cognitive and language scores in infants with postnatal but not antenatal diagnosis of TGA. These findings highlight the importance of antenatal diagnosis and the need to consider individual risk factors for adverse neurodevelopmental outcomes in infants with TGA. Identifying factors that mitigate the association between smaller brain weight and poorer outcomes may offer opportunities to support optimal neurodevelopment.

Neurodevelopmental status recognition in high-risk children with congenital heart disease

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Introduction: Advances in both surgical techniques and perioperative care have led to improved survival in infants and children undergoing surgery for complex congenital heart disease (CHD). Many infants who have undergone surgery for CHD in the neonatal period demonstrate a pattern of neurodevelopmental sequelae. Neurodevelopmental deficits have the potential to negatively impact quality of life throughout the lifespan of children with CHD, impacting poorer academic achievement, reduced employment opportunities, difficulties with emotional and behavioral function, self-esteem and social relation. Increasing knowledge about neurodevelopmental outcomes and identifying this high risk population may provide strategies to optimize long-term outcomes.
Our aim is to increase outpatient cardiology clinic identification of neurodevelopmental status from <1% to 20% by December 2022 and maintain for six months. The target population is children (3-18 years of age) with a history of open-heart surgery in the first year of life.
Methods: A multidisciplinary team conducted a quality improvement initiative to improve neurodevelopmental screening at a single-center cardiology outpatient clinic. A key driver diagram (fig. 1) establishing factors that may impair neurodevelopmental screening and potential interventions was developed. A screening tool was created and integrated into the electronic medical records to be used by nursing staff during the outpatient cardiology visits of eligible patients. The goal of the screening tool is to identify any concern(s) regarding child's development, mood or behavior and whether the child is receiving any neurodevelopmental or school related services. Parents voicing neurodevelopmental concerns are able to request a referral for neuropsychology evaluation.
Results: Identification of this high-risk population was low due the lack of formal screening methods. Using quality improvement (QI) methodology, we were able to improve the outpatient neurodevelopmental screening from <1% to 44%.

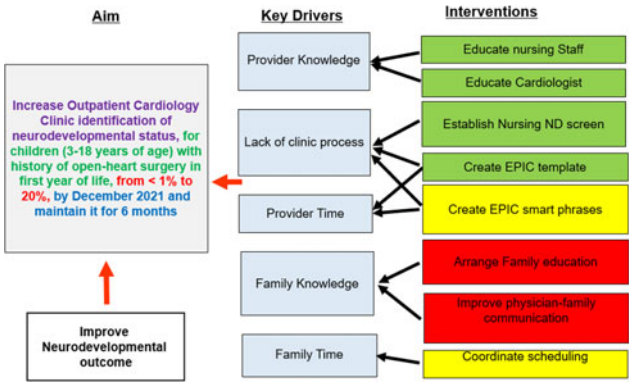
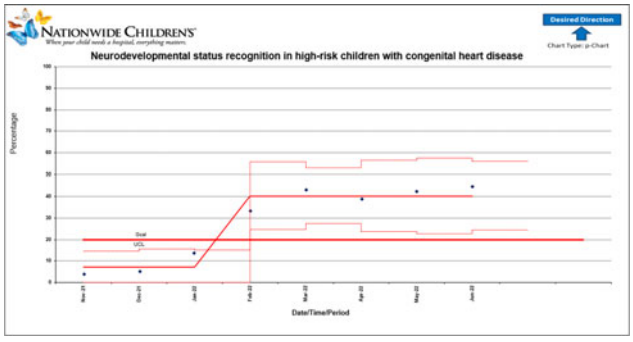


Fig 1: Key Driver Diagram



Discussion: With a QI approach we were able to increase neurodevelopmental screening in the cardiology outpatient clinic and increase awareness about the importance of screening and referral for formal evaluation. Integrating the neurodevelopmental screening questionnaire as part of nursing evaluation prior to being seen by the cardiologist helped streamline clinical care and improve compliance. Further improvements of screening and referral are still needed. We also are in the process of considering key drivers and interventions to improve the rate children referred are seen for formal neurodevelopmental evaluation.

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Impact of Quality Improvement Initiative on Early Intervention Referral and Evaluation Rates for At-Risk Infants with Congenital Heart Disease

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Background: Early Intervention (EI) programs provide evaluation and interventions to enhance the development of children aged birth to three with developmental delays (DD) or a medical condition likely to lead to DD. Children with congenital heart disease (CHD) are at risk for DD and are eligible for EI evaluation. The Heart Center (HC) at St. Louis Children's Hospital implemented a process to refer all at-risk CHD infants to EI upon hospital

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discharge (DC), but outcomes of the referral process and subsequent evaluation by EI were unknown.
Study Aims: 1. Increase % of eligible CHD infants who receive EI referral at hospital DC from baseline rate of 66% to 100% over 7 months. 2. Increase the % who receive EI evaluation from 47% to 90%.
Methods: This study utilized the Model for Improvement method of Plan/Do/Study/Act (PDSA) cycles. Study population included all infants <1y DC'ed from inpatient HC admission who met criteria for neurodevelopmental (ND) risk per American Heart Association guidelines. Baseline data were obtained over 6 months (Apr-Oct 2021). To confirm EI referral, the local EI office for each patient was contacted. To confirm EI evaluation, patient's guardian was contacted if not documented in medical records.
Four interventions over 7 months (Nov 2021-May 2022) were implemented in 45-day PDSA cycles: 1. Embedding the EI referral process into weekly inpatient ND rounds and discussing with families at bedside; 2. Follow-up call to families 4 weeks post-DC to confirm they had been contacted by EI; 3. Creating a master list to track EI referrals; 4. Documenting EI referral in patient's DC paperwork. Outcome measures of EI referral and evaluation were obtained post-interventions. Run charts were used for analysis.
Results: Baseline: Of 44 infants DC'ed, 86% (n= 38) met criteria for EI referral. Of these, 66% (n= 25) received EI referral at DC, and 72% (n= 18) of those were evaluated by EI. Of total eligible, 47% (18/38) received EI evaluation. Post intervention: Of 64 infants DC'ed, 10 were already receiving EI. Of the remainder (n=54), 85% (n=46) met criteria for EI referral, and of those 85% (n=39) received referral at DC. The 7 not referred were due to missed referral (n=4), and guardian declining referral (n=3). Of those referred, 92% (n=36) were evaluated by EI. Of total eligible, 78% (36/46) received EI evaluation.
Discussion: This quality improvement initiative improved the rate of EI referral and evaluation for hospitalized CHD infants at risk for DD. EI referral rate increased from 66% to 85% after interventions, and EI evaluation rate increased from 47% to 78%. Importantly, if EI referral was made, there was a high rate of completed evaluation that improved from 72% to 92%.
EI services can change a child's developmental trajectory and improve ND outcomes, and EI referral by the HC team should be a routine part of the DC process. This study showed the feasibility to successfully facilitate the important transition for CHD infants to outpatient EI, by introducing the concept of EI to families during the hospitalization, ensuring a referral is made at DC, and following up with families after DC. Further study is needed to continue to improve rate of EI referrals and understand and address barriers to EI evaluation.

"The Trauma of the Transition": Parent Experiences of Transition from Pediatric Intensive to Acute Care

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In addition to the psychosocial and neurodevelopmental risks posed by pediatric cardiac defects, illnesses, or injuries for children and families, a critical care admission also imparts physiological and psychological distress. To reduce the risk of Post-Intensive Care Syndrome in pediatric patients (PICS-p) and Post-Traumatic Stress Disorder in parents/caregivers, providers must identify, anticipate, and address the most distressing elements of care that families identify. One such event is the child's transition across units and services; in adult care, these transitions are characterized by ineffective communication across providers and families, as well as increased risk of adverse events and medical errors. However, little is known about how this is experienced by pediatric patients and families. Therefore, the purpose of this study was to explore parent/caregiver perceptions of their child's transition from the pediatric intensive care unit to the acute care or step-down unit. Research questions included: 1) How do parents/caregivers of pediatric patients perceive and describe their child's care in the ICU, the acute care unit, and the transition between the two; and 2) what stressors and supports do they identify when transitioning between units?
Using a convergent, mixed methods design, 62 parents/caregivers of children admitted to the pediatric cardiac or general intensive care units of the research site completed an online survey about their experiences; 17 completed an in-depth follow-up interview. Parents rated their perceptions on a Likert-type scale drawn from evidence on parent perceptions of pediatric healthcare quality. These dimensions of care quality included communication, time spent with providers, availability of physical resources, emotional support, and respect for spiritual and cultural needs. The semi-structured interview guide also addressed these areas while allowing parents to expand on their needs, experiences, and recommendations for improvement.
Demographic responses were analyzed using descriptive statistics, with paired and independent samples t-tests and linear regression to address hypotheses; interview data were analyzed using an inductive coding approach as per Boles et al. (2017). Overall, participants rated intensive care quality significantly higher than the quality of acute care ($p<.001$, $d=6.02$). Participant satisfaction with transition between units was significantly lower than their reported satisfaction with intensive care and acute care stays ($p<.05$). They verbally described transition as "being thrown from a moving train," "traumatic in and of itself," and "the scariest experience." They identified the need for specific preparatory information and support prior to transition, more training for acute care staff serving patients transferred from the ICU, and better communication between teams and families.
These findings reveal that transitions between intensive and acute care may challenge patient and family wellbeing and jeopardize the provision of high-quality care. Providers and staff must anticipate patient and family transition needs, and collaborate to provide effective preparation, education, and continuity of care to promote both physical health and emotional resilience.

Improving Adherence with Hearing Screen Recommendations in the Infant Cardiac ICU

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Introduction and Study Question: Infants with congenital heart disease are at increased risk of developing hearing loss due to high-risk exposures and underlying genetic predisposition.[1]

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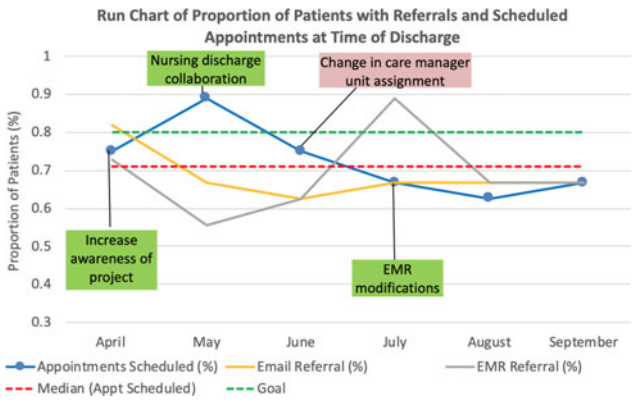
Surgical cardiac repair and ECMO exposure further increases this risk. Prevalence of hearing loss ranges from 5.9-28.6% amongst patients with history of surgical cardiac repair and 26% amongst neonatal ECMO graduates.[2–4] Timely intervention within the first 3-6 months of life has been shown to mitigate the adverse consequences of hearing loss.[5,6]

The purpose of this quality improvement project is to increase the percentage of infants with risk factors for hearing loss (congenital cardiac disease, history of cardiac repair, history of ECMO exposure) who have audiology appointments for hearing screens at 3-6 months of age from 0% to 80% within a 6-month period amongst infants discharged/transferred from the infant cardiac ICU in NYP - Morgan Stanley Children's Hospital.

Methods: This quality improvement project was conducted from April - September 2022 and utilized a key driver diagram to identify and test 3 Plan-Do-Study-Act Cycles. Initial cycles focused on increasing awareness among health care providers regarding the new hearing screen recommendation and expanding the care manager role to include audiology appointment scheduling. Primary outcome measure is percent of patients with audiology appointment scheduled at discharge. Secondary outcome measures include (1) percent of patients who had audiology referrals submitted via E-mail by the care manager and (2) percent of patients who had referrals submitted through the electronic medical record system by the front-line staff. Of note, EMR referrals are not utilized by the audiology clinic for scheduling and are being measured as an indicator of front-line provider retention of new hearing screen recommendations. Subsequent cycles focused on improved nursing collaboration and EMR modifications including adding audiology appointment to the discharge checklist in provider handoff and note templates.

Results: Decrease in appointment scheduling and e-mail referrals in June corresponds with re-assignment of care manager to cover general NICU in addition to infant cardiac ICU. Of 12 appointments scheduled for June – September, only 2 patients arrived for audiology evaluation. Primary reasons for lack of follow up include conflict with other medical appointments, hospital readmission, and parental assumption that repeat hearing screen was unnecessary if pre-discharge hearing screen was normal.

Discussion: Our process of scheduling infants for audiology appointments depended primarily on the care manager. A streamlined approach permitted rapid initial attainment of the desired outcome. However, sustained improvement requires a multifaceted approach that involves multiple care team members and EMR changes. Next steps include developing a functional ambulatory audiology referral order for scheduling appointments, parental education on the purpose and importance of audiology follow-up, and partnering with community health workers to monitor for and address barriers to adhering with audiology follow-up appointments.



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CNNN: Assessment and management of Feeding Challenges for Infants with CHD: What We Know and Future Directions

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Introduction: Despite the evidence for feeding challenges in infants with CHD, assessment tools and intervention strategies which consider their unique post-surgical sequelae have not yet been established. Current practice to improve oral feeding difficulties in this population applies knowledge based on neonatal literature. However, their effectiveness is unknown for infants with CHD, as there are significant gaps in the research examining these strategies. We review the medical complications of infants with CHD regarding assessment and management of feeding difficulties along with recommendations for care.

Recommendations for Assessment and Strategies for Oral Feeding: Infants with CHD often require respiratory support after surgery. Research examining safety of oral feeding on non-invasive respiratory support has been conducted with neonates, with lack of standardized protocols for assessment. Changing nipple flow rate

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and position are strategies used to improve breathing while weaning from respiratory support but has not been researched in infants with CHD. Gastrointestinal difficulties after cardiac surgery may result in feeding disruption. Collaboration with a gastroenterologist is beneficial to identify appropriate diagnostic testing to manage symptoms. Nonpharmacologic management has been recommended as the initial treatment for infants with GERD, followed by medication, however we do not know if these are effective strategies for infants with CHD.

Neurobehavioral abnormalities such as poor state regulation and attention can result in poorer feeding outcomes. The NICU Network Neurobehavioral Scale-II and the Newborn Behavioral Observations are assessments which have been used in research of infants with CHD. To facilitate neurobehavioral development, The Supporting of Oral Feeding in Fragile Infants method and Auditory, Tactile, Visual, and Vestibular have been found to be effective in preterm infants. In addition, the Newborn Individualized Developmental Care and Assessment Program has been shown to improve outcomes in neonates and is recommended in infants with CHD.

There are no standardized oral feeding assessments to evaluate bottle or breastfeeding skills of infants with CHD, requiring reliance on tools used for neonates. Strategies to support respiratory stability and safety include side-lying positioning, co-regulated pacing and use of slower flow nipple to change milk flow rate. Infants with CHD are also at high risk for dysphagia secondary to vocal cord paresis. Instrumental assessments evaluate swallow function and assist with clinical decision making. Dysphagia may be managed by altering liquid viscosity. However, thickeners may negatively impact the immature infant gut with unknown side-effects for infants with CHD.

Conclusion: We recommend early assessment and intervention by a skilled feeding therapist to promote oral motor strength, coordination and oral sensory processing for appropriate feeding development. Additional studies exploring oral feeding with non-invasive respiratory support, gastrointestinal complications and effect on oral feeding development and outcomes using common therapeutic strategies is necessary to determine effective management of feeding difficulties in infants with CHD.

Impact of Functional Feeding Impairments on Quality of Life and Family Functioning in Infants with Congenital Heart Disease

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Background: Infants with congenital heart disease (CHD) often have significant challenges in feeding, nutrition, and growth. When nutrients are delivered through supplemental nutrition, such as via nasogastric (NG) tube, quality of life and family functioning may be affected. Associations between standardized measures of functional oral intake, quality of life, and family functioning before and after feeding therapy have not been previously investigated in the pediatric cardiac population.

Methods: Infants with CHD who presented following cardiothoracic surgery with dysphagia at the time of discharge were studied. Functional oral intake was assessed by the clinician through the FOIS (Functional Oral Intake Scale) at therapy visits. Prior to or at the first feeding therapy visit and at discharge from therapy, caregivers also reported perceptions of infant quality of life and impact of the child's health on family function through administration of the PedsQL (Pediatric Quality of Life) Infant and the PedsQL Family Impact Scale. Demographic data, total hospitalization length of stay, type of cardiothoracic surgery and CHD were obtained from the electronic medical record.

Results: Nineteen patients completed the Infant PEDSQL and the PEDSQL Family Impact Scale questionnaires prior to or at the first feeding therapy visit and thirteen at discharge from feeding therapy (Table 1). Of the six patients with increased functional oral intake based on pre- and post-therapy FOIS scores, a clinically meaningful increase in PedsQL family impact scores was observed for 50% (N = 3), indicating a decrease in the impact of the child's health on family function. Of the seven patients with no change in functional oral intake, 57% (N = 4) exhibited a clinically meaningful increase in PedsQL family impact scores. Pre- and post-therapy PedsQL Family Impact Scale scores based on improvement in functional oral intake are represented in Figure 1. The two families with reduced PedsQL Family Impact Scale scores reported vomiting, discomfort, and gastroesophageal reflux as stressors throughout the therapeutic process.

Discussion: Based on current data, associations between functional oral intake, quality of life, and family impact are not clear. While functional oral intake may play a role in the impact of the child's health on family function, infants with congenital heart disease often have multiple comorbidities that impact the family. Data collection for this study is ongoing. Future analyses with a larger sample size will evaluate the impact of functional oral intake on infant quality of life and family functioning, while also considering the impact of other comorbidities and complications.

	Pre-Therapy FOIS	Post-Therapy FOIS	Pre-Therapy Family Impact	Post-Therapy Family Impact	Pre-Therapy Infant PEDSQL	Post-Therapy Infant PEDSQL
Mean	2.26	4.5	71.49	76.96	80.69	83.80
Standard Deviation	1.1	1.73	16.78	16.16	11.22	10.7

Note. Pre-Therapy N = 19, Post-Therapy N = 13

Table 1. A comparison of scores obtained before and after feeding therapy plan of care

Standardized Approach to Holding in the Infant Cardiac Unit

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As surgical outcomes continue to improve for infants with complex congenital heart disease (CHD), the need to support long term neurodevelopmental (ND) outcomes has become apparent. Infants with CHD are at increased risk for ND deficits, as well as behavioral and mental health problems as compared to their well peers. Brain development is structurally delayed in infants with certain forms of complex CHD. Many of these risk factors are non-modifiable related to disease processes or to the nature of prolonged inpatient status. The burden falls upon clinicians to examine unit practices and the environment to discover opportunities to augment modifiable factors as much as possible to facilitate the most favorable environment for infant development. At Columbia University Medical Center, a 17-bed infant cardiac unit serves infants under 12-months with CHD in perioperative phases of care. A previous unit-based quality improvement project

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assessed bedside nurse comfort level with mobilizing infants with invasive devices as well as barriers to achieving these ends. During 2020 and 2021, nurses were in-serviced on standardized line securement and a holding algorithm (Figure 1). Weekly interdisciplinary developmental care rounds were also incorporated during this time. The investigators then evaluated comfort level and perceived cultural change after educational intervention. A quality improvement project conducted in 2020 investigated nursing perceived barriers prior to educational intervention. A holding algorithm was added during a second PDSA cycle. A 6-question survey was developed to query nurses about comfort level and perceived cultural changes with regards to mobilizing infants with invasive devices. Responses were given in the affirmative or negative (Strongly agree, agree, disagree, strongly disagree). Educational intervention components: (1) algorithm for determining safe transfer out of bed, (2) demonstration and teach-back, (3) training of unit champions. Survey responses served as the outcome variables in the analysis. Of the 61 clinical nurses, there were 51 respondents (response rate 84%). When asked "I believe unit culture has changed," 82% of nurses agree or strongly agree with regard to umbilical lines, 80% with arterial lines, 70% with chest tubes. With regard to mobilizing infants, 86% reported comfort with umbilical lines and arterial lines, and 70% with chest tubes. The ICU environment may be adapted to promote optimal development during hospital stay. When pre-intervention surveys were conducted in August 2020, nurses noted comfort, safety and support as barriers to mobilizing patients in the infant cardiac unit. Two years later, nurses are reporting a perceived culture shift with regards to umbilical and arterial lines following standardization of line securent and initiation of holding algorithm. In the next PDSA, we need to evaluate chest tube management, comfort level, and culture. Strong commitment from leadership, staff education, family support, value of parents as the primary caregivers is needed, and policies to increase consistency of practice. Future directions: parent surveys assessing understanding of PT/OT/SLP role, experience with colostrum care. Family advisory council partnership. Expand outpatient to include a broader CHD population. Obtain IRB approval to investigate holding trends and invasive device data prior to and after intervention.

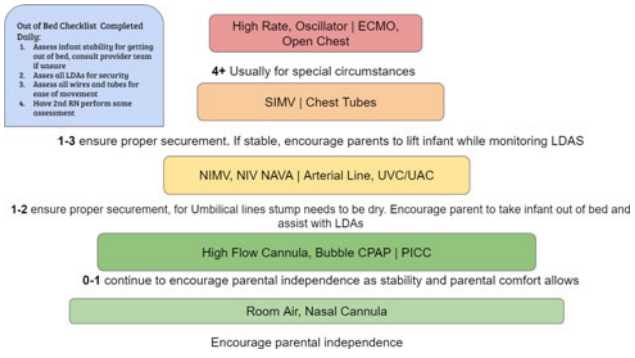

Figure 1. Holding Algorithm

Initiating CNOC Registry Participation for a Multidisciplinary Heart Center

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Introduction: Accurate collection and reporting of neurodevelopmental data requires a robust infrastructure and a multidisciplinary team. This study describes the experience of a new Heart Center and Cardiac Neurodevelopmental Outcomes Program in developing the necessary infrastructure de novo for CNOC participation and tracking of neurodevelopmental outcomes. We hope that our experience can provide help to other centers with beginning such an undertaking.

Methods: Our multidisciplinary Heart Center was created in 2018 as a novel collaboration between a stand-alone pediatric hospital and a new medical school. In partnership with the Pediatric Neurosciences department, the Center started participation in the CNOC registry in Spring 2021. Initiation of CNOC participation was a planned multistep process that included: 1) exploration of established registry processes; 2) recruitment of key stakeholders; 3) establishment of criteria for inclusion; 4) development of a workflow between clinical and outcomes personnel to minimize redundancy; 5) creation of a REDCap database consistent with existing clinical databases; 6) development of a data process to include different existing software interfaces and EMRs; 7) development of a process for inpatient and outpatient work; and 8) management of cultural differences between medical disciplines such as cardiology and neurology. The system was developed in a way to also support other quality, research, scholarly, and clinical operational activities for the Heart Center.

Results: A data system and workflow were developed as a multidisciplinary initiative between the Outcomes and Psychosocial teams in the Heart Center and team members in the Pediatric Neurosciences department, including both neurologists and neuropsychologists. A REDCap database was created in a way that could integrate with other REDCap databases used by the cardiac and neurosciences teams. Data entry began in July 2021 with an iterative case identification process with several opportunities for refinement of the process. A total of 190 cases for 157 unique patients were entered in the first year. Patient characteristics are listed in Table 1.

Major learning points:

– Identifying cases is not a one-time, definitive process, but rather an iterative, ongoing consideration of a wide pool of cases that the team reviewed to achieve consistent agreement on what is included.
– There is some amount of gray area with respect to deciding on registry inclusion for certain cases, due to the unique nature of each patient's cardiac defect and personal history of hospitalization and progress.

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Table 1. Demographic Information

Demographic	Patients
Number of distinct assessment cases	190
Number of unique patients	157
% Female	46%
Age range	0-18 years
Hispanic Ethnicity	46%
Race	
White	85%
Other	11%
Black	8%
Asian	6%
Native American	1%
Genetic Anomaly	25%

Conclusions: Optimal initiation of CNOC participation and data capture of neurodevelopmental outcomes requires a concerted multidisciplinary effort between multiple stakeholders. The experiences lived by our Center can provide other centers with useful information on how to establish a sustainable de novo CNOC registry workflow.

A Dedicated Volunteer Program for Pediatric Inpatients with Congenital Heart Disease

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Introduction: Children with congenital heart disease (CHD) are at increased risk of neurodevelopmental impairments. The etiology of these impairments is multifactorial with length of surgical hospitalization consistently identified as a primary predictor. Potentially modifiable risk factors associated with hospitalization which could impact neurodevelopment include being left alone for long periods of time with minimal interaction or opportunity to engage in developmentally appropriate play. Volunteers may be an underutilized resource to help providers and families deliver neurodevelopmental care to pediatric inpatients with CHD. We aimed to develop a volunteer program specific to our cardiac inpatient units, with the goal of volunteers providing targeted developmental care during patient interactions.
Methods: Our Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) interdisciplinary team developed a volunteer program specifically for inpatients with CHD. Volunteers underwent hospital volunteer training as well as CINCO-specific training with Heart Institute's child life specialists to best equip them in their bedside volunteer roles. This included education about working with cardiac patients, shadowing an experienced CINCO volunteer for two sessions, and an introduction to the Developmental Plans made by physical, occupational, and speech/language therapists. These include a goal from each discipline based on current skill level, caregiver priorities, and developmental milestones appropriate for patient's age. The Developmental Plans were used as therapy extenders to increase the amount of time children worked on therapy goals, as well as structure the volunteer's patient interactions. Patients were identified to be visited by a volunteer if they had therapy and CINCO orders, indicating they were well enough for visitors and activity. Priority was given to those without a parent/caregiver present at bedside and those with longer lengths of stay.
Results: The first volunteer started September 22, 2021. Between then and June 1, 2022, we onboarded 9 volunteers who worked an average of 18 shifts each for a total of 166, 3-hour shifts. In this time, 625 cardiac inpatients received developmental care from a volunteer. During these visits, 277 patients were played with, 178 patients read to, and 274 patients held in the volunteer's arms. In addition, Developmental Plans were used during 233 visits. Qualitatively, the volunteer program was received positively by inpatient multidisciplinary staff, families, and volunteers.
Discussion: Volunteers can provide targeted neurodevelopmental care to children with CHD who are inpatient, even during periods of critical illness, providing consistent developmental care when parents are unable to do so. Increasing developmental stimulation and interaction may help alleviate some of the ways in which hospitalization is disadvantageous for overall neurodevelopment. Furthermore, allowing parents time away from the bedside could improve their mental health, which may ultimately improve neurodevelopmental outcomes as well. Volunteers specifically trained to work with inpatient cardiac patients can be utilized to help mitigate potentially modifiable risk factors impacting neurodevelopmental outcomes.

Sounds Levels in a Pediatric Cardiac Intensive Care Unit are Higher than Recommended and May Lead to Patient Stress

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Introduction: The Environmental Protection Agency (EPA) and the World Health Organization (WHO) recommend that hospital A-weighted sound level in decibels (dB(A)) do not exceed 40-45 during the day and 35 at night. The American Academy of Pediatrics (AAP) also recommends sound levels for infants and neonates be less than 45 dB(A). Elevated sound levels in hospitals have been associated with disturbances in sleep, patient discomfort, delayed recovery, and delirium. We measured noise levels in a 26-bed dedicated pediatric CICU; our hypothesis was that the Cardiac Intensive Care Unit (CICU) is louder than current recommendations and is associated with elevations in heart rate and blood pressure, sedation administration and delirium.
Methods: Between January 25, 2021 and March 1, 2021, sound decibel meters (Tekpro data logging sound decibel meters) were placed at all 26 bedspaces to measure and record dB(A) levels continuously 24 hours per day with samples obtained every 5 minutes. Vital signs, CAP-D scores and sedation administration were obtained via chart review. The dB(A) levels were then converted to an hourly mean dB(A) level and analyzed using mixed effects nested regression models to account for the multiple repeated samples for multiple patients on multiple days and in multiple rooms throughout the time course.
Results: During the study period, 64 patients in 26 private and semi-private rooms were monitored with a total of 166,228 individual decibel readings. Sound levels for this cohort were consistently above the WHO, EPA and AAP recommendations with average daytime levels of 50.6 dB(A) and maximum 76.9 dB(A), and average nighttime levels of 49.5 dB(A) and maximum 69.6 dB(A). An increase in average and maximum noise levels during a 12-hour shift were not associated with an increase in CAP-D

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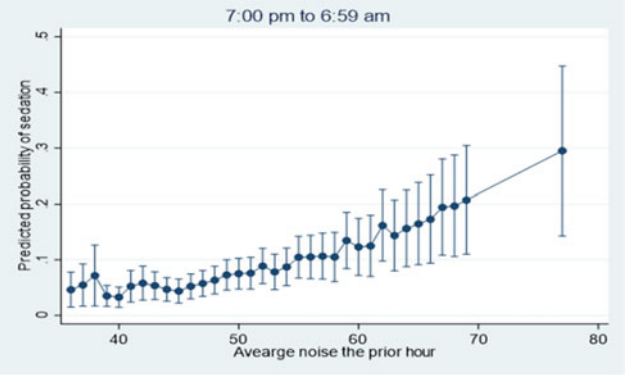

Figure: Predicted probability of receiving sedation given the average sound level during the prior hour.

scores the following shift. An increase in average and maximum noise level during the night shift increased the probability of sedation administration the following hour (p-value < 0.001 and 0.010, respectively) and was predictive of an increase heart rate and blood pressure (p-value < 0.001).
Discussion: Consistent with previous studies, the dB(A) levels in the CICU were consistently higher than the WHO, EPA and AAP recommendations. Differing from previous studies, sound levels were significantly elevated during the day compared to the night. An increase in heart rate, blood pressure and sedation requirement may suggest a stress response to persistent and sudden loud noises. Given the known negative impacts of excessive noise on stress, sleep, healing and brain development, reducing excessive and sudden noise may help decrease patient stress and possibly improve short- and long-term neurodevelopmental outcomes.

Neonates with Congenital Heart Disease have a Higher Total Opioid Exposure for 5 days post-Operatively than Infants

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Introduction: Both untreated pain and opioid exposure impact neurodevelopment in critically ill infants. Mitigating both the effects of opioids and pain remains challenging in the management of infants undergoing cardiac surgery. Our primary aim was to describe and compare opioid dosing in neonates and infants undergoing cardiac surgery.
Methods: We conducted a secondary analysis of a single center retrospective cohort of all CICU surgical patients <1 year of age to quantify opioid exposure within the first 5 days following cardiac surgery. Patient characteristics, demographics, surgical data, as well as pain and sedation scores and medications within 5 days following cardiac surgery were collected via chart review and analyzed.
Results: Of 170 patients less than 1 year of age, 75 were neonates <30 days of age at the time of surgery. The groups were similar with respect to gender, race, ethnicity and the presence of genetic abnormalities. Biventricular CHD without arch obstruction was more common in infants than in neonates. Neonates had significantly longer duration of mechanical ventilation, ICU and hospital length of stay. Mean total opioid exposure was significantly higher in neonates in morphine equivalents (ME) (10.39 ± 8.85 mgME/kg) than in infants (5.06 ± 10.01 mgME/kg) (p<0.001). Mean initial opioid infusion doses (0.09 mgME/kg/hr vs 0.07 mgME/kg/hr) and mean maximum opioid infusion dosing (0.13 mgME/kg/hr vs 0.11 mgME/kg/hr) were higher in neonates compared to infants. Neonates also received more PRN opioid doses than infants (22 doses vs 13 doses). Similarly, mean total Dexmedetomidine exposure was higher in the neonatal population (45.39 ± 39.09 mcg/kg) than in infants (29.01 ± 33.50 mcg/kg). Neonates were also more commonly discharged on Methadone than infants (31.3% of neonates and 10.8% of infants).
Discussion: Compared to infants 1-12 months of age, neonates with CHD had more complex disease and postoperative risks to neurodevelopment, including opioid exposure. Our results highlight the importance of a careful assessment and targeted response to pain and discomfort, perhaps including non-pharmacologic measures and parental engagement when possible. Multicenter trials and sharing of best practices may help improve neurodevelopmental care and reduce opioid exposure in this vulnerable population.

Neonatal Cerebrovascular Stability Index Is Associated With Neurodevelopmental Scores In 9-month Infants With Congenital Heart Disease

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Introduction: Infants with congenital heart disease (**CHD**) have an increased risk for poorer neurodevelopmental outcomes (**NDO**) compared to healthy controls (**HC**). Impaired cerebrovascular autoregulation (**CA**) may contribute to neurologic impairments in CHD infants. We examined neonatal cerebrovascular stability index (**CSI**) [a measurement of change in cerebral oxygenation during a postural change, as a proxy for CA] and its associations with future NDOs in infants with CHD compared to HC at 3 early-age timepoints.
STUDY QUESTION: Does neonatal CSI associate with future NDOs and does the association of CSI on NDOs vary significantly between groups? We hypothesized that neonatal CSI would associate significantly with future NDOs and that the association of CSI on NDOs would vary significantly between groups.
Methods: We conducted a prospective, longitudinal study in CHD infants and HC. We collected neonatal CSI and NDO at 3 early-age timepoints (3-months, 6-months, and 9-months of age). We performed 3 tilts (moving the infant from supine and sitting postures) while measuring cerebral oxygenation via near-infrared spectroscopy. CSI was determined by subtracting the average 2-minute sitting cerebral oxygenation from the 2-minute supine

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value for each tilt, then averaging these values at each age. The Bayley-III assessed the NDOs.

Results: We examined a total of 34 CHD and 26 HC infants. Linear regression analyses showed that neonatal CSI significantly associated with 9-month cognitive composite scores (β=1.26, 95% CI=0.22, 2.29, p=0.02). Moreover, we detected a significant group-by-CSI interaction (p=0.05), indicating that the association of group with CSI on NDOs varied significantly between groups. **Figure 1** depicts the estimated means of the interaction showing that CSI did not significantly associate with 9-month cognitive composite scores in HC (β=0.77; 95% CI=-1.10, 2.64; p=0.41), whereas CSI significantly associated with 9-month cognitive composite scores in CHD infants (β=1.49; 95% CI=0.22, 2.75; p=0.02). CSI, however, did not significantly associate with the other developmental domains at 9-months of age and for the other age timepoints.

Discussion: We found that better neonatal CSI significantly associated with higher cognitive development scores in 9-month-old CHD infants, suggesting that impaired cerebral blood flow may underlie neurodevelopmental abnormalities in CHD infants. Future studies are needed to better understand the mechanism of interaction between CSI and cognitive development.

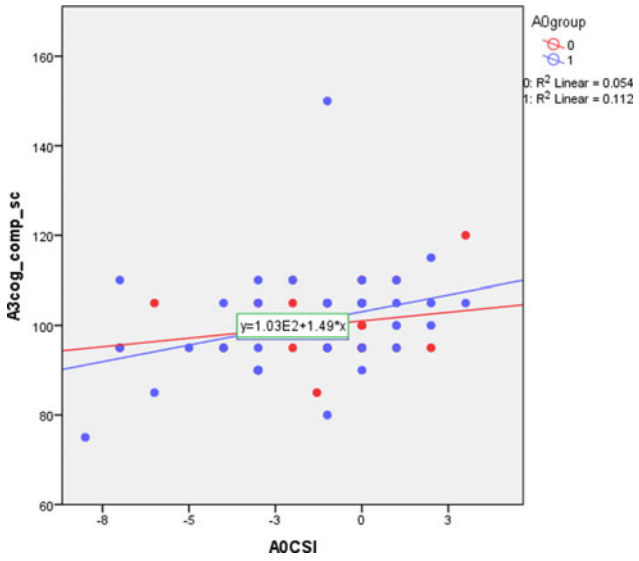

Figure 1. This image shows the relationship between cerebrovascular stability index (CSI) and 9-month cognitive scores between the congenital heart disease (CHD- represented in blue) and healthy control (represented in red) groups.

Beyond Pain Management: An Interdisciplinary and Developmentally Centered Approach to Optimize Comfort in Neonates Following Cardiac Surgery

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Introduction: Developmental care has become standard practice to optimize neurodevelopment. However, neonates after cardiac surgery face unique challenges, including painful procedures, immobility, parental separation, lines, tubes, wires, and many more. Recognizing the effects of undertreated pain and opioid exposure on brain development, we developed a Comfort Curriculum (CC) that included pharmacological and non-pharmacological methods of pain control for post-operative cardiac surgery patients. The aim of this study was to determine if the implementation of a CC could reduce opioid exposure without increasing pain scores.

Methods: The CC was developed by an interdisciplinary team and consists of a pain management pathway, non-pharmacologic support table and infant holding guidelines. We assessed patient demographics, type of congenital heart disease (CHD), surgical procedure, pain scores, opioid dosing, and other postoperative variables in neonates undergoing cardiac surgery pre- and post-CC implementation. Outcomes in neonates were compared using Wilcoxon rank sum tests for continuous variables and chi^2 tests for categorical variables.

Results: The pre-CC group (n=36) weighed significantly more than the post-CC group (n=39) (3.03 ± 0.85 vs 3.35 ± 0.71 kg; p=0.037) but was otherwise similar with respect to gestational age, age at surgery, gender, race, ethnicity, and surgical class. Despite similar pain scores between the groups, the post-CC had significantly lower initial opioid doses in morphine equivalents (ME) [0.12 ± 0.03 mgME/kg pre-implementation to 0.08 ± 0.02 mgME/kg post-implementation, (p<0.001] and maximum opioid doses [0.16 ± 0.05 mgME/kg pre-implementation to 0.11 ± 0.04 mgME/kg post-implementation, (p = <0.001)].

Discussion: The results of this study support that an interdisciplinary, developmentally centered approach to comfort care following cardiac surgery can significantly reduce opioid exposure without increasing pain scores in neonates. Effective implementation of the CC required a strong commitment by a dedicated interdisciplinary team and a willingness to adopt non-pharmacological measures to optimize comfort. This study may serve as baseline data for a multicenter trial to assess generalizability. Likewise, it may help support future studies on reduced opioid exposure and developmental outcomes of neonatal cardiac surgical patients.

Table 1

Characteristics	Pre-implementation		Post-Implementation		p-value
	N	Median (min, max)	N	Median (min, max)	
Age at surgery (months)	36	0.28 (0.03, 0.98)	39	0.23 (0.03, 0.82)	0.26
Surgery weight	36	3.00 (1.23, 5.55)	39	3.40 (1.51, 4.68)	**0.037**
Gestational age (weeks)	35	38 (32, 40)	39	38 (31, 40)	0.65
Gender					
Male	20 (55.6%)		23 (59%)		0.77
Female	16 (44.4%)		16 (41%)		
Race					
Asian	3 (8.6%)		1 (3.6%)		
Black	9 (25.7%)		7 (25%)		0.76
Native Hawaiian/Pac Islander	4(11.4%)		2 (7.1%)		
White	19(54.3%)		18 (64.3%)		
Ethnicity					
Hispanic/Latino	8 (22.9%)		12 (31.6%)		0.40
Non-Hispanic	27 (77.1%)		26 (68.4%)		
CHD class					
I	14 (38.9%)		15 (38.5%)		
II	9 (25%)		15 (38.5%)		0.53
III	5 (13.9%)		3 (7.7%)		
IV	8 (22.2%)		6 (15.4%)		
Genetic abnormalities					
No	23 (74.2%)		25 (65.8%)		0.45
Yes	8 (25.8%)		13 (34.2%)		
Total CICU LOS	36	24 (1, 405)	39	22 (1, 152)	0.51
Duration of mechanical ventilation	35	4 (0, 122)	38	5 (1, 83)	0.52
Pain POD1	36	0 (0, 3)	39	0 (0, 3)	0.60
Pain POD2	36	0 (0, 2)	39	0 (0, 4)	0.19
Pain POD3	36	0 (0, 4)	39	0 (0, 4)	0.65
Pain POD4	35	0 (0, 1)	39	0 (0, 3)	0.36
Pain POD5	35	0 (0, 4)	39	0 (0, 3)	0.53
Total opioid (MEQ)	36	11.08 (0.15, 34.48)	39	6.96 (0.05, 39.86)	0.18

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An Interdisciplinary Approach to Neurodevelopmentally Supportive Care in The Heart Institute at Children's Hospital Colorado

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Introduction & Study Question: While morbidity and mortality rates have improved for infants with congenital heart disease (CHD), neurodevelopmental outcomes remain a concern as these patients are at higher risk for delays in cognition, motor, and language development. Historically, neurodevelopmental care was implemented in the Cardiac Intensive and Progressive Care Units at Children's Hospital Colorado through discipline specific intervention. In order to standardize and integrate interdisciplinary, neurodevelopmental care, the Cardiac Inpatient Neurodevelopmental Optimization (CINCO) program was developed.
Methods: Therapy team involvement begins at hospital admission with automatic therapy orders, allowing for evaluation and plan of care development by each discipline. Additional standardized testing is completed on patients with complex needs, specifically the single ventricle population, to support referrals and track development. Patients under 2 years of age are eligible for additional neurodevelopmental care through CINCO (Fig. 1). Our interdisciplinary team continues to support neurodevelopment throughout the hospital stay and into outpatient (Fig. 2), as well as improving efficiency and provision of CINCO pillars.
Results: As a result of early therapy involvement and CINCO implementation, neurodevelopmentally supportive care increased (Fig.3A and 3B). Patients 2 years or younger with single ventricle physiology had a 100% completion rate for developmental assessments since 2016, 92% received a developmental plan prior to hospital discharge after Stage 1 palliation, and 85% after Stage 2 palliation.
Discussion: We effectively implemented institutional change to the culture and interventions provided to patients with CHD through early therapy involvement and CINCO. We provided direct intervention, education and resources for families, referral recommendations, and follow up after discharge to impact the long-term developmental outcomes of this high-risk population. While limited access to items impacted developmental kits during Phase 2 of CINCO implementation, the program's consistent drive for improvement and sustainable process allowed for increased utilization and impact of CINCO. Ongoing tracking of neurodevelopmental outcomes is necessary to understand the impact of this comprehensive program and guide future interventions to mitigate developmental risk factors.

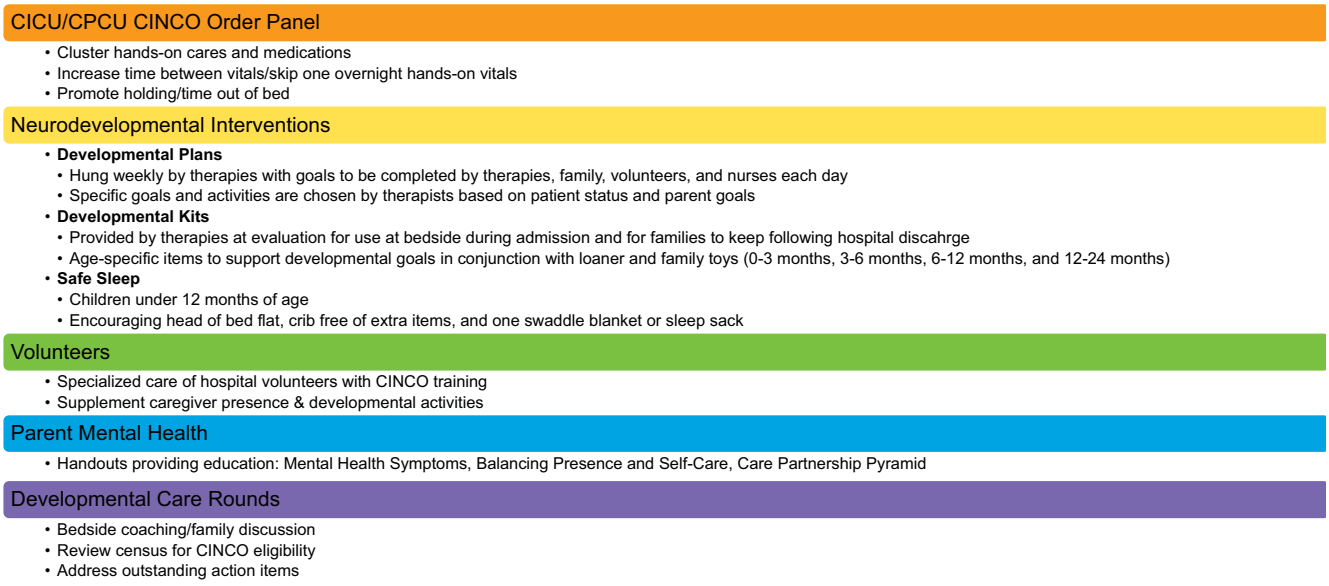

Figure 1. Five Pillars of the CINCO Program

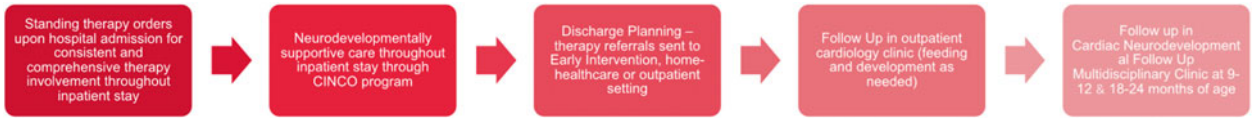

Figure 2. Neurodevelopmental Team Involvement Across Time

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Figure 3.A. Percent of Cardiac Inpatients Age 0-2 Years who Received CINCO Interventions across PDSA Cycles (* p < .05; ** p < .01)

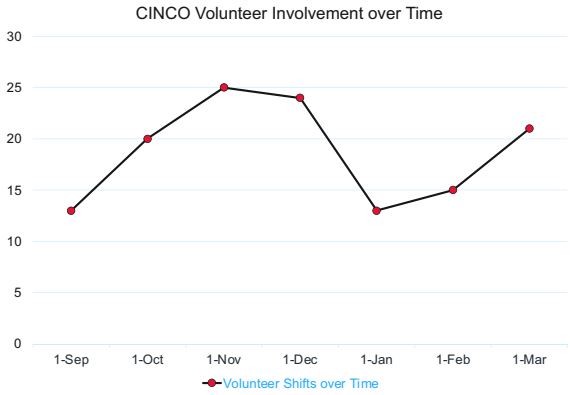

Figure 3.B. Number of Four-Hour CINCO Volunteer Shifts By Month

Figure 3: CINCO Implementation Process Measures

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Quantitative Morphological Alterations of the Olfaction Bulb Predict Executive Dysfunction in CHD

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Introduction: For patients with congenital heart defects (CHD), the sequelae are neurodevelopmental disabilities including executive function, attention, and socio-emotional deficits. Although these are common diagnoses for patients with CHD, limited research has investigated the mechanistic dysfunctions at play. Our past research examined the association between abnormal respiratory ciliary motion (CM) and brain abnormalities in infants with CHD. Results suggesting that abnormal CM correlated to a spectrum of subtle dysplasia, notably within the olfactory bulb (OB).[1] Our current study investigates whether OB anomalies predict neurodevelopmental outcomes for adolescents with CHD. We hypothesize that adolescents with CHD, who show aberrant volumetric OB measurements will demonstrate executive dysfunction.

Methods: A prospective, observational neuroimaging study utilizing 3D T2-weighted and T2 coronal blade MRI images were analyzed using ITK-SNAP, a software application for manual segmentation of bilateral regions of the OB and cerebrospinal fluid (CSF). The segmentation of 54 CHD and 80 healthy subjects, ages 6-25 years old, were completed under the supervision of a senior pediatric neuroradiologist. Volumetric measurements were reported based on automated 3D segmentation results. Imaging metrics were correlated to OB laterality, CSF to OB ratio, total CSF volume, total OB volume, independent left and right CSF and OB volumes. A linear regression was used to evaluate MRI volumetric measurements with co-variates: CHD status, sex, MRI age, and segmenter. Executive function was determined by the BRIEF. Olfaction function was measured with the NIH Toolbox.
Results: No statistically significant result was reported between cohorts for laterality of OB, CSF to OB ratio, total CSF volume, total OB volume, nor between left and right CSF and OB volumes. The CHD cohort demonstrated the worst performance on the BRIEF compared to controls. Enlarged total OB volume predicted worse performance on the BRIEF ($p \leq .028$). Increased laterality or asymmetry of OB displayed poorer executive functioning using BRIEF ($p \leq .049$). Across groups no significant association was reported for olfaction function.
Discussion: Enlarged and/or asymmetric OB in adolescent CHD and control subjects predicted poor executive functioning. Given that the OB becomes smaller and more asymmetric over the lifespan, CHD patients demonstrating extreme lack of maturation (enlarged bulbs) and/or accelerating aging (increased asymmetry/laterality) represent two subgroups with the highest risk of executive dysfunction that can impact their quality of life. These olfactory-based biomarkers may help target at-risk CHD patients for earlier intervention.

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Characterizing Cerebellar Growth in infants born with a congenital heart defect during the first year of life.

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Alteration of cerebellar development may result in long-lasting behavioural and socio-emotional issues. Preliminary evidence suggests that in utero cerebellar development is hindered in fetuses with complex congenital heart disease (CHD) and may be due to their impaired circulation. However, it remains unknown if cerebellar growth catches up following palliative or corrective cardiac surgery. Studies of growth trajectories have the potential to identify subtle variation patterns that cannot be detected by cross-sectional analyses and may provide novel insight toward the development of novel diagnostic approaches. Therefore, this study aims to compare typical and atypical cerebellar growth trajectories, as assessed by quantitative MRI, during the first year of life, in the hope of identifying novel biomarkers of abnormal neurodevelopment.

As part of an ongoing study, we collected brain MRIs in 20 infants born with a CHD who underwent open-heart surgery during the first 3 months of life. Infants with CHD were paired to 50 healthy controls evaluated as part of the Baby Connectome Project. Participants in both groups completed a brain MRI on a 3.0 Tesla scanner at the targeted time of 3, 6, 9, and/or 12 months. A total of 156 high-resolution T1w images (49 CHD, 107 controls) were considered of sufficient quality to be included in our analyses. Using Infant Freesurfer, we segmented the vermis and the two cerebellar hemispheres. Trajectories were characterized, for these 3 regions of interest and for total cerebellar volume (TCV), using mixed-effects models for repeated measured (MMRM), and linear, quadratic, logarithmic and exponential regressions were compared using r squared values to determine the best fit. Volume differences and growth rate between 3 to 12 months were also calculated.

Different growth trajectories functions were identified between the two groups. While in the CHD group, all 3 regions followed a linear trajectory, the different regions in the control group followed either an exponential, logarithmic or quadratic trajectory. TCV and left hemispheric volume were significantly smaller in the CHD when compared to controls at 3 months with a volume difference of 4,7% and 9,9% respectively. However, volumetric differences were no more significant by 12 months of age (<0.5%). No volumetric differences were found between the two groups in the other regions. During the evaluated period, controls showed volume gains of 40.9% for TCV and 36.3% for the left hemispheres, while infants with CHD presented with volume gains 50,6% for TCV and 49,5% for the left hemisphere.

Our preliminary results suggested that smaller cerebellar volumes previously reported in fetuses with CHD persist during the first months of life but may catch up by 12 months of age in a subset. Interestingly, total cerebellar volumetric differences were primarily driven by the left hemisphere which may indicate selective regional vulnerability. Future follow-up studies of outcomes are needed to confirm the clinical significance of our findings.

Fetal consultation to optimize neurodevelopmental outcomes in critical congenital heart disease: A conceptual preventive practice model for pediatric neuropsychology

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Introduction: Pediatric neuropsychologists play a meaningful role in supporting families affected by critical congenital heart disease (CHD), given increasing recognition of the broad impact of CHD on neurodevelopmental and psychosocial outcomes. Traditional neuropsychological services are typically utilized beginning in childhood and often in response to concerns that have already been identified. However, with advancements in early detection enabling increased rates of fetal diagnosis of CHD, prevention-oriented fetal neuropsychological consultation is a novel avenue through which to begin mitigating CHD-related risks and promoting positive neurodevelopmental outcomes as early as the prenatal period.

We present a novel, conceptual model for fetal neuropsychological consultation with recommendations for specific services and their timing. Such services might include a) screening for and responding to relevant caregiver mental health needs, b) identifying and expanding upon family support/coping resources, c) providing education on risks and evidence-based strategies for promoting neurodevelopment in children with CHD during infancy and early childhood, d) alerting families to cardiac neurodevelopmental resources/services and planning for follow-up care, and e) serving as consultant-liaison to other members of obstetric, maternal-fetal medicine, cardiac, and neonatal intensive care teams.

Research is needed to determine feasibility (e.g., proof of concept), family perceptions of the services, and long-term outcomes.

Discussion: We discuss implications of our position that fetal consultation can reasonably fall within the purview of pediatric neuropsychological care for families affected by CHD. If healthcare institutions can circumvent pragmatic barriers to implementation (e.g., third-party payor requirements such as identifying the patient, issues pertaining to access and telehealth delivery), there is great potential for fetal neuropsychological consultation to facilitate early and enduring partnerships with families, through which to promote adaptive trajectories for child development. Attunement to unique psychological stressors in the context of pregnancies complicated by a fetal CHD diagnosis post-U.S. Supreme Court 2022 ruling to overturn Roe v. Wade will soon be essential to standard of care for these families. We anticipate fetal neuropsychological consultation in CHD may also serve as a model for more widespread re-imagining of pediatric neuropsychological practice—extending subspecialty boundaries to include prevention neuropsychology.

Keeping patients moving: Risk Factors for Gross Motor Impairment

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Multiple factors can impact neurodevelopment in the congenital heart disease population[1] but the degree of impact for each remains undetermined. Using a combined theory and data drive approach,

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this research project investigated predictors of development delays (DD) in the shunt dependent single ventricle population.

Established risk factors for neurodevelopmental delay were examined.[2] History of DD and total days hospitalized (LOS) were used as predictors due to relatively balanced cell sizes within the sample. Patient initial Ages and Stages Questionnaire (ASQ-3) scores (n=58), completed within 12 months of age, were used as outcome variables. Sample demographics are presented in Table 1. Variable frequencies and descriptives are presented in Table 2. Standard multiple regression was used to examine predictors of developmental outcomes.

Demographics

	Total (n = 58)
Age at screening in months	6.0 (6.0 – 8.0)
Gender, Male	41 (71%)
Ethnicity	
Non-Hispanic or Latino	34 (59%)
Race	
White	48 (83%)
Black	8 (14%)
Other	2 (3%)

All continuous variables shown as median (IQR)
All categorical variables shown as n (%)

A multiple linear regression was conducted to test if DD history and LOS significantly predict patient development. The results of the gross motor regression model indicated these two predictors explained 28% of the variance (R^2 = .28, F(2, 55)=10.92, p < .001. Patient LOS significantly predicted gross motor development (β = -.38, p < .01), as did history of developmental delay (β = -.37, p < .01). The problem-solving regression model was significant, (R^2 = .08, F(2, 55)=4.57, p < .05), with patient LOS significantly predicting problem-solving development (β = -.28, p < .05). The communication, fine motor, and personal-social domains of the ASQ-3 did not evidence significant regression models.

Patient LOS is likely to negatively influence gross motor and problem-solving development when compared to other AHA risk-factors[(2)]. History of DD significantly influences gross motor development. Results suggest utilization of evidence-based developmental care interventions that focus on LOS reduction and strategies to prevent developmental delay, including implementation of the Newborn Individualized Developmental Care and Assessment Program.

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Outcome Variables Frequencies and Descriptives

AHA Criteria	Total n (%)
Open heart surgery	58 (100%)
Cyanotic heart lesion, no open-heart surgery	0 (0%)
Prematurity (<37 weeks)	5 (9%)
Developmental Delay	33 (57%)
Genetic abnormality	5 (9%)
History of mechanical support	4 (7%)
Heart transplantation	0 (0%)
CPR history	5 (9%)
Prolonged hospitalization of >2 weeks	58 (100%)
Pre-/Peri-/Post-operative seizures	3 (5%)
Abnormalities on neuroimaging, microcephaly	18 (31%)

ASQ-3 Domains	At-risk n (%)	Delayed n (%)	M(SD)	Age-appropriate n (%)
Communication	10 (17%)	3 (5%)	46.29(11.61)	45 (78%)
Gross Motor	23 (40%)	23 (40%)	27.33(15.54)	12 (20%)
Fine Motor	11 (19%)	12 (21%)	45.52(15.56)	35 (60%)
Problem-Solving	6 (10%)	10 (17%)	42.53(12.87)	42 (72%)
Personal-Social	9 (16%)	13 (22%)	41.47(14.20)	36 (62%)

	Median (IQR)
Hospital LOS (days)	70.50 (49 - 124)

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Getting it all done: Utilizing dedicated developmental program personnel

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Cardiac Intensive Care Units are establishing developmental care practices, with emerging evidenced-based standards for developmental care programs[1-3]. A key recommendation for these programs is the utilization of a multidisciplinary group to steer practice, participate in developmental care rounds, and perform developmental assessments and interventions[1,3]. In June 2020, our center implemented a part time inpatient advanced practice provider (APP) to support the cardiology inpatient developmental care program. Literature has briefly described benefits of developmental clinical champions in these programs[2]. An analysis of the APP role was completed.

The total amount of APP patient encounters was tracked from June 2020 through June 2022. An encounter consisted of any interaction, greater than 10 minutes in length, with a patient and or caregiver where recommendations were provided to support developmental care. The target population was patients under 1 year of age with congenital or acquired heart disease and an actual or anticipated length of stay greater than 2 weeks. The APP organized, led, and documented multidisciplinary developmental care rounds, which were included in encounter totals. Other encounters included cardiac neurodevelopmental program introductions and consultations and routine follow-up. Billing practices were established, in April 2021, for encounters that provided extensive developmental education and intervention.

Since implementation, the APP has completed 455 encounters with 182 unique patients; in comparison, the developmental care team totaled 104 encounters from July 2018 through March 2020 via developmental rounds alone. This resulted in a 283% increase in average number of monthly developmental care encounters for the inpatient developmental program. We have maintained weekly developmental care rounds for four years. When assessing a 12-month span of billable encounters (May 2021 through May 2022), 160 Relative Value Units (RVUs) were generated (average of 2.06 per encounter) with an estimated collection rate of $108.30 per encounter.

Increased encounters provide an avenue for dissemination of recommended neurodevelopmental information, education, and intervention for parents and staff. A consistent presence has contributed to maintaining developmental care rounds since initiation. This data encourages the implementation of dedicated personnel for an inpatient cardiac-focused developmental care program. An APP can offer the ability to bill for developmentally focused care, generating revenue for the program.

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The Phenotypic Expression of Autism Spectrum and Neurodevelopmental Traits in Individuals with Congenital Heart Disease

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Introduction: Individuals with congenital heart disease (CHD) have an increased chance of developing autism spectrum traits (AuST).[1-3] Social and communication autistic trait deficits are more prevalent to individuals with CHD.[1,2] The association between AuST and neurodevelopmental deficits (NDD) in CHD remain unclear. The primary aim of the current study was to examine the neurodevelopmental profile of those with CHD and AuST. Secondarily, we examined risk factors (i.e., demographic, clinical, genetic variation) associated with AuST and NDD.

Methods: Study Design – The study is a secondary analysis of a multicenter prospective observational study. All participants were previously enrolled in the PCGC (ClinicalTrials.gov number, NCT03347214) or Single Ventricle Reconstruction (SVR) trial (ClinicalTrials.gov number, NCT00115934).

Measures – Primary Outcomes - Intellectual and Adaptive domains. The *Wechsler Intelligence Scale for Children, Fifth Edition*[4] for participants < 16 yo, or the *Wechsler Adult Intelligent Scale, Fourth Edition*[5] for participants ≥ 16 yo. assessed IQ. The *Vineland Adaptive Behavior Scales, Third Edition* assessed adaptives.[6] Secondary Measures – The *Social Responsiveness Scale, Second Edition (SRS-2)*[7] and the *Autism Diagnostic Observation Schedule, Second Edition(ADOS-2)*[8] were utilized to assess phenotypical expression of AuST and stratification. The participants were stratified into three risk classifications based on the SRS-2 T-score and ADOS: Low Risk, SRS-2 T-Score <59; At Risk, SRS-2 T-Score ≥ 60 Negative ADOS or ADOS not performed; and High-Risk SRS ≥60 & ADOS Positive.

Results: The study cohort (n = 200) had a median IQ score of 99 (IQR, 86, 110) and a high percentage (86.5%) of maternal college/post college education. The prevalence of AuST was 18% (At Risk n=23, High Risk n=12). Cognitive and adaptive scores were consistently lower for those At Risk and High Risk (Figure 1), with no difference between the At Risk and High Risk AuST groups. The probability of full scale IQ <75 was 5.5% for the entire cohort but 20.2% for those with AuST. There was also increased risk for IQ <75 for those with a damaging genomic variant (RR 1.22; CI 1.02,1.35), history of cardiac arrest (RR 2.36; CI 1.01,2.49) and cardiac anatomy of single ventricle with arch obstruction (RR3.57; CI 1.01,4.62).

Discussion: In the PCGC/PHN cohort with selection bias for high socioeconomic status, we found a greater prevalence of AuST then previously reported.[3,9] Genetic, demographic, and clinical course factors were all associated with IQ, but the presence of AuST appears to be one of the more significant associated traits with low IQ in CHD. SRS-2 risk stratification was associated with NDD and further ADOS stratification did not predict significantly more impairment than SRS-2 alone. Given the challenges of

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administering the ADOS at many programs, these findings may help guide screening strategies for neurodevelopmental follow-up programs with limited resources.

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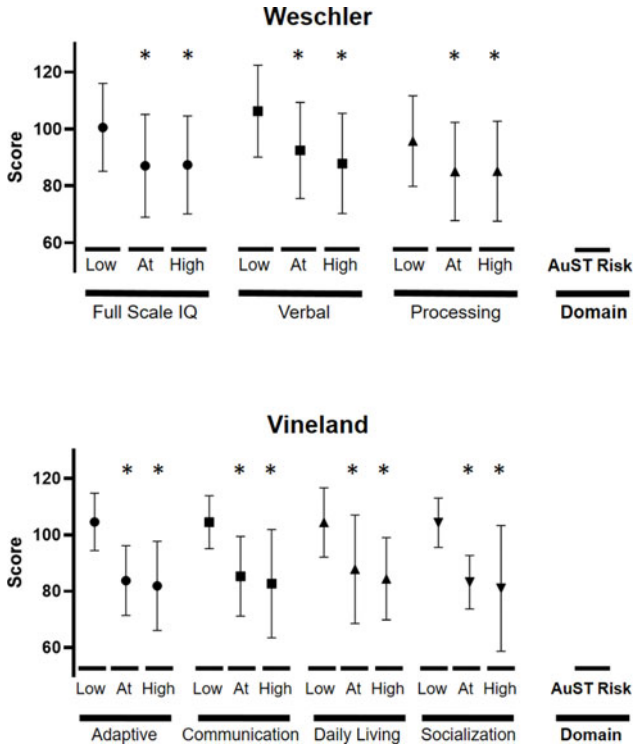

Figure 1: Autistic Traits and Intelligence and Function. Weschler Intelligence and Vineland Adaptive scaled scores across test domains for those with low risk (Low), at risk (At) and high risk (High) for autism spectrum traits (AuST). *p<0.05 compared to low risk.

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A systematic review of associations between neuroimaging and neurocognitive function among adolescents and adults with complex congenital heart disease

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Introduction: Meta-analytic data indicate that brain abnormalities are significantly more prevalent in adolescents and adults with complex CHD compared with healthy peers. There are fewer data in this population on the relationship of neuroimaging findings to functional outcomes. In this review, we systematically identified, synthesized, and critically evaluated evidence on associations between neuroimaging and neurocognitive, emotional, and behavioral outcomes among adolescents and adults (aged ≥13 years) with transposition of great arteries (TGA) or single-ventricle congenital heart disease (SVCHD).
Methods: Six electronic databases were systematically searched according to a pre-registered protocol (CRD42021229617) to identify relevant studies reporting both neuroimaging ***and*** neurocognitive, emotional, or behavioral outcomes. Records were independently screened by two reviewers. Risk of bias was assessed by two reviewers using NIH Quality Assessment tools. Relevant data were extracted from included studies using a standardized form and checked for accuracy.
Results: The initial search yielded 5,424 articles. After removal of duplicates, 2,725 articles were screened and 210 full-texts were reviewed. After exclusion criteria were applied and risk of bias was assessed, 43 articles rated 'fair' to 'good' were included (publication dates ranging from 2011-2021). Of these, 15 articles reported outcomes for adolescents and adults in six unique studies. Two samples included individuals with TGA, three included individuals with SVCHD, and one included individuals with TGA or SVCHD. Only one article included patients aged ≥21 years. Sample sizes ranged from 17-139 participants, 4 of 6 studies were conducted in the U.S., and neurocognitive outcomes assessed included intelligence, attention, memory, social cognition, and learning. Nine articles reported on associations between neurocognition and structural magnetic resonance imaging (MRI; 3

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using a 3 Tesla scanner, 6 using a 1.5 Tesla scanner); presence of cerebral injury was associated with poorer functional outcome in only a minority of associations tested, whereas smaller total, grey and white matter volumes were associated with poorer functional outcome across several articles. Five articles investigated associations between neurocognition and diffusion tensor imaging (DTI) and found global differences in white matter network topology and regions of reduced microstructure were associated with outcomes such as executive function and attention. Only one study used functional MRI (fMRI) and four articles investigated associations between neuroimaging and emotional outcomes (e.g., anxiety, depressive symptoms), with none reporting associations with neuroimaging.
Discussion: This review highlights the limited studies examining associations between neuroimaging and neurocognitive outcomes in this population require replication. Structural neuroimaging had limited utility in predicting functional outcomes in the samples studied, highlighting the need for wider adoption of multi-modal neuroimaging techniques, such as DTI and fMRI, and a greater focus on neural circuitry, as opposed to single brain regions, to inform intervention approaches for individuals with TGA and SVCHD.

Parental Sense of Competence among Parents of Young Children with Congenital Heart Disease Before and After Virtual Community-Based Music Program Participation: A Pilot Study

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Introduction: Children with congenital heart disease (CHD) are more likely to have difficulties with academic achievement, expressive and receptive speech and language delays, gross and fine motor deficits, and attentional concerns compared to non-CHD peers (Nattel 2016, Wernovsky 2016). Additionally, compared to parents of children with other disabilities, parents of children with CHD experience increased rates of depression, anxiety, PTSD symptoms, and reduced health-related quality of life (Lawoko 2002, Gerasimos 2017). The purpose of this study was to examine the influence of a virtual, live, community-based music program on families with a child with critical CHD.
Methods: Participants included 12 children between 6 and 36 months with congenital heart disease (CHD) requiring surgical intervention in the first 6 months of life and their parent(s). These parent-child dyads were enrolled in a 10-week virtual music class. The music classes were 45 minutes each, utilized a variety of rhythm instruments and household objects, and required active, ongoing engagement between the parent and child. All parents completed pre- and post- measures to compare differences in parent-reported stress (Parenting Stress Index), perceived child vulnerability (Child Vulnerability Scale) and parent-reported sense of competence (Parenting Sense of Competence Scale) before and after the 10-week session. Additionally, parents completed a satisfaction survey following class completion.
Results: A paired samples t-test found that parent-reported sense of competency was higher at the end of the 10-week music class (M=66.00, SD=3.06) than at the beginning (M=63.00, SD=5.10), $t(12) = 2.60$, $p < .05$. These was no significant difference between parent reported child vulnerability scores before (M=41.77, SD=5.26) and after (M=41.54, SD=5.75) the 10-week class, $t(12) = 22$, $p > .05$. Parents reported similar levels of parenting stress before (M=77.54, SD=11.89) and after (M=73.77, SD=12.40) the 10-week music class, $t(12) = 1.28$, $p > .05$. Parent-reported satisfaction was rated as "agree" and "strongly agree" in several areas including satisfaction with choosing to enroll (M=4.38), classes being worthwhile to my child (M=3.08), and classes being worthwhile to me (parent) (M=4.3).
Discussion: A limitation of this study is attrition that contributed to an already small sample size. Overall, this study suggests that those who complete the classes virtually find them to be worthwhile for both parent and child. In-person classes may also be considered. Whether they directly provide neurodevelopmental benefit to children with CHD is not known. Future research that expands the number of participants and which can follow children longitudinally is warranted.

Predicting Long-Term Developmental Outcomes Using Inpatient Developmental Screening for Infants with Congenital Heart Disease

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Introduction: Infants with congenital heart disease (CHD) often have cognitive, language, and motor delays. Early identification of delays can increase the quality and accessibility of care. We explored the utility of an inpatient standardized developmental screener in predicting developmental functioning in early childhood for infants with CHD.
Methods: In this retrospective observational study, a convenience sample of inpatient postoperative infants with CHD, between 3 and 12 months, underwent pre-discharge neurodevelopmental screening using the Bayley Scales of Infant and Toddler Development Screening Test, Third Edition (Bayley Screener) within 3 days of discharge. Demographic and medical information was abstracted from the child's medical record. Ordinal logistic regression identified predictors of increased risk on the inpatient Bayley Screener. Outpatient neurodevelopmental follow-up, 12-42 months, included the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III). Jonckheere-Terpstra trend tests assessed the relationship between Bayley Screener domains and outpatient Bayley-III domain scores.
Results: The inpatient Bayley Screener was completed on 325 infants at an average age of 5.9 months (SD=2.4). Of these, 18% were single ventricle, 15% were born preterm, 15% had a genetic condition, 4% had seizure or stroke, and 38% had a long length of stay (LOS) >2weeks. Across all domains, a greater proportion of study subjects fell in the At Risk and Emerging groups compared to the normative sample used to create the Bayley Screener (each P<0.001, Figure 1). The odds of falling in a higher risk category increased for infants with genetic conditions and long LOS, across all domains. Additionally, 59 subjects returned for the outpatient Bayley-III at a mean age of 24.4 months (SD=8.8). Individuals falling in higher-risk categories on the Bayley

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Screener were significantly likely to have worse performance on the outpatient Bayley-III (each scale P<0.01, Figure 2).
Discussion: Clinical implications for inpatient standardized neurodevelopmental screening are immense. The inpatient developmental screener is relatively easy to implement and aided in identifying infants who were delayed at the time of discharge along with predicting those with long-term delays and disability. For centers struggling to prioritize resources for developmental follow-up, our data show that infants who perform poorly on the inpatient neurodevelopmental screener will continue to show delay and should be routinely connected to the cardiac neurodevelopmental follow-up program in addition to intensive early intervention services.

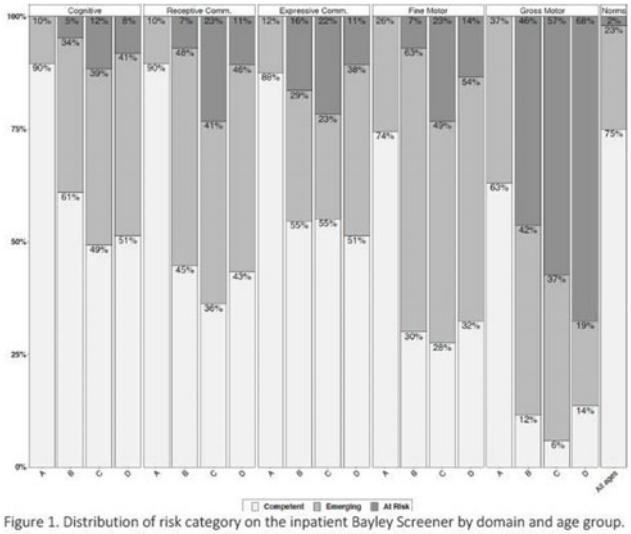

Figure 1. Distribution of risk category on the inpatient Bayley Screener by domain and age group. A=3m–3m, 15d (n=48); B=3m, 16d–6m, 15d (n=170); C=6m, 16d–9m, 15d (n=70); D=9m, 16d–12m, 15d (n=37).

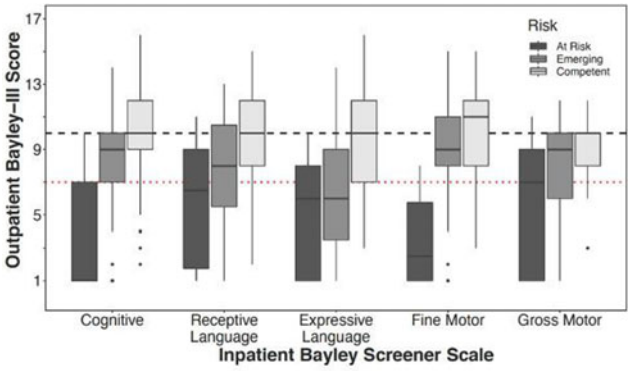

Figure 2. Distribution of respective outpatient Bayley-III scores by inpatient Bayley Screener risk for each domain. Black dotted line = mean score (X=10) and red dotted line = one standard deviation below the mean (SD=3) for the subscales of the Bayley-III.

Executive functions and primary neurodevelopmental processes in adolescents born with congenital heart disease after cardiopulmonary bypass surgery

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Introduction and study question: Children with congenital heart disease (CHD) are at risk for neurodevelopmental impairments, in particular executive function (EF) problems. Inhibition, working memory and flexibility have been described as core EF that are the foundation for higher-level EF such as planning and organization. Little is known about how primary neurodevelopmental processes (PNP) such as attention, processing speed and fine motor abilities are associated with EF in patients with CHD. We therefore aimed to determine the degree of core EF and PNP impairments in a cohort of adolescents with CHD and to examine the correlation between these functions.
Methods: In a prospective cohort study, 101 adolescents with CHD undergoing cardiopulmonary bypass surgery in infancy at the University Children's Hospital Zurich, Switzerland were recruited. A control group of 108 typically developing adolescents was also recruited. Participants were assessed with an extensive EF test battery, assessing working memory, inhibition, and cognitive flexibility, using the Corsi Block Tapping-Test, various subtests of the Wechsler Intelligence Scale-IV (WISC-IV) and of the Delis-Kaplan Executive Function System (DKEFS). The primary processes attention (divided into phasic and intrinsic alertness), processing speed, and fine motor abilities were assessed using subtests of the Test of Attentional Performance (TAP), the WISC-IV and the Zurich Neuromotor Assessment (ZNA). Differences between groups and correlations between functions were assessed using multiple regression analyses (adjusted for parental education, age and sex and corrected for multiple testing) and are expressed as standardized betas.
Results: The analysis of the CHD group included 61 (64.2 %) adolescents with severe, 19 (20 %) with moderate and 15 (15.9 %) with mild CHD. Mean age at assessment was 13.32 years (*SD* = 1.34) across both groups (group difference $p < .01$, added as control variable). Compared to healthy peers, adolescents with CHD showed deficits in all three EF ($ß_{inhibition} = .20$, $ß_{flexibility} = .30$; $ß_{working\_memory} = .36$; all $p < .05$ and R^2 between 0.10 to 0.28). They performed poorer in processing speed and intrinsic alertness ($ß_{alertness} = .26$, $p = .002$, $R^2 = 0.11$; $ß_{processing\_speed} = .28$, $p < .001$, $R^2 = 0.18$), but not in phasic alertness and fine motor abilities ($p > .05$). CHD severity was not significantly associated with EF or PNP. The three EF were correlated with processing speed and fine motor skills (Spearman Rho 0.25-0.74, all $p < .05$). Flexibility and working memory were correlated with intrinsic alertness (Spearman Rho 0.31-0.34, all $p < .01$).
Discussion: Adolescents with CHD show poorer performance in EF, and in processing speed and intrinsic alertness. There is a strong interrelation between these PNP and EF. Further analyses will evaluate the detailed pathways and the role of other variables in the development of EF difficulties in this population.

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	Inhibition	Flexibility	Working memory	Processing speed	Intrinsic alertness	Phasic alertness	Fine motor skills
Inhibition							
Flexibility	**0.71**						
Working memory	**0.46**	**0.65**					
Processing speed	**0.53**	**0.74**	**0.58**				
Intrinsic alertness	0.13	**0.34**	**0.31**	**0.37**			
Phasic alertness	0.05	-0.0	-0.09	-0.19	-0.39		
Fine motor skills	**0.26**	**0.43**	**0.25**	**0.60**	**0.34**	-0.06	

Note: Correlations in bold are significant at $p < .05$. For all measures, higher values indicate better performance.

Table 1. Correlations of EF and PNP.

The integration and evaluation of infant-family mental health services in fetal maternal comprehensive care for the CHD population

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Introduction & Study Question: The poster will present both QI information and a case study series (3) to highlight a fetal maternal comprehensive care model. The antenatal and postnatal periods are characterized as a time of great physiological, psychological, and social change. As such, caregivers may experience increased distress and psychological vulnerability.[3] Diagnosis of a fetal anomaly during pregnancy increases risk for perinatal mental health difficulties.[1] Pregnancies marked by the presence of congenital heart disease can be especially traumatic and alter the transition to parenthood and the attachment to the baby.[2] As such, an infant-family mental health and trauma-informed perspective is paramount. Psychologists are uniquely positioned to assess mental health risk and address the needs of expectant caregivers.[1] Likewise, psychologists with specialized training are uniquely attuned to infant mental health and the caregiver/infant relationship.
Methods: The fetal maternal comprehensive care model, emphasizes the importance of the relationship and focuses on minimizing the impact of traumatic stress during the pre- and postnatal period for the CHD population by facilitating continuity of care. Because multiple surgeries and/or admissions over infancy and the early childhood period may be more likely and many families experience medical complexity, continuity of care is vital. In the fetal maternal comprehensive care model, the same provider(s) is present in multiple settings and provides services through all phases of care (i.e. prenatal/Fetal Maternal Center and Fetal Cardiology, Labor & Delivery and/or Recovery; inpatient/Cardiothoracic Intensive Care Unit, Cardiovascular Acute; follow-up/outpatient, Newborn Follow-up Program.) There is also an emphasis on the interstage period (i.e. between surgeries), as this is known to be a time of increased stress for families. Overall, infant-family mental services provided by an embedded psychologist and trainees are largely focused on prevention/early intervention, perinatal mental health, medical trauma and stress, development, grief and bereavement, attachment and bonding, sibling support, communication with interdisciplinary medical team members, and staff support.
Results & Discussion: A case study series (3) will highlight the impact and reach of the fetal maternal comprehensive care model for the CHD population. This model may be replicated in different settings with other populations. Lessons learned and future directions are outlined.

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Effect of Inpatient Program Introduction on Follow-up Rates and Family Satisfaction in a Cardiac Neurodevelopmental Program

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Introduction: Return rates for cardiac neurodevelopmental evaluations have been tracked across several centers. A recent study found 73% of patients who qualify for cardiac neurodevelopmental evaluations are not being seen (Ortinau et al, 2021). We hypothesized that a neurodevelopmental provider introducing themselves and explaining the purpose of the cardiac follow-up program during a family's inpatient stay would improve the program's follow-up rate and family's level of reassurance regarding neurodevelopmental monitoring for their children.
Methods: At a single center, AHA guidelines were followed to determine which patients qualified for cardiac neurodevelopmental follow-up evaluations. Starting in March 2021, a provider from the cardiac neurodevelopmental program then met with families of these patients in person during their inpatient hospital stay or

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spoke with them over the phone regarding the purpose of the outpatient cardiac neurodevelopmental program. Data on introductions and whether the patient returned to the clinic was collected. Families completed a survey during the neurodevelopment clinic visit to determine if 1) based on the introduction the parent understood the purpose of the program, 2) the family felt motivated to come to the appointment, and 3) how reassuring it was that their child is monitored for developmental delays and neurologic conditions.
Results: 342 patients met AHA criteria to be followed in the cardiac neurodevelopmental clinic between 2019 and 2022, including 243 after inpatient provider introductions were initiated. If an introduction and explanation was given to caregivers, patients had an 83% show rate. If no introduction or explanation was given, patients had a 67% show rate. A chi-squared test was used to evaluate the statistical significance of introduction on follow-up rate. The p-value was significant at $p < 0.01$. 96% of parents responded that based on the introduction regarding the program they understood why they were being referred. 100% of caregivers said they felt encouraged to attend the visit. 90% of caregivers found it reassuring their child is being monitored for developmental delays and neurologic conditions.
Discussion: We found that speaking with caregivers of patients regarding the purpose of the cardiac neurodevelopmental clinic during their child's inpatient stay improved follow-up rates. After the conversation, caregivers felt motivated to attend visits and reassured that their child was being monitored.

The Process to Expertise: A Constructivist Grounded Theory Study with Caregivers of Hospitalized Infants with Critical Congenital Heart Disease

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Introduction: Congenital heart disease (CHD) is the most diagnosed congenital anomaly, and one-quarter of infants diagnosed with CHD have critical congenital heart disease (CCHD), are immediately hospitalized after birth, face one or multiple surgical procedures soon after, and a lifetime of medical management for their heart disease. Caregivers of hospitalized infants with CCHD learn to do much more than parent; they navigate stress, unfamiliarity, and altered roles in providing and managing the care needs of a chronically ill child. Learning occurs in an environment that is novel, stressful, and unpredictable. Caregivers mitigate this burden by managing emotions, accessing support systems, and "becoming the expert" of their hospitalized infant's care in a critical care setting, even during high emotions and stress. This study aimed to construct an explanatory theory, based on the analysis of the caregivers' perspectives and words, to uncover the process caregivers of hospitalized infants with CCHD go through to become experts in their infant's care in a critical care setting. Knowing this process to expertise will help guide healthcare providers who deliver medical, developmental, and psychosocial support and education. The central research question is, "What is the process that caregivers of hospitalized infants with CCHD go through to become experts of their infant's care in the context of a critical care setting?" Additional sub-questions supported the research inquiry question and subsequent data collection and analysis.
Methods: This study employed a constructivist grounded theory approach to answer the research question and evolving sub-questions. Participants were English-speaking primary caregivers of infants with a CHD diagnosis who were hospitalized for at least two weeks and underwent open heart surgery within the first three months of life. The study criteria for participant recruitment acknowledged that caregivers with recent experience (discharged within 365 days) navigating their infant's diagnosis, initial hospitalization, and transition home would be the best fit. Grounded theory methodology provided a framework to learn about the real-world processes that caregivers go through and allowed the researcher to develop a theory to understand that process.
Results: A Process Model of Expertise, co-constructed between the researcher and participants, emerged, depicting how caregivers' roles changed and how people, time, environment, and support systems helped or hindered the process to expertise.
Discussion: There is evidence that understanding this process will fill a knowledge gap to improve healthcare delivery, education, and family-centered support in the hospital setting. A process framework helps guide education for healthcare providers by providing a touchstone for methodology, defining concepts to be measured, establishing a standard or criterion of success or failure, and opening the door for further empirical research. Further, it acknowledges that caregivers are not alone in this journey. Knowledge of the adaptive progression that caregivers go through to becoming an expert in their infant's care may lead to improved family-centered care and continuity in healthcare delivery.

Optimizing motor outcomes in the hospitalized infant with congenital heart disease

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Introduction: Neurodevelopmental challenges are the greatest comorbidity associated with congenital heart disease (CHD), with a high incidence of gross and fine motor delays noted in early infancy. Hospitalized infants with CHD face challenges in progressing motor milestones while healing from cardiac interventions. Inpatient cardiac developmental therapists are integral in supporting motor skill development in hospitalized infants with CHD. However, minimal literature defines their role, appropriate assessment measures, or interventions in the cardiac intensive care unit (CICU) or acute care unit (ACU). A multidisciplinary team of cardiac developmental therapists through the Cardiac Newborn Neurodevelopmental Network (CNNN), a Special Interest Group of CNOC, collaborated to describe how typical infant motor skills develop, examine the potential disruptions in that process, and provide best practice suggestions for motor assessment and interventions in infants hospitalized with CHD.
Methods: A multidisciplinary, multicenter team of experts composed a comprehensive literature review of evidence-based practice strategies and clinical experiences to provide recommendations to optimize motor skill development in hospitalized infants with CHD.
Results: Many infants with CHD have delays in sensory-motor and gross motor development, state/behavioral disorganization and dysregulation, a higher prevalence of atypical general movements, tone abnormalities, and delayed prone progression. Standardized

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neurobehavioral and neuromotor and/or non-standardized developmental evaluations conducted by cardiac developmental therapists identify neurological impairment, tone and motor discrepancies, guide intervention strategies, and contribute to therapy recommendations after hospital discharge. While not created for infants with CHD, many standardized assessments have been utilized in the infant CHD population. Therapeutic interventions to support motor development include providing an optimal environment for motor learning; facilitating essential self-regulation activities; supporting state regulation; providing developmentally supportive positioning that facilitates midline development and symmetrical support of the infant's body; graded therapeutic interventions to promote typical movement patterns and interaction with the environment; incorporating family and caregivers into developmental activity throughout the hospital stay.
Discussion: Motor support of infants with CHD must be integrative, holistic, and understood within the context of the critical care environment and a collaborative focus of all interdisciplinary healthcare team members (See Figure). All infants hospitalized with CHD should receive developmental therapies upon admission and have a plan in place to optimize motor skill development throughout their hospitalization. Interdisciplinary collaboration and education are vital to ensure optimal motor outcomes for infants with CHD.

Comparison of Neurodevelopmental Outcomes and Predictors of Change Over Time in Children with Congenital Heart Disease and Children Born Very Preterm
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Introduction: Children diagnosed with congenital heart disease (CHD) and children born very preterm (VP) have similar patterns of brain injury and dysmaturation. Yet, limited research has compared neurodevelopment profiles of these groups, and longitudinal outcomes and predictors of progress remain unclear. This study compared neurodevelopmental outcomes of children with CHD and children born VP at 18-months corrected age (m), examined profile changes from 18m to 36m, and identified predictors of progress over time.
Methods: A clinical research sample of 178 infants born VP (≤32wks; n=99) or with CHD (n=79) from the Hospital for Sick Children and Mount Sinai Hospital were tested at 18m. CHD diagnoses included two ventricles with no arch obstruction (57%), two ventricles with arch obstruction (4%), single ventricle with no arch obstruction (33%), and single ventricle with arch obstruction (6%). Neurodevelopmental outcomes were assessed using the Bayley Scales of Infant and Toddler Development and the Child Behavior Checklist. Descriptive statistics and chi-square analyses were used to compare diagnostic groups, and regression analyses were used to examine 18m predictors of 36m outcomes. Of these, 103 infants (n_{VP}=61; n_{CHD}=42) returned for their 36m assessment. To compare group differences over time, 2x3x2 repeated measures ANOVAs were used.
Results: At 18m, there were no group differences on Cognitive, Language or Motor Composite mean scores, subtests of Expressive and Receptive language, or Fine Motor functioning. VP had higher Gross Motor scaled scores compared to CHD (p=.023). Eighteen percent of the CHD group had scores ≤70 on Language composite compared to 6% of the VP group (p=.024). More infants in the CHD group had impaired Expressive Language (20%; p=.034) and Gross Motor (14%; p=.020) scores compared to the VP group (7%; 3%). Parents in the VP group reported higher Anxious/Depressed (p=.007), Internalizing behaviours (p=.045), and Total Problems (p<.001) compared to the CHD group. Parents in the CHD group reported higher Attention (p=.008) and Aggression concerns (p<.001) compared to the VP group. English as the child's primary language (p=.001), lower brain injury severity score (p=.035), and higher median income (p=.083) was associated with higher cognitive scores at 18m. Biological female sex (p=.037) and English as first language (p<.001) were associated with higher language composite scores. Lower brain injury severity score (p=.010) was associated with higher motor scores. Longitudinal analyses revealed a main effect of time for cognition (p<.001), with lower scores at 36m for both groups. There was a group by time interaction for language (p=.005) and motor scores (p=.015). Language scores remained stable in the VP group but improved at 36m in the CHD group. Post-hoc analyses revealed that 65% of the CHD infants that improved over time had a diagnosis of Transposition of the great arteries. Motor scores in the VP group decreased over time but were stable in the CHD group. Internalizing behaviours increased over time for both groups (p=.005).
Discussion: Findings highlight unique and shared neurodevelopmental changes in children born VP and children with CHD in early development.

Public-private partnerships can offset programmatic expenses for therapeutic tools while increasing community engagement: A case study of a novel approach to support an inpatient neurodevelopmental program
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Intro: Public-private partnerships (PPP) are a hallmark of public health. We used this model to support inpatient neurodevelopmental care plans. Community members sought ways to support infants and children with congenital heart disease (CHD). Our Neurodevelopmental team partnered with a large private foundation in a match program. We met our goal to raise enough funds to purchase therapeutic play mats. An aspiring Eagle Scout (Boy Scouts of America) joined us in a second partnership. His team raised money, designed, built, and delivered play gyms that fit inside open cribs and on the play mats. The play mats and play gyms allow for more advanced therapies for patients in the inpatient setting. This creates for more opportunities to work on developmental tasks such as rolling over, reaching/kicking objects and prone positioning. All while providing a sense of normalcy for caregivers.
Methods: Entering PPP is a unique method of supporting hospital-based efforts. Partnership agreements were completed. Timelines for completion of fundraising and delivery of goods were established. doTERRA Healing Hands Foundation provided a matching campaign which raised the needed funds for the purchase of the therapeutic mats ($2000). The Eagle Scout recruited his construction team, acquired the necessary components, hosted the build day, and delivered the play gyms.
Results: The therapeutic play mats and play gyms have been in use at the bedside in the CVICU, stepdown, and cardiology floor care areas. They are widely used by parents, therapist, and nurses to offer a variety of engagement and enrichment opportunities. This is particularly helpful for our long-term patients who otherwise would miss many important developmental milestones.

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Discuss: PPP are novel opportunities to engage community members to support ongoing needs of patients with CHD, which is unknown to many outside the hospital setting. These partnerships benefit all involved. To the community they offer an increased opportunity for engagement by increasing awareness of CHD and the challenges patients and families face. To the patients & families, they increase their exposure to more advanced therapeutic opportunities and provide a sense of normalcy. To the hospital they provide cost-sharing opportunities and additional opportunities for future partnerships. As Heart Centers look to invest wisely into this population, partnering with outside institutions is fiscally responsible. Particularly for smaller programs with limited funding, PPP help offset those costs. Creating these opportunities to engage community members and larger non-profit organizations is a novel approach for meeting the developmental and therapeutic needs of infants and children with CHD.

Regional differences in cortical expansion in fetuses with congenital heart defects

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Introduction and Study Question: For children with congenital heart disease (CHD), differences in brain structure and function are already present at birth and emerge as early as the third trimester of pregnancy.[1] Prenatal alterations in the pattern of cortical folding have been observed,[2] and a growing body of evidence suggests cortical expansion is a driving force in brain folding.[3] We hypothesize that localized differences in cortical expansion exist in fetuses with CHD, which may in turn drive observed alterations in brain folding. In this study, we aim to quantify regional cortical growth differences over the third trimester in fetuses with CHD compared to their control counterparts.

Methods: Fetal magnetic resonance imaging (MRI) scans were collected from Boston Children's Hospital and St. Louis Children's Hospital at 26-31 weeks and again at 34-39 weeks gestation. Images were reconstructed using a high resolution, motion-corrected pipeline and an automated segmentation was applied.[4] Cortices were manually segmented in ITK-Snap and converted to cortical surfaces using Caret. Individualized maps of cortical surface expansion were generated using anatomically constrained multimodal surface matching (aMSM). Subject-specific results were mapped to a study-specific atlas, and group differences were analyzed using Permutation Analysis of Linear Methods (PALM), as described previously.[5]

Results: Analysis compared 21 fetuses with CHD (6 with dextro-transposition of the great arteries, 3 with hypoplastic left heart syndrome, 4 with Tetralogy of Fallot, 8 other) to 13 control fetuses. While only minor differences in total cortical expansion were observed, normalized cortical expansion maps revealed striking differences in the pattern of cortical growth between CHD and control fetuses (Figure 1). Specifically, control fetuses exhibited relatively high expansion in the lateral temporal lobes, whereas relative expansion of this region was reduced in CHD fetuses. Additional differences were observed in the motor and somatosensory cortices, as well as the medial frontal and visual cortices.

Discussion: The novel analysis employed in this study allows us to observe regional differences not detected by previous global analyses of cortical growth. These alterations among fetuses with CHD, such as reduced growth of the lateral temporal cortex, are consistent with previous reports of atypical folding in this region. This detailed understanding of altered growth trajectory in-utero may improve understanding of functional deficits associated with specific cortical areas, ultimately helping to inform clinical decisions surrounding the need and timing of interventions.

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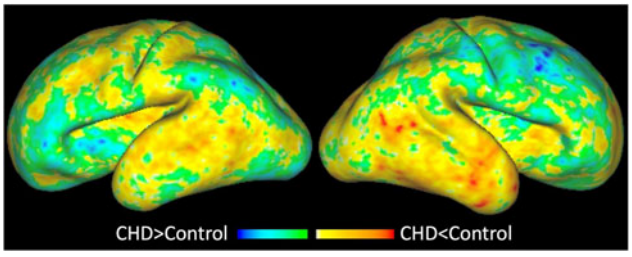

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Connecting with Families about Cardiac Neurodevelopmental Services Online

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Introduction: Online information is a primary source of information for parents with concerns about their child's health and development, however only half of patients confirm the results of web-based research with their physician. We aimed to assess online information about neurodevelopmental services offered by individual institutions for children who had cardiac surgery during infancy, and associations between online information and sociodemographic and institutional factors. We hypothesized that institutional factors would more strongly correlate with online information than would the sociodemographic makeup of the community in which the program was located.
Methods: A total population sample of all programs in the 2021-2022 Congenital Cardiology Today (CCT) Directory was conducted. Online information about each program's neurodevelopmental follow up program was systematically ascertained, and its robustness was assessed using a scoring system modified from previous research. Institutional and sociodemographic information was extracted from the following databases: Society of Thoracic Surgeons Public Reporting for Congenital Heart Surgery database; American Medical Association Fellowship and Residency Information Database; US Census; American Community Survey; Kaiser Family Foundation; National Center for Education Statistics; and IDEA Part B Child Count and Educational Environments. Uni- and multi-variate regression was analyses were conducted using SPSS. All P values were 2-sided and $p<0.05$ was used to indicate statistical significance.
Results: Of the 129 programs listed in the CCT directory, 38 (29%) had information about a neurodevelopmental follow up program that could be found by searching the program website and 47 (36%) had information that could be found by performing a Google search. Of the 91 programs in the STS database, 42 (46%) had information that could be found using Google. Factors positively associated with online information about neurodevelopmental follow up were surgical volume, surgical complexity, and affiliation with a pediatrics residency program or a pediatric cardiology fellowship program. State-level sociodemographic factors were neither positively nor negatively associated with online information.
Discussion: Fewer than half of programs performing heart surgery in children have information about neurodevelopmental follow up available online. This presents challenges for parents searching for information on their child's developmental, behavioral, and mental health concerns, and may represent a potential barrier to families seeking appropriate follow-up for their children. Improved online messaging and pointed anticipatory guidance during regular clinic visits regarding the neurodevelopmental needs of children after cardiac surgery are needed.

Relationship between 4-month functional network topology and 24-month neurodevelopmental outcome in children with congenital heart disease: Preliminary results

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Introduction: In the past years, several studies showed brain structural and functional network alterations in neonates with CHD.[1–5] However, the relationship between brain function and neurodevelopment is not fully established in this population. For the first part of this longitudinal prospective cohort study, Fourdain et al.[6] compared cortical functional connectivity in 4-month-old infants with repaired CHD to healthy controls using resting-state functional near-infrared spectroscopy (fNIRS). Results suggested that a global reduction in the connectivity strength of the CHD group persisted after the corrective cardiac surgery. These findings spiked our interest in exploring the brain function of this specific CHD cohort in greater depth using the graph theory approach. This study aims at identifying early brain markers of neurodevelopment in children with CHD by investigating the association between 4-month functional network topology and 24-month developmental outcomes.
Methods: A total of 30 healthy children and 19 full-term children with CHD underwent a rs-fcNIRS data acquisition at 4 months and a developmental assessment at 24 months. rs-fcNIRS was recorded for 12 minutes during natural day time sleep in frontal, frontotemporal, temporal and parietal regions using a tissue oximeter (ISS Inc, Champaign, IL, USA). For network metrics, we computed the clustering coefficient, the normalized clustering coefficient, the characteristic path length, the normalized characteristic path length, the global efficiency, the local efficiency, and the small-world index. Neurodevelopment was evaluated using the Bayley-III. ANCOVA were used to identify significant differences between groups' scores variances at 24 months while controlling for cofounding variables (e.g., sex, socioeconomic status). Corrections for multiple comparisons were performed using Bonferroni correction. Pearson correlation analyses were used to explore the association between functional network topology and statistically lower developmental scores at 24 months.
Results: Preliminary results suggest similar network topology between CHD and control participants. At 24 months, children with CHD obtained significantly lower mean scores on the Bayley-III language composite score ($p = .024$) and the expressive communication scaled score ($p = .022$). Preliminary correlation results revealed a significant positive association between the clustering coefficient and two language scores (composite score; $p = 0.03$, expressive communication subscale; $p = 0.014$) as well as between the local efficiency and the same language scores (composite score; $p = 0.016$, expressive communication subscale;

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$p = 0.011$). The characteristic path length, the global efficiency, and the small-world index were not statistically associated with any language scores.
Discussion: These preliminary results suggest the feasibility of identifying early cerebral predictors of neurodevelopmental outcome in CHD. Further analyses are required to confirm these findings and explore the unique contribution of graph theory and CHD status on neurodevelopment.

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Importance of ongoing developmental screening in congenital heart disease: A single center experience

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Introduction and Study Question: Systematic developmental surveillance, screening, and assessment of patients with CHD is recommended by AHA guidelines. Many centers focus on neurodevelopmental (ND) follow-up for infants and toddlers with CHD, however developmental challenges are common at school-age even if early milestones were normal and early intervention (EI) services were not required. Even subtle developmental impairments can have a significant impact on academic achievement. Furthermore, mental health concerns are more likely to be evident during school-age years. The primary aim for this study was to describe rates of new neurodevelopmental disorder (NDD) diagnoses, mental health concerns and recommendations for services among school-age children evaluated through our ND follow-up program.
Methods: We reviewed pertinent medical, demographic, and developmental assessment data, from patients referred to our program from January 2018 to June 2022. We analyzed data from children between 4-12 years who had received a cardiac operation during the first year of life. Recorded comorbidities included neurological conditions, genetic disorders, and prematurity. Primary outcomes included NDD diagnoses resulting from the evaluation, whether new services were recommended, and if any mental health concerns were identified. Descriptive statistics were performed.
Results: Among 74 patients evaluated in this period, mean age was 6.6 years and 55.4% were male. 41.9% had comorbid diagnoses, including genetic (17.6%) and/or neurological conditions (23.0%). Mean Full Scale IQ of the cohort (93+/-19.4) was within the average range. Two-thirds (66.2%) were diagnosed with a NDD and new services were recommended for 87.8%. NDDs were more frequent in patients with CHD + comorbidity (77.4%) vs. isolated CHD (48.8%). While 56.8% received EI, only 36.5% were receiving special education services at the time of evaluation. Of children who received services from EI programs and/or schools, 76% were given new NDD diagnoses, and new services were recommended for 96%. Among those who had never received EI or school services, new services were recommended for a majority (70.8%) and 37.5% met criteria for a NDD. Mental health concerns were identified for 41.9% of patients.
Discussion: ND follow-up visits during early childhood facilitate early identification of developmental concerns and referrals to crucial intervention programs. However, the profile of cognitive, social-emotional, and academic difficulties often observed in children with CHD may become more pronounced during the school-age period. While the cohort of patients seen through our clinic have overall cognitive scores within the average range, a majority met diagnostic criteria for a NDD and/or received recommendations for additional services and supports. Importantly, among children who never required EI services, a large percentage were diagnosed with a new NDD and/or were referred for new services at school-age. Findings from this study highlight the importance of ongoing developmental monitoring and clinical assessment past the early childhood period for diagnostic clarification, detection of mental health concerns, and to provide recommendations for educational planning and clinical management.

Maternal pregnancy-related stress is associated with smaller fetal brain volumes in congenital heart disease

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Introduction: A prenatal diagnosis of moderate-severe congenital heart disease (CHD) increases risk of maternal depression, anxiety, and stress. In utero exposure to maternal psychological distress is associated with altered brain development in offspring, particularly within the cerebral cortex, hippocampus and cerebellum. Recent data in fetuses with CHD show similar associations, but studies that assess pregnancy-related stress symptoms, and the impact of these symptoms on fetal brain development, are limited. We aimed to measure pregnancy-specific stress in women who received a prenatal diagnosis of fetal CHD and to determine its association with late third trimester fetal brain development. We hypothesized that higher maternal stress would be associated with smaller cortical plate, hippocampal, and cerebellar volumes.
Methods: Pregnant women with a prenatal diagnosis of moderate-severe fetal CHD were recruited into a prospective, longitudinal fetal brain magnetic resonance imaging (MRI) study. Exclusion criteria were gestational age (GA) >30 weeks, fetal congenital

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infection, multiple gestation pregnancy, and contraindication to MRI. Participants underwent two prenatal study visits at 28-30 weeks' gestation (Prenatal 1) and 34-36 weeks' gestation (Prenatal 2). At each study visit, fetal brain MRI was performed and participants completed the revised Prenatal Distress Questionnaire (NuPDQ), which measures stress symptoms related to the pregnancy, with higher scores reflecting greater stress. To evaluate the cumulative impact of stress symptoms over the pregnancy, data were analyzed using the Prenatal 2 MRI. Images were reconstructed using a high resolution, motion-corrected pipeline, an automated segmentation was applied, and manual modification was performed to ensure accurate delineation of brain structures. Brain regions included cortical plate, hippocampus, cerebellum, white matter, subcortical gray matter (SCGM), diencephalon, brain stem, total brain volume (TBV), cerebrospinal fluid, and intracranial volume (ICV). Linear regression models were used to evaluate the association of NuPDQ scores with brain volumes, adjusting for fetal sex and GA at MRI.

Results: There were 42 pregnant women enrolled who received a fetal diagnosis of moderate-severe CHD at a median of 22.0 (IQR =21.1-26.1) weeks' gestation. The most common diagnoses were hypoplastic left heart syndrome (23.8%), transposition of the great arteries (14.3%), and tetralogy of Fallot (11.9%). The Prenatal 2 MRI was conducted at a mean GA of 35.5 weeks (SD = 1.2 weeks). NuPDQ scores at Prenatal 1 (mean [SD] = 9.9 [6.5]) and Prenatal 2 (mean [SD] = 8.6 [5.2]) were highly correlated ($r[36] = .83$, $p<.001$). Higher Prenatal 1 NuPDQ scores were associated with smaller cortical plate ($\beta=-.28$; $p=.03$), cerebellum ($\beta=-.32$; $p=.02$), TBV ($\beta=-.26$; $p=.04$), and ICV ($\beta=-.33$; $p=.02$). All other regions were non-significant.

Discussion: The association of maternal pregnancy-specific stress with smaller fetal brain volumes suggests that increased pregnancy-related stress may adversely affect fetal brain development in CHD. These data highlight the importance of providing mental health support and resources to help alleviate pregnancy-related stress after prenatal CHD diagnosis.

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