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CLINICAL RESEARCH ARTICLE

Practice variations for fetal and neonatal congenital heart disease within the Children's Hospitals Neonatal Consortium

Rachel L. Leon[1]✉, Philip T. Levy[2], June Hu[1], Sushmita G. Yallpragada[1], Shannon E. G. Hamrick[3], Molly K. Ball[4] and the CHNC Cardiac Focus Group*

BACKGROUND: Many aspects of care for fetuses and neonates with congenital heart disease (CHD) fall outside standard practice guidelines, leading to the potential for significant variation in clinical care for this vulnerable population.
METHODS: We conducted a cross-sectional survey of site sponsors of the Children's Hospitals Neonatal Consortium, a multicenter collaborative of 41 Level IV neonatal intensive care units to assess key areas of clinical practice variability for patients with fetal and neonatal CHD.
RESULTS: We received responses from 31 centers. Fetal consult services are shared by neonatology and pediatric cardiology at 70% of centers. Three centers (10%) routinely perform fetal magnetic resonance imaging (MRI) for women with pregnancies complicated by fetal CHD. Genetic testing for CHD patients is routine at 76% of centers. Preoperative brain MRI is standard practice at 5 centers (17%), while cerebral NIRS monitoring is regularly used at 14 centers (48%). Use of electroencephalogram (EEG) after major cardiac surgery is routine in 5 centers (17%). Neurodevelopmental follow-up programs are offered at 30 centers (97%).
CONCLUSIONS: Many aspects of fetal and neonatal CHD care are highly variable with evolving shared multidisciplinary models.

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IMPACT:

- Many aspects of fetal and neonatal CHD care are highly variable.
- Genetic testing, placental examination, preoperative neuroimaging, and postoperative EEG monitoring carry a high yield of finding abnormalities in patients with CHD and these tests may contribute to more precise prognostication and improve care.
- Evidence-based standards for prenatal and postnatal CHD care may decrease inter-center variability.

INTRODUCTION

Congenital heart disease (CHD) is the most common birth defect affecting approximately 1% of liveborn infants.[1,2] The care of patients diagnosed with CHD and their families requires complex multidisciplinary coordination starting at prenatal diagnosis and extending throughout the neonatal period into pediatric care and beyond (Fig. 1). Many aspects of CHD care fall outside standard practice guidelines leading to the potential for significant variation in practice.

Prenatal diagnosis of CHD has become increasingly common in the past decade and clear standards exist regarding recommended cardiac views for both screening ultrasound[3] as well as diagnostic fetal echocardiography.[4] No clear recommendations or consensus exist regarding other aspects of fetal CHD care. For example, fetal magnetic resonance imaging (MRI) for surveillance of extracardiac anomalies lacks clear recommendations from the American College of Obstetricians and Gynecologists (ACOG) and the joint statement from the American College of Radiology and Society of Pediatric Radiology. Furthermore, the role of neonatologists and other services in prenatal consultations remain nebulous despite potential benefit to families grappling with the well-described psychological stress of a fetal CHD diagnosis.[5–8]

Beyond the surgical interventions and medical management, postnatal CHD care has numerous potential areas of variation in practice as well. Care often occurs at multiple hospitals due to transfer after birth, and with variable primary providers across cardiac intensive care units (CICUs), neonatal intensive care units (NICUs), or both.[9] Following birth, clear recommendations exist regarding pathologic examination of the placenta,[10] but access to the expertise required for interpretation may not exist in some centers. The impact of CHD on long-term neurodevelopment is well chronicled, but there is not widespread agreement regarding appropriate modality and timing of neurological imaging or monitoring. Neuromonitoring using cerebral near-infrared spectroscopy (NIRS) is an evolving technology[11] and potential source of variation with limited clinical data in pediatric CHD patients outside of surgery. Electroencephalography (EEG) for the detection of seizures in postoperative care of neonates who undergo

[1]Department of Pediatrics, University of Texas Southwestern Medical Center, Dallas, TX, USA. [2]Boston Children's Hospital, Harvard Medical School, Harvard University, Boston, MA, USA. [3]Department of Pediatrics, Emory University and Children's Healthcare of Atlanta, Atlanta, GA, USA. [4]Department of Pediatrics, The Ohio State University College of Medicine, Columbus, OH, USA. *A list of authors and their affiliations appears at the end of the paper. ✉email: Rachel.Leon@UTSouthwestern.edu

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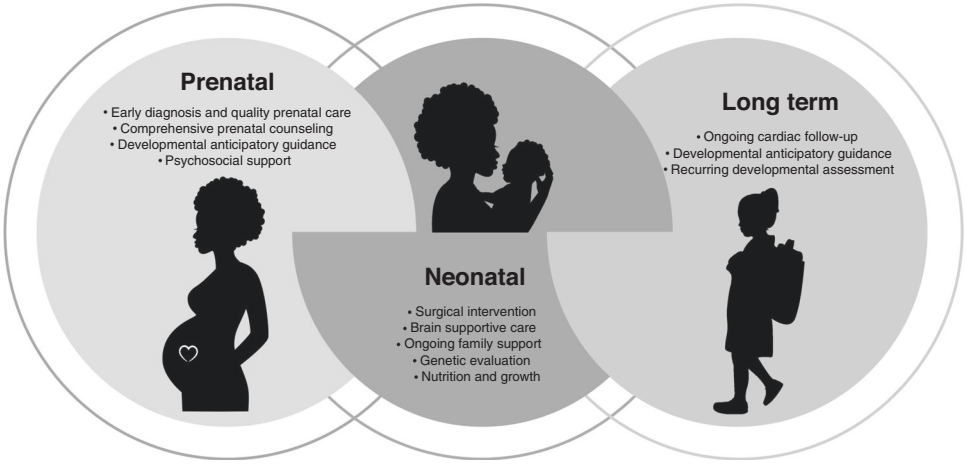

Fig. 1 Optimizing care for patients with congenital heart disease (CHD) from prenatal diagnosis to neonatal care and beyond. Patients diagnosed with moderate and severe CHD and their families require complex multidisciplinary care during pregnancy, throughout their neonatal course, and long term.

cardiopulmonary bypass has also been recommended,[12] but it remains unclear whether this practice is routinely employed across children's hospitals or hospital units. After discharge, expert recommendations support neurodevelopmental services for all neonates with operative CHD,[13] but who receives access to these services at each center is unknown.

Our group has previously investigated the evolving cardiac care models for neonates and the role of neonatologists in the immediate postnatal period.[9] We have not yet explored variability in practice during fetal stages or long-term follow-up care. Accordingly, we sought to determine current variation in practice for specific aspects of prenatal and neonatal CHD care within a network of large quaternary care children's hospitals in North America with high-volume neonatal cardiac surgery programs.

METHODS

Data source

The Children's Hospitals Neonatal Consortium (CHNC) is a multicenter collaborative of 41 Level IV NICUs in children's hospitals in the United States and Canada dedicated to developing quality and research initiatives across participating institutions. All participating NICUs have at least 400 admissions annually or greater than 25 NICU beds, and a patient population that is >50% outborn. The CHNC was established in 2006 and prospective data collection in the Children's Hospitals Neonatal Database (CHND) began in 2010. This data is used to study clinical outcomes and resource utilization of a unique population of medically complex neonates and infants (https://thechnc.org). The Institutional Review Board at each participating institution approved participation in CHND and associated research studies. Additionally, this survey study was approved by the Institutional Review Board at University of Texas Southwestern Medical Center.

Study design

We conducted a cross-sectional survey of CHNC member hospitals targeting key aspects of fetal and neonatal CHD care lacking well-accepted practice standards. The survey questions were developed by the investigators, who are members of the CHNC Cardiac Focus Group, and reviewed by the remainder of the Cardiac Focus Group to ensure clarity. This was a descriptive study design with no attempt to correlate our results with outcome measures.

Survey development

We utilized the secure REDCap platform for survey development and data collection.[14,15] The goal of the survey was to determine variations across centers in specific tests, interventions, and counseling for fetuses and neonates diagnosed with moderate or severe CHD requiring postnatal hospital admission and surgical intervention. Questions elicited information regarding center-specific approaches to prenatal counseling, fetal cardiac interventions, frequency of fetal MRI and cerebral artery Doppler ultrasound, gestational age and typical mode of delivery, placental pathologic examination and genetic testing practices, use of cerebral NIRS, timing and type of neonatal brain imaging, use of postoperative EEG monitoring, and practices regarding neurodevelopmental follow-up care. Finally, perceptions regarding variability of care for fetuses with CHD were assessed. Separately, perception of practice variability in neonatal CHD care was queried. Many questions offered free text fields to allow more descriptive explanation. The final survey contained 25 questions (Supplemental Table 1).

Survey distribution

The survey was distributed to CHNC site sponsors by email via the organizational listserv in April 2021. The email contained a link to the online survey and responses were anonymously collected in REDCap. Site sponsors could designate an appropriate faculty member to complete the survey. Two reminder emails were sent until closure of data collection in September 2021.

Statistical analysis

We conducted data analysis using descriptive statistics. Descriptive data are presented as median with interquartile ranges (IQRs). Categorical data are presented as proportions of survey respondents or percentages. Statistical analysis was performed using IBM Statistics (SPSS v. 24) software.

RESULTS

Center characteristics

A total of 31 centers out of 41 member hospitals in the CHNC provided responses to the survey (76% response rate). Of the 31 centers that provided responses, prenatal counseling and postnatal cardiac interventions are offered at 29 (94%). A summary of results is provided in Table 1.

Prenatal counseling

Nineteen of the cardiac centers (66%) report >15 years' experience offering care for pregnancies complicated by fetal CHD, and 20 centers have both cardiology and neonatology prenatal services housed within the same fetal care program. An additional four centers plan to unite these service lines in their fetal care program. Joint counseling by pediatric cardiology and neonatology at the same prenatal visit is routine at nine centers (31%). Seven centers (24%) provide counseling from only pediatric cardiologists. The remaining 13 centers (45%) report that prenatal counseling is performed by both pediatric cardiology and neonatology, but most often at separate clinical encounters. Of the 22 centers

where neonatologists provide prenatal counseling, the median number of consultations annually is 50 (IQR 20, 80). When asked about ancillary services offered to families with a fetal CHD diagnosis, 25 centers (86%) have nurse coordinators and 20 centers (69%) have social workers. Fewer centers routinely offer assistance from financial navigators (11, 38%), psychologists (10, 34%), and palliative care providers (2, 7%).

Prenatal testing and interventions

Regarding prenatal imaging beyond fetal echocardiography, Doppler ultrasound to assess cerebral blood flow in fetuses with CHD is performed in 16 centers (55%) with 10 centers (34%) unsure whether this was routine practice. Fetal MRI is performed for nearly all fetuses requiring fetal or neonatal intervention in just three centers (10%) and is rarely used at 10 centers (34%). More than half of centers (18, 62%) obtain fetal MRI for specific indications, some of which include screening for pulmonary lymphangiectasia, further characterization of extracardiac anomalies identified by ultrasound, and additional surveillance for extracardiac anomalies in fetuses with single-ventricle anatomy. Fetal cardiac interventions are offered in 7 centers (24%) responding to the survey. Specifically, balloon dilation for aortic stenosis is offered in all seven of those centers, maternal hyperoxygenation in three centers, and atrial septostomy in five. Multidisciplinary discussions about fetal CHD patients are held at least monthly in 28 centers surveyed (90%). Genetic testing is routine practice at most centers (23, 79%) with 20 of those reporting chromosomal microarray as the preferred genetic test for all moderate or severe CHD patients. Two centers (7%) routinely use genetic testing other than microarray and seven centers (24%) target genetic testing to patients with dysmorphic features or multiple risk factors. Amniotic fluid or cord blood are preferred for genetic testing in 10 centers (34%), while neonatal blood is used in the remaining two-thirds.

Table 1. Frequency of select clinical practices.

Clinical practice area ($n = 29$)	Frequency number of centers (%)		
	Rarely	Sometimes	Routinely
Prenatal counseling with neonatologist	0 (0)	20 (69)	9 (31)
Fetal MRI	10 (34)	16 (55)	3 (10)
Placental pathologic examination	5 (17)	7 (24)	15 (52)
Genetic testing	0 (0)	7 (24)	22 (76)
Preoperative brain MRI	10 (34)	14 (48)	5 (17)
Cerebral oximetry with NIRS	5 (17)	10 (34)	14 (48)
Postoperative EEG monitoring	0 (0)	24 (83)	5 (17)
Neurodevelopmental follow-up	1 (3)	3 (10)	25 (86)

MRI magnetic resonance imaging, *NIRS* near-infrared spectroscopy, *EEG* electroencephalogram.

Postnatal practices

Following delivery, placentas are commonly submitted for pathologic examination at half of centers (15, 52%) surveyed. The remaining centers do not routinely send placentas to pathology as part of clinical care unless there are additional fetal or maternal indications, or as part of a research protocol. Postnatal cerebral NIRS monitoring is routinely used across hospital units in 48% of responding centers while an additional 10 centers utilize cerebral NIRS in the CICU, but not in the NICU; cerebral NIRS is rarely used at just five centers (Fig. 2a). No details on timing of cerebral NIRS monitoring in relation to cardiac operative care were included in the survey. Regarding postnatal brain imaging, the majority of centers do not perform routine preoperative brain MRI (Fig. 2b), and at those centers who do (5, 17%), it is most commonly reserved for patients who will require cardiopulmonary bypass during their surgical intervention. Following cardiac surgery, only five centers (17%) routinely use EEG monitoring across hospital units and two additional centers use postoperative

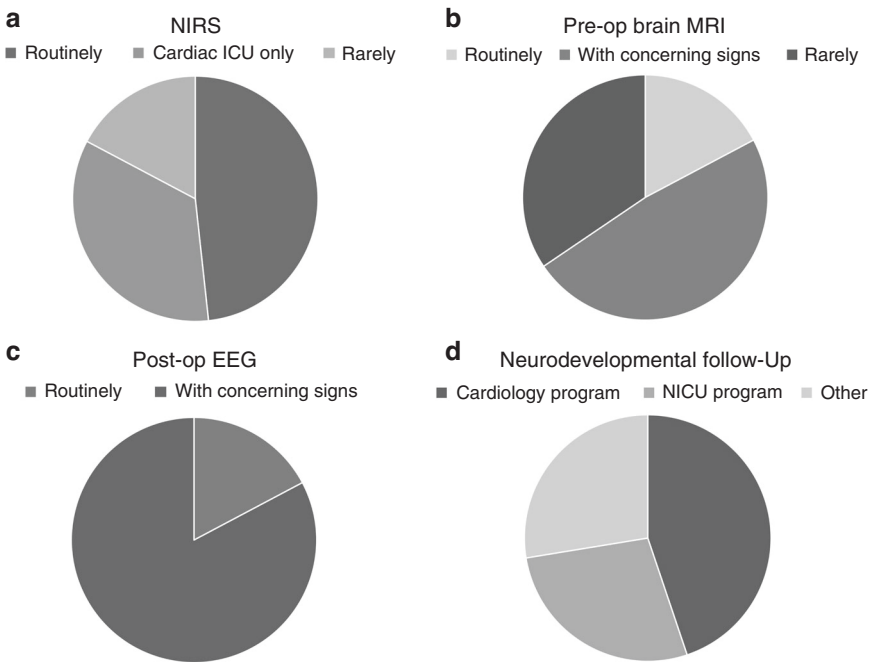

Fig. 2 Postnatal neuromonitoring. Neonatal care practices involving (**a**) near-infrared spectroscopy (NIRS), (**b**) preoperative brain magnetic resonance imaging (MRI), (**c**) postoperative electroencephalogram (EEG), and (**d**) neurodevelopmental follow-up vary significantly between hospital centers.

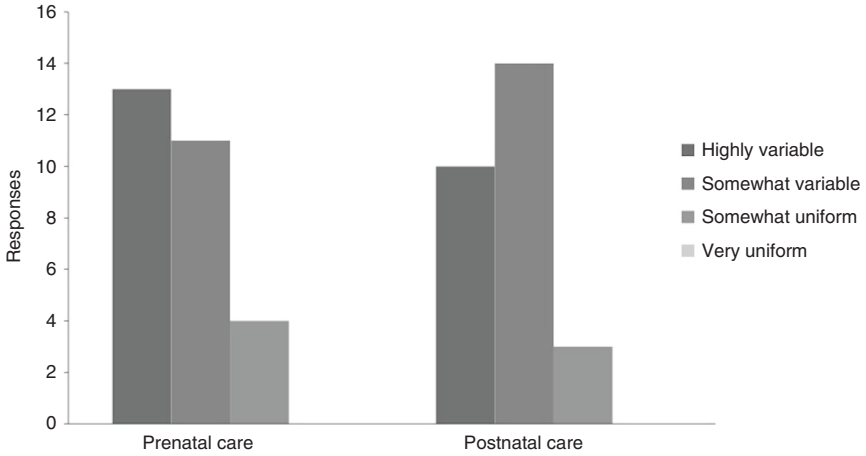

Fig. 3 Perceived variability of prenatal and postnatal congenital heart disease (CHD) care. Responses from neonatologists at 31 centers within the Children's Hospitals Neonatal Consortium demonstrate a high rate of perceived variability in both prenatal and neonatal care of patients with CHD. No respondents reported a perception of "Very uniform" care for either fetal or neonatal CHD.

EEG for neonates in the CICU, but not the NICU. Most respondents (22, 76%) reported that postoperative EEG is employed only if clinical concern for seizure arises (Fig. 2c).

Neurodevelopmental follow-up care

After hospital discharge, neurodevelopmental follow-up care is provided in nearly all centers that perform cardiac intervention (97%). One center does not routinely provide follow-up at this time and one center has neurodevelopmental follow-up only for patients with hypoplastic left heart syndrome. Fifteen centers (52%) have neurodevelopmental follow-up embedded within their pediatric cardiology program (Fig. 2d). In three centers (10%) neurodevelopmental follow-up is provided by specialty hospital-based or complex care programs. Neurodevelopmental follow-up care is offered through a neonatology program at eight centers (28%) with an additional three centers (10%) dividing this care between pediatric cardiology programs (single-ventricle patients) and neonatology programs (other types of CHD). Type of neurodevelopmental evaluation was known by respondents from 18 centers, with five reporting that the Bayley Scales of Infant Development is used at one time point, 10 reporting Bayley testing is performed at multiple time points, and the remainder reporting that Ages and Stages Questionnaires are utilized. Respondents were unsure about the type of neurodevelopmental evaluation used at 11 centers (38%).

Perception of practice variability

The final survey questions sought to gauge perceived variability in practice between centers for fetuses and neonates with CHD (Fig. 3). Fourteen respondents (45%) ranked clinical practice for fetuses with CHD across centers as "highly variable," while 4 respondents (14%) considered fetal CHD care to be "somewhat uniform." Neonatal CHD practice variability was rated as "highly variably" by 11 respondents (35%), and "somewhat variable" by 15 respondents (48%). Zero respondents considered fetal or neonatal CHD care to be "very uniform" between centers.

DISCUSSION

This survey study builds upon prior work from this group describing the evolving landscape of clinical care for neonates with CHD including current models for preoperative and post-operative care delivery as well as the evolving role of the neonatologist as a consultant within the multidisciplinary care team.[9] In this current study, we utilize our unique access to the CHNC member hospitals to assess variations in clinical care for fetuses and neonates diagnosed with moderate or severe CHD, with specific focus on areas without well accepted practice guidelines. Our main finding is that significant variations in clinical practice exist between centers as it pertains to prenatal counseling, fetal imaging, postnatal neuromonitoring, as well as post-discharge developmental follow-up. These results affirm that variability in practice still exists in the care of fetal and neonatal patients with CHD and reveals specific areas where creation of best-practice guidelines may be helpful.

For families with a fetal CHD diagnosis, one-third of centers have joint service lines for pediatric cardiology and neonatology prenatal counseling, which allows centralization of information and pooling of resources. Yet, most centers still require patients to attend two separate appointments for prenatal counseling by a cardiologist and a neonatologist, or do not routinely provide prenatal neonatology consultation. We would propose that the benefits of collaborative multidisciplinary care involving neonatologists contributes to more comprehensive prenatal consultation and better coordination of care for families affected by CHD. The value of neonatologists in fetal consultation has been demonstrated in other populations.[16] Specific topics that are uniquely suited to neonatologists include delivery room management, initial central line placement, respiratory management, initial neurodevelopmental care, feeding and nutrition, neonatal morbidities, and hospital and unit transfer procedures. Additionally, parents want to know when they can see, touch, or hold their infant after delivery, and about breastfeeding and other sources of nutrition—domains that neonatologists are well-equipped to address comprehensively. The reduced access to neonatology prenatal counseling at many CHNC sites represents a potential area for further investigation regarding optimization of prenatal counseling services and topics to meet diverse family needs.

Similarly, access to specific key ancillary services during or after prenatal diagnosis has been shown to improve coping and anxiety.[17] The psychological distress related to a fetal CHD diagnosis is well known[18,19] as there are adverse effects of maternal stress on pregnancy outcomes.[20–23] Importantly, recent studies focused on the fetal CHD population have described an association of maternal stress with impaired fetal brain growth.[8] Together, this information supports a potential benefit of targeted support services for all families dealing with a fetal CHD diagnosis, particularly psychologists who are best equipped to identify and address parental psychological distress, anxiety, depression, and/or grief.[24,25] In addition, perinatal palliative care services play a vital role for caregivers faced with a potentially uncorrectable or exceptionally high-risk fetal CHD diagnosis;[26] some clinicians

argue they can improve shared decision-making, communication, and coping for all families with fetal CHD diagnoses.[27] While 90% of centers report utilizing a nurse coordinator, less than half offer assistance from a financial navigator or psychologist. Re-envisioning comprehensive counseling represents one significant opportunity that can further improve care for families affected by a fetal diagnosis of CHD.

The role of prenatal MRI for fetuses with CHD is rapidly evolving, and practice guidelines are not clear or unified among the various organizations. ACOG uses vague language regarding indications for fetal MRI,[28] but the American College of Radiology includes in their practice parameters an indication for fetal MRI to determine presence of pulmonary lymphangiectasia (primary or secondary to fetal CHD).[29] Particularly for fetuses diagnosed with hypoplastic left heart syndrome, pulmonary lymphangiectasia may be an important predictor of survival[30] and may impact parental decision-making. While our results suggest that current use of fetal MRI remains limited to select centers, thoughtful expansion of this non-invasive imaging modality in an identified high-risk patient population may represent an important opportunity to improve prognostication and counseling.

Regarding delivery practices, this question was eliminated from our analysis due to ambiguity in the multiple choice options and the free text answers that were provided by some centers. Results from other studies report induction of labor at 39 weeks in approximately half of women with prenatally diagnosed fetal CHD.[31] In our survey, no center endorsed late-preterm delivery (between 34 and 36 weeks gestation), but many studies have demonstrated that prenatally diagnosed fetuses with CHD are at-risk of premature or earlier term delivery.[32–35] This earlier delivery is not likely related to a higher incidence of comorbidities in these pregnancies because prenatally diagnosed patients deliver earlier even when compared to those diagnosed postnatally.[31,36] This is a metric that warrants ongoing local surveillance and further investigation since higher rates of adverse outcomes are reported in neonates with CHD born at late preterm and early term gestation.[37] Prior work in this area shows that targeted quality improvement efforts, such as that described by Afshar et al., can improve adherence to clinical best-practice recommendations.[38]

The placenta was commonly sent for pathologic examination in only half of centers surveyed. This is in contrast to recommendations from the American College of Pathologists which recommends placental pathologic examination in all pregnancies with one or more fetal anomalies.[10] Placental pathology can provide important clues about the etiology of adverse pregnancy outcomes,[39] management of future pregnancies,[40] risk stratification for neurodevelopmental outcomes,[41–43] and medical–legal risk assessment.[44] Furthermore, in our own experiences and those reported by other investigators,[45,46] the fetal CHD placenta has high rates of malperfusion lesions as well as chronic inflammation. Best-practice recommendations support placental pathologic examination for all pregnancies complicated by fetal CHD, thus expanding this practice to all high-risk delivery centers should be fostered.

For postnatal care of neonates with CHD, we found significant variation across CHNC centers in genetic testing practices, preoperative brain MRI, use of cerebral NIRS neuromonitoring, and post-discharge neurodevelopmental follow-up care. Genetic testing identifies pathologic variants in up to 30% of neonates with CHD;[47] yet, a lack of clear best-practice testing recommendations leads to high regional variability in their utilization, as demonstrated in our results where one-fourth of centers do not routinely send genetic testing for CHD patients prenatally or during postnatal hospitalization. Our study did not query whether these neonates receive outpatient genetic testing. Multiple studies show the clinical importance of genetic information to guide decision-making and anticipatory management, to understand recurrence risk and support reproductive decisions of parents (and ultimately the child), and to discern risk stratification for adverse outcomes.[47–50] Together, these facts support the need for additional guidance from national organizations on the application, type, and timing of genetic testing for patients with CHD.

Preoperative brain imaging also has a high yield for finding abnormalities in preoperative neonates with CHD.[51] Most common lesions include foci of ischemia, white matter volume loss, and immature sulcation pattern.[52–56] Although these findings should not be used to determine surgical candidacy, they provide important indicators of potential neurodevelopmental issues and may warrant repeat imaging to assess evolution of the lesions after cardiac surgery.[57] Cerebral NIRS monitoring has become commonplace in most CICUs across North America, but the impact of this neuromonitoring tool has not been proven and warrants further study and evidence-based guidance on its use for neonates with CHD.[11] In contrast, EEG is recommended after neonatal cardiac surgery by the American Clinical Neurophysiology Society[12] due to the high rate of seizures postoperatively, the majority of which are subclinical.[58] Despite this recommendation, only one-fourth of centers responding to the survey follow this practice. Ultimately, further research to correlate brain monitoring and neuroimaging with short- and long-term neurodevelopmental outcomes will be important to guide best practices.

Neurodevelopmental follow-up is another area of high practice variability with centers housing these services within pediatric cardiology, neonatology, complex care, or a mixture of these specialties. Two programs offer neurodevelopmental follow-up only to those with the most severe cardiac lesions or other qualifying conditions, despite clear evidence that all neonates with operative CHD are at risk of neurodevelopmental delays and impairments.[13] Nevertheless, all centers except one currently have neurodevelopmental follow-up programs demonstrating the success of recent campaigns to increase awareness and direct resources toward the long-term neurodevelopmental challenges facing CHD survivors. These existing programs may benefit from more standardized, multidisciplinary care approaches to guide neuroimaging practices, types and frequency of neurodevelopmental assessments, and duration of follow-up.

Finally, there is high perceived variability in fetal and neonatal CHD care from survey respondents. This is not surprising given that most survey questions were targeted to areas of fetal and neonatal CHD care without well-accepted best-practice guidelines. However, the variability in clinical practices for these vulnerable patients warrants further exploration. This study has specific key limitations such as the small sample size of centers, and that responses that were unverified due to anonymity of the survey and lack of access to center-specific data. In addition, despite a recommendation in the survey invitation to consult with colleagues to determine appropriate responses, our survey provides primarily the neonatologist perspective, and therefore is not able to capture all details of each unique program in a multiple-choice survey format. Furthermore, there may be selection bias inherent within the member centers of the CHNC or those centers that provided answers to our survey as well as response bias in some questions where one choice is clearly favored as the best or most accepted practice. The underlying reasons for practice variability between institutions were also not explored here and would be a useful next step to further characterize the key areas of practice variability. Despite these limitations, this survey provides novel data from an elite group of large Children's hospitals within the U.S. and Canada and elucidates specific areas where fetal and neonatal CHD care may benefit from establishing or refining best-practice recommendations (Table 2).

CONCLUSION

CHD requires multidisciplinary care from prenatal diagnosis to adulthood to meet the complex and multifocal needs of patients

Table 2. Areas of high variability in need of further study and best-practice guidelines.

Fetal CHD care	Neonatal CHD care
1. Prenatal counseling by neonatologists in addition to fetal cardiologists 2. Access to mental health services focusing on stress management, grief, and coping 3. Early involvement of perinatal palliative care services 4. Indications for fetal MRI 5. Discussion of risk for neurodevelopmental delays and impairments	1. Ongoing surveillance of local practices regarding timing and mode of delivery 2. Routine pathologic examination of placenta 3. Genetic testing 4. Timing and type of brain imaging 5. Use and response to NIRS neuromonitoring 6. Use of postoperative EEG monitoring 7. Outpatient neurodevelopmental follow-up for all patients with moderate or severe CHD

and their families. Across CHNC centers, many aspects of fetal and neonatal CHD care are highly variable. Neonatology input in prenatal counseling is lacking or disjointed in many centers. Genetic testing, placental examination, preoperative neuroimaging, and postoperative EEG monitoring all carry a high yield of finding abnormalities in patients with CHD, and evidence is mounting that these tests may contribute to more precise prognostication and improve care. Moving forward, additional research is needed to better understand the influence of perinatal factors on CHD outcomes, as well as the role of neonatal neuromonitoring, imaging, and neurodevelopmental testing in patients with CHD. As a next step, development of evidence-based standards for prenatal and postnatal CHD care will decrease inter-center variability and may facilitate improved outcomes for children and families affected by CHD.

DATA AVAILABILITY

All data generated or analyzed during this study are included in this published article and its Supplementary Information file.

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AUTHOR CONTRIBUTIONS

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Correspondence and requests for materials should be addressed to Rachel L. Leon.

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THE CHNC CARDIAC FOCUS GROUP

Kevin Sullivan[5], Victor McKay[6], Jamie Limjoco[7], Karna Murthy[8], Gustave Falciglia[8], Robert Lyle[9], Becky Rogers[9], Cherie Welch[10], Anthony Piazza[11], Priscilla Joe[12], Anne Hansen[13], Theresa Grover[14], Carl Coghill[15], Toby Yanowitz[16], Rashmin Savani[17], Eugenia Pallotto[18], Billie Short[19], An Massaro[19], Gregory Sysyn[20], Rachel Chapman[21], Girija Natarajan[22], Lynne Willett[23], Nicole Birge[23], Michael Uhing[24], Ankur Datta[24], Michel Mikhael[25], Beth Haberman[26], Annmarie Golioto[27], Annie Chi[28], Yvette Johnson[28], Rajan Wadhawan[29], Kyong-Soon Lee[30], Ajay Talati[31], Kristina Reber[32], Con Yee Ling[33], Mark Speziale[34], Laurel Moyer[34], William Engle[35], Elizabeth Jacobsen-Misbe[36], Robert DiGeronimo[36], Suzanne Touch[37], Rakesh Rao[38], Beverly Brozanski[38], Gautham Suresh[39], Michael Padula[40] and David Munson[40]

[5]AI DuPont Hospital for Children, Wilmington, DE, USA. [6]All Children's Hospital, St, Petersburg, FL, USA. [7]American Family Children's Hospital, Madison, WI, USA. [8]Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. [9]Arkansas Children's Hospital, Little Rock, AR, USA. [10]Brenner Children's Hospital, Winston Salem, NC, USA. [11]Children's Healthcare of Atlanta, Atlanta, GA, USA. [12]Children's Hospital & Research Center Oakland, Oakland, CA, USA. [13]Children's Hospital Boston, Boston, MA, USA. [14]Children's Hospital Colorado, Aurora, CO, USA. [15]Children's Hospital of Alabama, Birmingham, AL, USA. [16]Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA, USA. [17]Children's Medical Center, Dallas, TX, USA. [18]Children's Mercy Hospitals & Clinics, Kansas City, MO, USA. [19]Children's National Medical Center, Washington, DC, USA. [20]Children's Healthcare of Atlanta at Scottish Rite, Atlanta, GA, USA. [21]Children's Hospital Los Angeles, Los Angeles, CA, USA. [22]Children's Hospital of Michigan, Detroit, MI, USA. [23]Children's Hospital of Omaha,

Omaha, NE, USA. [24]Children's Hospital of Wisconsin, Milwaukee, WI, USA. [25]Children's Hospital Orange County, Los Angeles, CA, USA. [26]Cincinnati Children's Hospital, Cincinnati, OH, USA. [27]Connecticut Children's Hospital, Hartford, CT, USA. [28]Cook Children's Health Care System, Fort Worth, TX, USA. [29]Florida Hospital for Children, Orlando, FL, USA. [30]Hospital for Sick Children, Toronto, ON, Canada. [31]Le Bonheur Children's Hospital, Memphis, TN, USA. [32]Nationwide Children's Hospital, Columbus, OH, USA. [33]Primary Children's Medical Center, Salt Lake City, UT, USA. [34]Rady Children's Hospital, San Diego, CA, USA. [35]Riley Children's Hospital, Indianapolis, IN, USA. [36]Seattle Children's Hospital, Seattle, WA, USA. [37]St. Christopher's Hospital for Children, Philadelphia, PA, USA. [38]St. Louis Children's Hospital, St Louis, MO, USA. [39]Texas Children's Hospital, Houston, TX, USA. [40]The Children's Hospital of Philadelphia, Philadelphia, PA, USA.