

Review

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Neurodevelopmental and psychosocial interventions for individuals with CHD: a research agenda and recommendations from the Cardiac Neurodevelopmental Outcome Collaborative

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Abstract

In 2018, the Neurodevelopmental and Psychosocial Interventions Working Group of the Cardiac Neurodevelopmental Outcome Collaborative convened through support from an R13 grant from the National Heart, Lung, and Blood Institute to survey the state of neurodevelopmental and psychosocial intervention research in CHD and to propose a slate of critical questions and investigations required to improve outcomes for this growing population of survivors and their families. Prior research, although limited, suggests that individualised developmental care interventions delivered early in life are beneficial for improving a range of outcomes including feeding, motor and cognitive development, and physiological regulation. Interventions to address self-regulatory, cognitive, and social-emotional challenges have shown promise in other medical populations, yet their applicability and effectiveness for use in individuals with CHD have not been examined. To move this field of research forward, we must strive to better understand the impact of neurodevelopmental and psychosocial intervention within the CHD population including adapting existing interventions for individuals with CHD. We must examine the ways in which dedicated cardiac neurodevelopmental follow-up programmes bolster resilience and support children and families through the myriad transitions inherent to the experience of living with CHD. And, we must ensure that interventions are person-/family-centred, inclusive of individuals from diverse cultural backgrounds as well as those with genetic/medical comorbidities, and proactive in their efforts to include individuals who are at highest risk but who may be traditionally less likely to participate in intervention trials.

The November 2020 issue of *Cardiology in the Young* contains the inaugural five manuscripts from the Cardiac Neurodevelopmental Outcome Collaborative,¹⁻⁵ marking the beginning of the partnership between the Cardiac Neurodevelopmental Outcome Collaborative and *Cardiology in the Young*. In this issue of *Cardiology in the Young*, this article is part of the first set of three papers from the Cardiac Neurodevelopmental Outcome Collaborative R13 Grant funded by the National Heart, Lung, and Blood Institute of the National Institutes of Health of the United States of America, which defines the research agenda for the next decade across seven domains of cardiac neurodevelopmental and psychosocial outcomes research.⁶⁻⁸

Now that individuals with CHD are living longer, it is clear that the neurodevelopmental and psychosocial challenges they face are among the strongest correlates and predictors of quality of life across the lifespan.⁹ This risk is especially great among those diagnosed with critical CHD requiring surgery within the first year of life. Elevated risk of early feeding, motor and self-regulatory difficulties during infancy give way to later-emerging deficits in attention, executive function, visual-spatial processing, and social cognitive capacities during childhood and adolescence, which in turn undermine the development of adaptive skills necessary to successfully manage the transition to adulthood and subsequent independence.¹⁰ Despite increasing recognition of these challenges,^{10,11} little attention has been given to the design and implementation of CHD-specific neurodevelopmental and psychosocial interventions.^{12,13}

Table 1. Neurodevelopmental and Psychosocial Interventions Working Group participants

WG participants	Discipline/role	Institution/organisation	Country
Adam R. Cassidy *	Pediatric Neuropsychologist	Boston Children's Hospital; Harvard Medical School	United States of America
Jennifer Butcher *	Pediatric Psychologist	C.S. Mott Children's Hospital; Michigan Medicine	United States of America
Samantha Butler	Developmental and Clinical Psychologist	Boston Children's Hospital; Harvard Medical School	United States of America
Jennie Briend	Parent Stakeholder	Sisters by Heart	United States of America
Johanna Calderon	Pediatric Neuropsychologist	Boston Children's Hospital; Harvard Medical School	United States of America
Frank Casey	Pediatric Cardiologist	Paediatric Cardiology Belfast Trust; Royal Belfast Hospital For Sick Children	Ireland
Lori E. Crosby **	Pediatric Psychologist	Cincinnati Children's Hospital Medical Center; University of Cincinnati College of Medicine	United States of America
Jennifer Fogel	Speech-Language Pathologist	Advocate Children's Hospital	United States of America
Naomi Gauthier	Pediatric Cardiologist	Boston Children's Hospital; Harvard Medical School	United States of America
Carol Raimondi	Patient Stakeholder	Conquering CHD	United States of America

WG = working group.

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At this time, our knowledge of the risks for adverse neurodevelopmental and psychosocial outcomes in individuals with CHD dramatically outstrips our knowledge of how to mitigate those risks – an imbalance that has become untenable as patients, families, care providers, and other stakeholders increasingly look for guidance regarding how best to optimise individual potential and maximise the quality of life for each child and family affected by CHD. Further, since both biological and social determinants of health are critical when optimising wellness, interventions must be designed to have socio-ecologic validity and the capacity to reach all individuals, especially those facing greater psychosocial challenges and health disparities.¹⁴

The *Neurodevelopmental and Psychosocial Interventions Working Group* of the Cardiac Neurodevelopmental Outcome Collaborative included content area experts in psychology and neuropsychology, cardiology, feeding and speech/language pathology, health disparities, and family support including a patient and a parent stakeholder (Table 1). Working Group participants included members from the United States of America and Europe who convened in 2018 to address the following goals: 1) Describe the state of neurodevelopmental and psychosocial intervention research in CHD and 2) propose an intervention research agenda aimed at optimising the neurodevelopmental and psychosocial potential of individuals affected by CHD. The effort was supported by a National Heart, Lung, and Blood Institute R13 grant awarded to the Cardiac Neurodevelopmental Outcome Collaborative in collaboration with the Ann & Robert H. Lurie Children's Hospital of Chicago, which funded a two-day meeting of multidisciplinary, multinational experts and patient/caregiver stakeholders in Kansas City, MO.

To achieve its goals, the Working Group developed five critical questions to guide the development of an intervention research agenda for CHD for the next decade (Table 2). Each critical question focused on interventions that are inclusive for individuals of all backgrounds including those who traditionally face health disparities and those with genetic diagnoses and other medical comorbidities. The research agenda included interventions that have both randomised controlled trial and quality improvement designs, occur across settings (e.g., home, school, hospital,

e-Health/telemedicine, camp), are tailored to the challenges associated with CHD, are preventative, include cost-effectiveness analysis, and are focused on optimisation for both individual and group differences.

Critical question 1: How do we adapt effective interventions in other medical populations that address known risk factors in CHD?

Existing knowledge

There is a sizeable body of evidence supporting the efficacy of interventions which address known neurodevelopmental and psychosocial risk factors in other high-risk populations such as children born preterm and those diagnosed with developmental disabilities. Moreover, theoretical frameworks exist for adapting interventions for use in individuals with various medical conditions.^{15,16}

Individualised developmental care programmes show particular promise for promoting positive neurodevelopmental outcomes among medically at-risk children when implemented in the newborn period. Individualised developmental care is a model of care that minimises the mismatch between infant neurobiological needs and the often toxic hospital environment. The Newborn Individualized Developmental Care and Assessment Program^{17,18} is the only evidence-based developmental care programme and is well validated in the preterm infant population where it has been shown to decrease the length of hospital stay and improve physiological functioning, long-term neurodevelopment, parent confidence, and patient and family satisfaction among infants born preterm.¹⁸⁻²¹ Other programmes, such as Trauma Informed Care and Family Centered Care, incorporate an understanding of trauma and need to recognise the central importance of family into routine care and treatment of illness.²²⁻²⁴ Specific aspects of these programmes, such as skin-to-skin contact, interdisciplinary developmental care rounds, cue-based care, family support, and education for providers, have been found to be developmentally supportive of children and families affected by CHD and contribute to improved neurodevelopmental outcomes.^{17,25-31} The use of breast milk and breastfeeding can also

Table 2. Interventions: critical questions, significant gaps in knowledge, and investigations needed

Critical questions	Significant gaps in knowledge	Investigations needed
CQ1. How do we adapt effective interventions that address known risk factors in CHD?	<ul style="list-style-type: none"> • Despite considerable research evaluating the effectiveness of a range of neurodevelopmental and psychosocial interventions in other medical populations, the safety, feasibility, acceptability, and effectiveness of these interventions are limited among individuals with CHD • Very little is known about the effectiveness of neurocognitive interventions, particularly among school-age children, adolescents, and young adults with CHD 	<ul style="list-style-type: none"> • Investigate the safety and feasibility of individualised developmental care interventions in the CICU • Examine best practices for promoting handling and moving of infants while inpatient. • Study short- and longer-range outcomes associated with individualised developmental care interventions in the CICU • Conduct translational research studying empirically supported psychosocial and neurocognitive interventions developed for other populations in individuals with CHD • Investigate new modalities for delivering neurodevelopmental and psychosocial interventions within the CHD population
CQ2. What is the impact of neurodevelopmental and psychosocial interventions in individuals with CHD?	<ul style="list-style-type: none"> • Most prior neurodevelopmental and psychosocial intervention studies in CHD are limited to single-centre, concurrent, observational studies • Many CHD neurodevelopmental intervention studies exclude individuals with genetic conditions 	<ul style="list-style-type: none"> • Operationalise clinically meaningful intervention outcomes for each developmental stage • Conduct prospective randomised controlled trials with longer-term follow-up to investigate efficacy and effectiveness beyond the typical snapshot of a pre-post intervention • Partner with key stakeholders to define “clinically meaningful” outcomes
CQ3. How are CND programmes currently utilised, in what ways do coordinated CND programmes impact outcomes, and what are the best programme practices?	<ul style="list-style-type: none"> • Limited number of published studies examining the benefits of developmental follow-up programmes among individuals with CHD 	<ul style="list-style-type: none"> • Conduct feasibility, acceptability, and accessibility studies to examine processes (e.g., screening, monitoring procedures) and components (e.g., types of services) that result in the most beneficial CND programmes • Examine whether centres that have coordinated CND programmes show improved neurodevelopmental and psychosocial outcomes for individuals with CHD • Develop efficient ways of triaging patients seen in CND programmes to different levels of intervention based on individual needs
CQ4. How do we foster the development of resilience in individuals with CHD?	<ul style="list-style-type: none"> • Experiences driving the development of resilience among individuals with CHD and interventions to bolster the development of resilience in the CHD population have not been adequately examined 	<ul style="list-style-type: none"> • Adopt a conceptual framework for designing and conducting resilience-promoting intervention studies that appropriately captures the nature and complexity of resilience • Capitalise on early identification to support caregiver/family resilience prior to delivery • Recognise individual and family-based differences in perception regarding the experience of living with CHD • Identify interventions for promoting resilience during childhood and adolescence • Include resilience as a primary outcome in CHD surgical trials
CQ5. How do we develop systematic and effective approaches to optimise developmental transitions and transitions in care for individuals with CHD and their families?	<ul style="list-style-type: none"> • The full range of transitions inherent to the experience of living with CHD has neither been adequately characterised nor have interventions to support effective transitions been examined • It remains unclear how best to promote functional independence, adaptive skills, and self-awareness among individuals with CHD 	<ul style="list-style-type: none"> • Comprehensively characterise the full range of transitions inherent to living with CHD • Utilise quality improvement science to improve strategies to assist families in navigating CHD-specific challenges and transitions

CQ = critical question, CND = cardiac neurodevelopmental

support infant growth and oral feeding, as well as promote bonding with family and improve cognitive development,³² and social-emotional growth over time.^{33,34}

In addition to inpatient supports, early intervention has demonstrated positive effects on the developmental achievements of children with or at-risk for developmental disability.³⁵⁻³⁷ Families from high-risk populations who received prenatal and infancy home visits by nurses showed improved

cognitive, academic, behavioural, and sociodemographic outcomes for their children.³⁸

Interventions targeting areas of deficit commonly observed among individuals with CHD have been developed and well-established with non-CHD populations. As an example, practice guidelines for behavioural and psychotropic interventions for individuals diagnosed with attention-deficit/hyperactivity disorder are established for other populations, yet there has been limited

research involving individuals with CHD who have special considerations due to cardiovascular effects of common medications^{39,40}. Similarly, the efficacy of behavioural and psychotropic interventions for individuals with mood⁴¹ and anxiety disorders,^{42,43} including procedural anxiety⁴⁴ and coping with medical illness,⁴⁵ has been established, but these interventions have been understudied among individuals with CHD. A 2013 Cochrane review identified no randomised controlled trials demonstrating the efficacy of cognitive-behavioural interventions for depression in adolescents or adults with CHD, and a⁴⁶ more recent review continued to report limited efficacy among these populations.¹³

Among healthy school-age children and adolescents, as well as those with various medical conditions, there is a strong interest in addressing neurocognitive deficits (e.g., in executive function, attention), using, for example, computerised interventions such as Cogmed; however, data on the effectiveness of these programmes have been mixed.^{47,48} Therapeutic camp programmes have been shown to improve mood, self-concept, empathy, quality of life, and emotional well-being for children with cancer and their families.⁴⁹ Adolescents with chronic illness also benefit, in terms of adjustment and well-being, from peer-based support programmes, including programmes that are school-based and disease-specific, as well as those that are community-based.⁵⁰ Emerging evidence exists for telemedicine and e-Health interventions in improving outcomes for adolescents with chronic medical and psychiatric conditions, including PTSD.⁵¹

Significant gaps in knowledge

Despite decades of research evaluating neurodevelopmental and psychosocial interventions for other medical populations, the safety, feasibility, acceptability, accessibility, efficacy, and effectiveness of these interventions for use in individuals with CHD are largely unknown. Adapting interventions from other populations will require an understanding of the unique characteristics and challenges inherent in CHD, and their relevance to the particular intervention considered. In addition, while continued surveillance and consultation are recommended for children with complex CHD, it is unclear how many are receiving early intervention following discharge and how this impacts long-term development.

Outside the hospital setting, and particularly among school-age children, adolescents, and young adults with CHD, we remain largely uninformed regarding the long-term effectiveness of neurocognitive interventions (e.g., Cogmed), as well as their potential impact on academic and social domains; the effectiveness of specific educational and peer mentorship interventions; the impact of health inequities and barriers that may prevent individuals and families from accessing interventions; how best to engage telemedicine and e-Health, social media, and other technology tools to broaden the reach of interventions beyond the clinic setting; and the short- and longer-range economic implications and cost-effectiveness of intervening to mitigate the host of risks associated with CHD.

Investigations needed

- (1) Investigate the safety and feasibility of individualised developmental care interventions delivered during a cardiac hospitalisation

Safety and feasibility studies of individualised developmental care interventions in the cardiac ICU are needed to adapt evidence-based programmes to the unique needs of infants with

CHD and their families. Smaller-scale quality improvement studies should lead to larger-scale, multi-centre, randomised controlled trials to assess child neurodevelopmental and physiologic outcomes in the newborn period, as well as in early infancy and over the course of the lifespan. Such research could potentially highlight the implications of early-life intervention on later markers of health and well-being, along with improved family outcomes, decreased parent stress, and reduced healthcare utilisation and economic burdens.

- (2) Examine best practices for promoting handling and moving of infants and young children during cardiac hospitalisation

Concept and safety/feasibility studies are necessary to examine safe practices for handling/moving infants in the inpatient acute cardiac care setting, providing skin-to-skin holding, and increasing parent involvement in care and handling. This should be followed thereafter by quality improvement projects geared at increasing parent/caregiver comfort regarding the full range of developmental care interventions while hospitalised. These endeavours would be strengthened by a team-based, interdisciplinary approach that includes collaborative partnerships among nursing, cardiology/cardiac surgery, physical therapy, occupational therapy, child life and music therapy, nutrition, speech/language pathology, and psychology.

- (3) Study short- and longer-range outcomes associated with individualised developmental care interventions in an acute cardiac inpatient setting

As mentioned, there are many positive outcomes associated with individualised developmental care intervention, including decreased length of hospitalisation and improved feeding, among children born preterm.^{19-21,35} In the case of infants with CHD, for which length of hospital stay is among the strongest risk factors for adverse outcomes,⁵²⁻⁵⁴ reduced length of hospital stay would lower hospital costs and reduce exposures to potentially noxious elements in the acute inpatient environment (e.g., plasticizers,⁵⁵ loud sounds, bright lights, inadequate protection of sleep, inadequate attention to parent mental health, separation from family, stress reduction, and the use of non-pharmacologic comfort interventions⁵⁶) that may contribute to worse outcomes for these children. Individualised developmental care interventions also advocate for staff support to reduce stress and burnout, which would positively affect the patient and family. Interventions to support growth and weight gain, use of human milk, early breastfeeding, and decreasing time to full oral feeding in patients with CHD⁵⁷⁻⁶¹ are of utmost importance as oral feeding ranks the greatest stressor for caregivers following cardiac surgery and often lengthens hospital stay.^{62,63} In addition, there is no current gold standard programme for infant feeding in cardiology, but this should be explored. Programmes that monitor development over time and provide intervention beyond infancy such as early intervention and early supports in the school system would likely reduce concerns seen in adolescence and adulthood.

- (4) Conduct translational research studying empirically supported psychosocial and neurocognitive interventions developed for other populations in individuals with CHD

Building on existing knowledge of interventions that work in other populations, translational studies are needed to effectively adapt interventions for use among children with CHD. Psychosocial interventions targeting anxiety, mood concerns, and the effectiveness of cognitive-behavioural therapy in addressing these issues will be

particularly important given their high prevalence among individuals with CHD. Efficacious interventions developed for individuals with other chronic illnesses, such as cancer and diabetes, that address comorbidities such as pain, adherence to medical regimens, family functioning, transition from paediatric to adult healthcare, and traumatic stress could be adapted to benefit individuals with CHD.⁶⁴ Neurocognitive interventions that address attention, executive function, and visual-spatial deficits are also necessary and should investigate a range of delivery modalities including computerised and in-person formats.

- (5) Investigate new modalities for delivering neurodevelopmental and psychosocial interventions within the CHD population

Concept, pilot, and quality improvement studies can explore new modalities of intervention delivery, followed thereafter by larger-scale, multi-centre implementation studies. For example, telemedicine for post-surgical developmental follow-up may promote earlier identification and treatment of neurodevelopmental and psychosocial issues.^{65,66} Randomised controlled trials of these interventions in hospital settings or via telemedicine⁶⁷ may establish effectiveness for patients with CHD, reach a larger population, and provide preventative intervention.

Critical question 2: What is the impact of neurodevelopmental and psychosocial interventions in individuals with CHD?

Existing knowledge

Preliminary interventions in infants with CHD show improvement in infant oral feeding,^{68,69} physiological regulation,⁷⁰ early cognitive development,⁷⁰ family functioning,⁷⁰ and reduced length of hospital stay following surgery.^{68,69} Moreover, findings from the Congenital Heart Disease Intervention Project, a series of controlled trials aimed at improving psychosocial and neurodevelopmental outcomes among young children with severe CHD, support the use of parent-oriented psychoeducation for improving infant mental, social, and emotional development at 6 months of age and gains in family functioning and fewer days of missed school among 4–6-year-old children.^{71–75} However, a similarly designed randomised controlled trial utilising both parent- and child-oriented psychoeducation reported only small, non-significant improvements in child psychosocial adjustment relative to standard care.⁷⁶ For children and adolescents with CHD, computerised interventions are being studied to examine their impact on executive function and social skills.⁷⁷ Aerobic exercise has been associated with self- or proxy-reported improvements in cognitive functioning, social outcomes, and health-related quality of life. Recommendations for reducing child anxiety related to invasive cardiac procedures⁷⁸ have been documented but not clinically tested. Single centre interventions including psychotropic medication,¹⁰ access to a psychologist in clinic,¹¹ mindfulness training,¹² and increased physical activity^{13–15} have demonstrated reduced symptoms of depression, anxiety, stress, and improved quality of life for adolescents and adults with CHD.

Significant gaps in knowledge

Most prior neurodevelopmental/psychosocial intervention studies are single-centred, cross-sectional, and have not made use of randomised controlled designs which remain the gold standard for clinical trials. Many of these investigations had limited statistical power to detect a meaningful effect, and outcome measurements

varied greatly between studies. Further, the efficacy of interventions in adolescence, to date, has been weak,¹³ and more trials are needed. Finally, many of these intervention studies exclude individuals with CHD with comorbidities such as genetic syndromes, which may substantially impact intervention design, administration, interpretation, and generalisability of findings.

Investigations needed

- (1) Operationalise clinically meaningful intervention outcomes across development

It is critical to carefully consider outcome measures based on the age and functional status of the child, and any behavioural and emotional constructions of relevance to the intervention. Initially, studies focused on global neurodevelopmental skills such as overall intelligence quotient scores, but as more has been learned about risk, outcomes are being tailored to aspects of neurodevelopment that are more often impaired among a CHD population such as executive function and visual-spatial processing. Standardised measurement protocols to assess neurodevelopmental outcomes, as well as key moderators of intervention efficacy and effectiveness (e.g., SES, language), must be identified and may include formal assessment, structured observational measures, caregiver-/self-report questionnaires, and measures of neurobiological change (i.e., structural or functional variations on neuroimaging). It is important to have consistency across sites to reduce bias that can come from single-centre reporting and promote generalisability of findings. The Cardiac Neurodevelopmental Outcome Collaborative has made recommendations^{4,5} for a standardised assessment battery from infancy through teen years, which will help to guide future intervention research when selecting outcome measures to assess the impact of interventions on the neurodevelopment of individuals with CHD.^{4,5} Large-scale, multi-centre studies, which will be feasible within the context of the Cardiac Neurodevelopmental Outcome Collaborative data registry, are necessary to allow for adequate clinical stratification and inclusion of potential comorbidities as well as more diverse sociodemographic variables.

- (2) Conduct prospective randomised controlled trials with longer-term follow-up to investigate efficacy and effectiveness beyond the snapshot of a pre-post intervention

Studies with sequential post-intervention visits, at predetermined time intervals, would provide evidence of cost-effectiveness and potential generalisation of treatment effects in the long term. The number and timing of follow-up should take the developmental period into account with more immediate follow-up during early development and longer-term follow-up of more complex neurodevelopmental skills into adolescence and beyond. Further, efficacy trials (does an intervention work in an ideal setting) should be developed with a mind to effectiveness (does an intervention work in a real-world setting and are they feasible given limitations such as cost).

- (3) Partner with key stakeholders to define “clinically meaningful” outcomes

Determining what constitutes a clinically meaningful change post-intervention involves more than statistical significance. Indeed, the threshold for clinically meaningful changes pre- versus post-intervention should be interpreted in light of both individual and population-based changes in CHD.⁷⁹ In all interventions

research, it will be important to enlist the input of patients, families, and other stakeholders to ensure an accurate understanding of the real-world relevance of selected outcome measures and to consider such an understanding alongside quantitative indicators of change (e.g., effect sizes quantification and use of reliable change index estimates, along with statistical significance). For instance, a 2-point standard score drop on a measure of externalising behaviour may be a statistically significant change but is unlikely to be a noticeable change in real-world behaviour.

Critical question 3: How are cardiac neurodevelopmental programmes currently utilised, in what ways do these coordinated programmes impact outcomes, and what are the best programme practices?

Existing knowledge

Early intervention programmes for high-risk populations, such as preterm and/or very low birth weight infants, are well-established and associated with improved neurodevelopmental⁸⁰ and psychosocial functioning⁸¹ and have demonstrated the positive impact of inpatient neurodevelopmental care^{82,83} and outpatient neurodevelopmental follow-up.⁸⁴ Networks of newborn follow-up programmes serve as data registries providing programme benchmarks, initiating multi-site quality improvement projects to improve the standard of care, and allow for the development of best practice guidelines.⁸⁵ Indeed, the importance of standardised follow-up programmes for former medically fragile neonates is so strongly recognised that it is a requirement for accreditation for graduate medical education in neonatal–perinatal medicine by the Accreditation Council for Graduate Medical Education.⁸⁶

The National Pediatric Cardiology Quality Improvement Collaborative⁸⁷ and the Cardiac Neurodevelopmental Outcome Collaborative have created data registries to track neurodevelopmental outcomes for children with CHD. The creation of data registries and benchmarking, especially when approached through the lens of quality improvement science, will inform the development, implementation, and dissemination of best practice guidelines. For other complex paediatric conditions including cancer⁸⁸ and cystic fibrosis,⁸⁹ the best practices of care have been driven by data derived from patient registries.

Significant gaps in knowledge

While much is known about the neurodevelopmental and psychosocial benefits of developmental follow-up programmes in neonatology, there are no published studies on the impact of participation in cardiac neurodevelopmental follow-up programmes. These programmes provide what are thought to be critical intervention supports and services, and yet empirical data are currently lacking.

Investigations needed

- (1) Conduct feasibility, acceptability, and accessibility studies to examine processes (e.g., screening, monitoring procedures) and components (e.g., types of services) that result in the most beneficial outcomes

Outcome measurements, standardised across programmes, should focus on assessing domains that are most clinically meaningful to individuals with CHD and their families (e.g., quality of life, successful transition to independence). Studies may also

include measurement of programme access, utilisation, cost-effectiveness, and socio-demographic variation as well as patient experience and pathways to care. Determining methods to reduce barriers to accessing cardiac neurodevelopmental programmes would boost attendance, a key aspect of universal protection/prevention screening and assessment programmes. It will be particularly important to examine the availability of trained personnel, time to appointment date or waitlist, physical space, cost, and insurance coverage.

- (2) Examine whether centres that have coordinated cardiac neurodevelopmental programmes actually have improved neurodevelopmental and psychosocial outcomes for individuals with CHD

Study designs should include pre-post programme implementation data collection and should compare outcomes across time points as well as between centres with and without cardiac neurodevelopmental programmes on variables such as percentage of children entering school with appropriate educational supports, patient/family satisfaction, quality of life, and performance on formal measures of neurodevelopmental and psychosocial functioning. Establishing model programmes as the standard of care across medical centres will require clear evidence of effectiveness for a variety of stakeholders, including patients and families, advocacy groups, hospital administration, and insurance carriers.

- (3) Develop efficient ways to screen individuals seen in cardiac neurodevelopmental programmes and tailor to different levels of intervention

Insofar as timely and appropriate identification and stratification of risk facilitate efficient access to limited assessment and treatment resources, it will be important to design and test procedures for screening individuals with CHD to ensure that resources are allocated appropriately. In line with screening models proposed by Kazak and colleagues,⁹⁰ for paediatric psychology, and Hardy et al.,⁹¹ for paediatric neuropsychology, large-scale, multi-site studies which evaluate the appropriateness of tiered screening procedures implemented within primary care/cardiology clinic settings would identify individuals most in need of neurodevelopmental and/or psychosocial support. As these models suggest, the majority of patients may succeed with only periodic surveillance and recommendations, while the minority will require more intensive interventions. Developing a way to screen patients into these tiered interventions should result in more efficient care and could result in resource savings.

Critical question 4: How do we foster the development of resilience in individuals with CHD?

Existing knowledge

The concept of resilience, defined as “a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma,”⁹² is perhaps best understood as a capacity that develops over time, rather than as an inherent personality trait.⁹³ Resilience, and other wellness-promoting concepts such as post-traumatic growth and grit, is positively associated with better health outcomes⁹⁴ and decreased stress responses⁹⁵ within the general population, and improved psychosocial functioning and self-management in individuals with chronic illness.^{96–98} For example, among young, highly stressed children in

foster care, therapeutic interventions have been shown to promote resilience by mitigating the effects of early adversity on hypothalamic-pituitary-adrenal axis activity and promoting the development of adaptive caregiver attachment relationships.⁹⁹ In addition, adolescents with greater knowledge of their own medical history and associated complications, higher resilience, and more positive family dynamics have been found to better adhere to health-promoting behaviours such as following exercise and nutrition recommendations and reporting more adaptive stress management strategies.¹⁰⁰ Resilience in individuals with CHD is also related to a lower level of depressive symptoms¹⁰¹ and is influenced by parenting factors such as emotional warmth, rejection, punishment, control, and overprotection in adolescence.¹⁰²

Other than a feasibility study¹⁰³ and some evidence to support the use of a group-based intervention to improve aspects of resilience in adolescents with CHD,⁴² studies examining resilience in individuals with CHD are limited. Numerous studies report that participation in disease-specific camp programmes positively influences perceived health, interpersonal relationships, and self-esteem,^{49,104-108} which are components of resilience, but resilience has not yet been specifically measured.

Significant gaps in knowledge

Literature on the experiences impacting resilience, interventions to bolster resilience, and measurement is limited in the CHD population. For both children and adolescents, there is evidence to suggest that exercise/physical activity interventions promote improved cardiovascular health and enhanced psychosocial functioning and quality of life in individuals with CHD,¹⁰⁹⁻¹¹² although findings are somewhat mixed¹¹³ and the impact of physical activity interventions on resilience remains to be examined. Even with more than 35 years of physical activity promotion and exercise training in patients with CHD,^{114,115} research into optimal training methods and resilience as an outcome of physical exercise programmes is lacking.

Investigations needed

- (1) Adopt a conceptual framework for designing and conducting resilience-promoting intervention studies that appropriately capture the nature and complexity of resilience

A model from the National Scientific Council on the Developing Child recommends that interventions designed to facilitate resilience should include 1) ways to improve the caregiver-child relationship, 2) methods for building self-efficacy and perceived control, 3) strengthening adaptive and self-regulatory functioning, and 4) incorporating faith, hope, and cultural traditions.⁹⁵ Moreover, resilience interventions should encompass the entire lifespan and should begin with monitoring, supporting, and promoting the development of adaptive coping strategies for the family, if possible, before the child with CHD is even born, as further discussed below.

- (2) Capitalise on early identification to begin bolstering caregiver/family resilience prior to delivery

At prenatal cardiac diagnosis, interventions designed to shape the communication provided to the family, with a particular focus on the developing parent-infant relationship, education regarding infant neurodevelopment, and maternal and paternal self-care would support family well-being. By focusing on optimisation

and resilience, the emphasis of the prenatal visit may shift to infant neuroprotection and promotion of optimistic parent perceptions of their child, potentially reducing parental stress during the pregnancy. This focus on family well-being before the child is born could result in improved long-term outcomes for the child with CHD.¹¹⁶

- (3) Recognise individual and family-based differences in perception and experience in living with CHD

The development of valid, CHD-specific tools to measure aspects of resilience will be important for assessing each child/family's unique experiences with CHD, including systemic and cultural factors, and family stress and available support. Adding measurement of resilience to a standardised battery could help to better understand how different experiences bolster resilience and identify targets for future intervention.

- (4) Identify interventions for promoting resilience during childhood and adolescence

Studies are needed to directly evaluate the potential benefit of physical activity interventions on resilience among individuals with CHD. Additionally, specifically measuring resilience as part of a CHD camp programme could help to better understand positive outcomes from this experience. Other potential interventions may include developing a mentoring programme for individuals with CHD or qualitative research with focus groups of adults with CHD to examine individual factors associated with resilience. Studies similar to those in adults with cancer, which utilise stress management to improve resilience,¹¹⁷ would likely benefit adults with CHD as well and should be investigated.

- (5) Include resilience as a primary outcome in CHD surgical trials

The effects of decreased stress⁹⁵ should be looked at with respect to surgical outcomes, in addition to ICU length of stay, post-operative complications, and other aspects of health and recovery. Furthermore, child, family, and cultural markers of resilience should be carefully examined in clinical and surgical trials as potential moderators of outcomes.

Critical question 5: How do we develop systematic and effective approaches to optimise developmental and medical transitions for individuals with CHD and their families?

Existing knowledge

The experience of living with CHD includes numerous transition points with possible vulnerability and potential for intervention. Some of the most salient transitions include: 1) acute inpatient care to stepdown unit care; 2) tube to oral feeding; 3) inpatient to outpatient settings; 4) surgical centre to local medical care; 5) early intervention to the school system; 6) childhood to adolescence; 7) adolescence to young adulthood; 8) paediatric to adult CHD care; and 9) for caregivers, from being primarily an observer of their child's medical care to being the primary provider of daily medical surveillance and care and eventually becoming less active participants as their child moves towards independence.

The parents of medically complex infants with CHD can experience high levels of stress, post-traumatic stress, anxiety, and depression,¹¹⁸ which may negatively impact their ability to parent in ways most supportive of the high-risk child. The need to access

services from multiple hospital and community systems makes communication and coordination among providers and caregivers critical. However, clear and understandable communication is often lacking.¹¹⁹ Discharge instructions, for example, often include difficult medical terminology and can be confusing for families. School systems that are unfamiliar with the needs of children with CHD are unlikely to provide appropriate supports and services, increasing the risk for academic underachievement and discouragement. School-liaison programmes, which serve as a bridge between clinic and school and are considered standard-of-care in paediatric cancer,¹²⁰ are effective in promoting access to services and associated with increased parent satisfaction and parent beliefs that their child is meeting his/her academic potential.^{121,122}

Specific to CHD, deficits in executive function, which are highly prevalent,^{123,124} are likely to become more problematic during the transition to adolescence, undermining the development of independence and adaptive skills that may further compromise the transition to adulthood. Indeed, 40%–60% of CHD patients experience a lapse in their care, particularly during the transition to adult medical care, and those who experience a lapse are three times more likely to require urgent cardiac intervention.^{125,126} Lack of knowledge, self-management, and self-advocacy skills have also been documented among heart transplant patients.¹²⁷ However, participation during adolescence in a nursing-led educational intervention designed to prepare transplant patients for transition to adult care resulted in better maintenance of medical follow-up and increased CHD knowledge and self-management skills,¹²⁸ so an initial transition intervention has shown some promise.

Significant gaps in knowledge

Intervention research aimed at promoting optimal adaptation across the full range of transitions inherent in CHD is limited, and existing research focuses almost exclusively on the transition from paediatric to adult care.¹²⁸ Interventions are still needed to aid parents in the transition from inpatient to outpatient care; to increase the effectiveness of patient/family CHD educational tools; and to support successful transitions from hospital to community-based CHD providers and schools. Moreover, among adolescents with CHD, it remains unclear how best to promote functional independence, adaptive skills, and self-awareness/knowledge of one's medical condition.

Addressing these critical questions should result in a more accurate understanding of the range of transitions inherent to CHD, which would in turn facilitate the generation of smoother and more standardised procedures and practice guidelines for promoting optimal development across times of transition. With enhanced communication and coordination across providers and settings, fewer patients would be missed or lost to follow-up, child and family support needs would be more readily identified and would trigger appropriate referrals and access to therapeutic services, and barriers to accessing services would be recognised and addressed to reduce healthcare inequities.

Investigations needed

- (1) Comprehensively characterise the full range of transitions inherent to living with CHD

Large-scale, population-based parent and/or self-report surveys with both qualitative and quantitative analytic techniques are needed to characterise the full range of transitions experienced

by individuals with CHD, as well as key challenges to adaptive/functional independence across the lifespan.

- (2) Utilise quality improvement science to improve strategies for assisting families in navigating CHD-specific challenges and transitions in the medical system

Quality improvement-oriented intervention studies are also indicated to evaluate and improve the effectiveness of strategies for preparing parents following prenatal CHD diagnosis. Additional interventions may include providing developmental summaries, modifying discharge information, and increasing the frequency of post-discharge follow-up and should deliberately consider how technology such as phone-based apps and teleconferencing may be used to support families following discharge.

Conclusions

Advancements in neurodevelopmental and psychosocial interventions for individuals with CHD have the potential to radically reshape prevailing paradigms related to patient care and expectations regarding short- and long-range outcomes from infancy to adulthood. The establishment of a coordinated cardiac neurodevelopmental programme data registry,² the use of standardised measurement of key neurodevelopmental and psychosocial outcomes across programmes, and administrative support for follow-up and data collection are critical. From the perspective of research and quality improvement science, results of well-designed intervention trials, including trials within a well-designed data registry,^{129,130} would directly inform practice guidelines and improve long-term outcomes for children and families managing CHD. Finally, to promote resilience and optimisation for all individuals with CHD, it is crucial for outcomes to be individualised, to avoid exclusion based on genetics and other medical comorbidities, to address cultural differences and values that may impact the development of resilience, and to include outreach efforts to study interventions for those less likely to participate. Improvements in neurodevelopment and parent support will, in turn, result in a healthier, happier, more independent, more productive, and generally more resilient population, requiring fewer federal and state governmental services and well-positioned to contribute to society to the fullest extent possible.

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Conflicts of interest. None

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