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Exercise and Activity Recommendations in Children After Cardiac Surgery: Current Practice Survey

Jesse M. Boyett Anderson, MD, MS; Megan A. Moreno, MD, MSEd, MPH; John S. Hokanson, MD

Introduction

Approximately 7,000 babies with a critical Congenital Heart Defect, requiring surgery or other procedure during their first year of life, are born each year in the United States.[1,2] Following cardiac surgery, these patients are typically placed on post-operative activity restrictions and many are given life-long activity restrictions.

There is scant evidence regarding activity restriction following any pediatric surgery, and none regarding restrictions after cardiac surgery.[3] Current guidelines for children who have had cardiac surgery are extrapolated from adult guidelines, which, themselves are based on limited evidence and are not standardized.[4,5] Both the *American Heart Association/American College of Cardiology (AHA/ACC)* and the *European Association of Cardiovascular Prevention and Rehabilitation (EACPR)/European Congenital Heart and Lung Exercise Group (ECHLEG)/ Association for European Paediatric Cardiology (AEPC)* have developed guidelines for ongoing participation in sports and other physical activities for older children and young adults with Congenital Heart Disease.[6-8] These recommendations are based on expert opinion and the American guidelines are tailored to the adolescent and young adult competitive athlete, offering no guidance for other types of activity or for children under the age of 12 years.

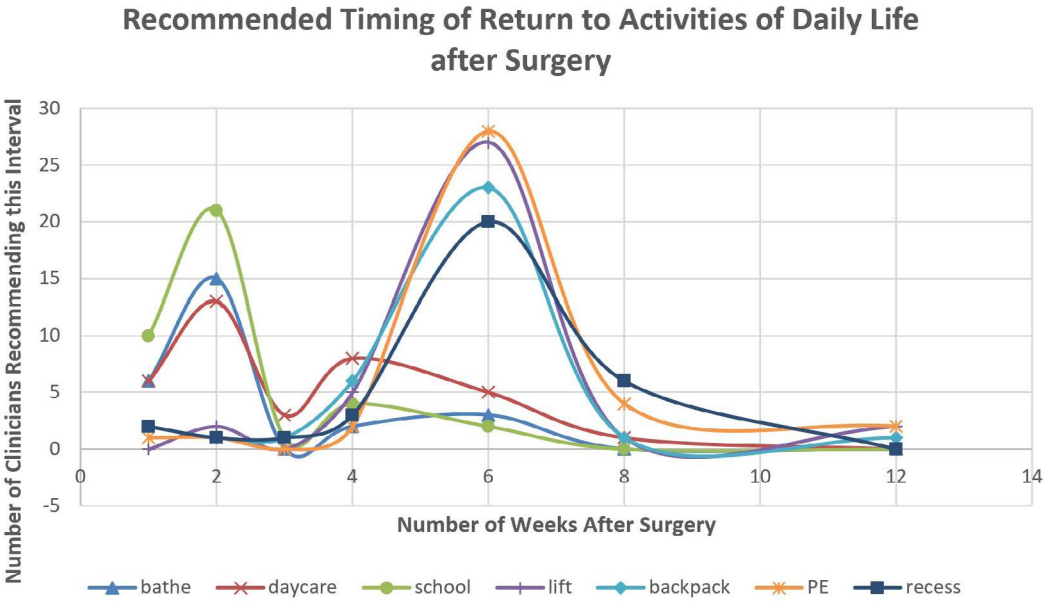

FIGURE 1 *Clinician recommendations regarding optimal interval after cardiac surgery for return to activities of daily living. Lift = lift under arms.*

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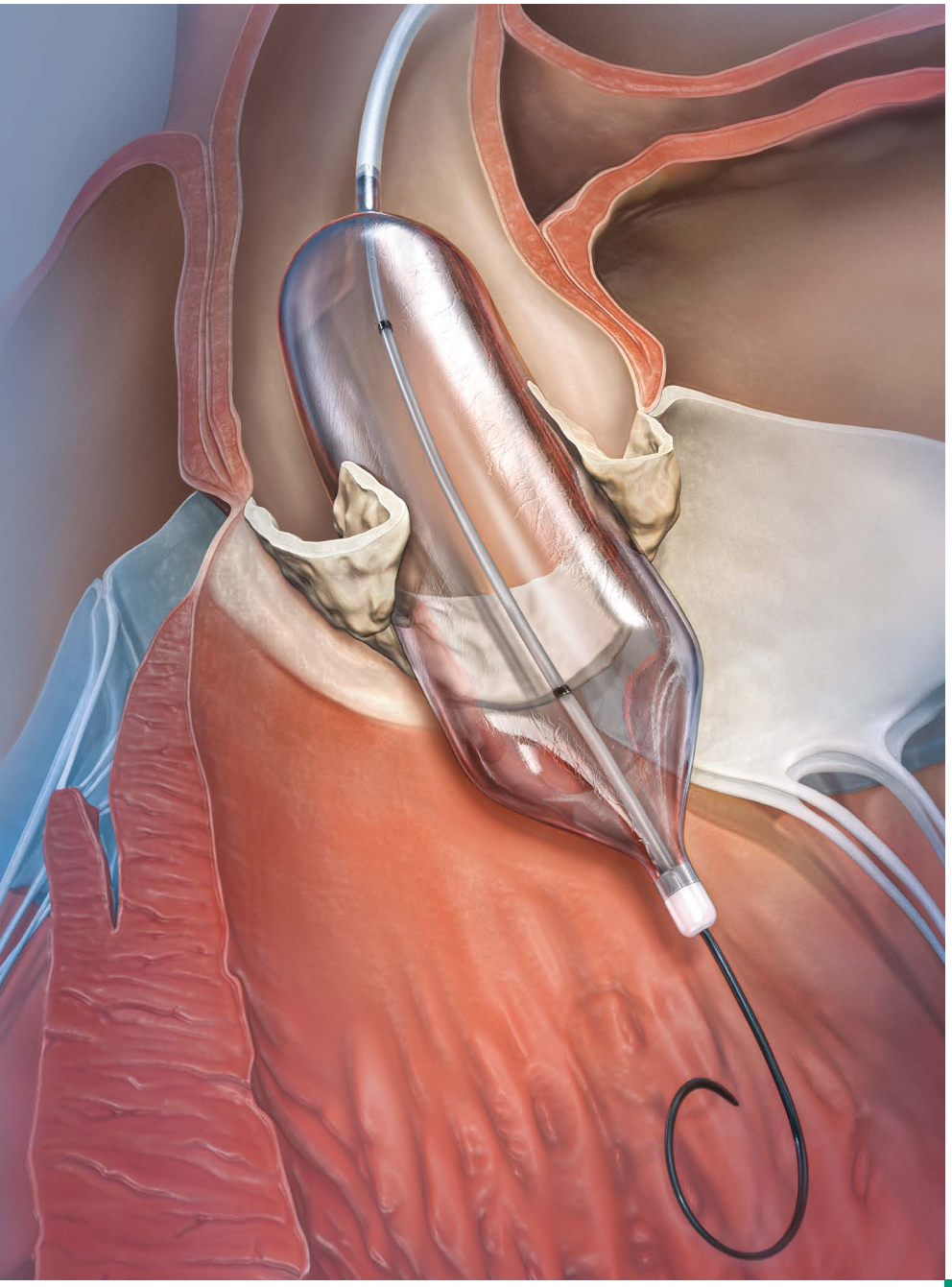

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Although exercise and activity restrictions are recommended in the hopes of decreasing postoperative complications and injury or negative health outcomes, the potential adverse effects of these restrictions are not always considered. Mounting evidence demonstrates the benefit of regular physical activity on physical health, mental health, longevity, academic performance, social adjustment, and quality of life for everyone.[9-12] Patterns of physical activity established during childhood often carry over into adult life, the association between physical activity and physical health increases across the lifespan,[13] and early patterns of physical activity impact cognitive functioning during adulthood.[14] Activity restrictions in the immediate post-surgical period and in the long term may limit the early acquisition of healthy activity habits in children who have surgery for Congenital Heart Disease.

There are unique benefits that accrue to patients with Congenital Heart Disease (CHD) who participate in regular physical activity. Adolescents and young adults with CHD who participate in competitive sports (including those restricted by current guidelines) experience marked physical and emotional health benefits, including increased quality of life and exercise capacity.[15] Improved childhood exercise capacity in patients following the Fontan procedure is correlated with better adult prognosis.[16] Additionally, while children who undergo cardiac surgery have a higher risk of poor neurocognitive outcomes, including impaired executive function,[17-19] a recent meta-analysis shows that long-term physical activity can help improve executive function.[20]

With advances in the care of children with Congenital Heart Disease, the focus of care has extended beyond survival to include optimization of quality of life for the child and their family. Traditional guidelines designed to minimize postoperative complications may not adequately account for their impact on families in the short term and of the impact on patients over their lifespan.

We created our survey specifically to address activity recommendations for children under 12 years of age as these represent the majority of patients undergoing their first cardiac surgery for Congenital Heart Disease and for whom no published recommendations exist.

Methods

This cross-sectional survey study was conducted between March and April 2018. The survey was reviewed by the Executive Committee of the *Midwest Pediatric Cardiology Society* and this study received an exemption from the University of Wisconsin Health Sciences Institutional Review Board.

Study Population and Recruitment

We invited the 477 members of the *Midwest Pediatric Cardiology Society (MWPCS)* to participate in a web-based survey of their immediate and long-term activity recommendations for children under 12 years of age after pediatric heart surgery. Membership of the *MWPCS* includes: cardiologists, cardiac surgeons, nurses, medical staff, and trainees. Study eligibility included *MWPCS* membership, active email address, and self-reported engagement in discussions regarding activity recommendations and restrictions for children less than 12 years old with a history of surgery for a congenital heart defect.

Survey Development

The survey was developed in Qualtrics using an iterative design process, starting with known post-operative and long-term activity recommendations at our home institution and the guidelines referred to in making these recommendations. The *AHA* guidelines for competitive activity in adolescents and young adults were used as a starting point for describing types of activity in which children might participate and were modified to include more age-appropriate activities for our younger age cohort based on activities in which parents have asked about their child's participation. Vignettes were developed to reflect six prototypical patients. Vignettes have a long history of providing insight into people's response to various situations and have been shown to be more effective than chart abstraction in modeling clinician practice as measured by standardized patients.[21,22] All survey questions were reviewed by two members of the Division of Pediatric Cardiology and their feedback was incorporated into a beta version of the survey which was pilot tested by members of our division. Additional revisions for question clarity and to allow for a full range of possible responses were made based on feedback from these beta testers.

Survey Questions

Demographic information: Participants were asked to indicate their professional training, medical or surgical specialty, and years of practice.

TABLE 1

Activities of Daily Living Restricted after Cardiac Surgery

Bathing
Lift the child under the arms
Return to daycare
Return to school
Wear a backpack
Participate in physical education class
Participate in unsupervised recess
Completion of all restrictions

NOTE *Cardiovascular providers were asked to indicate the number of weeks they recommended patients to wait after cardiac surgery prior to resuming each activity.*

TABLE 2

Factors Considered in Formulating Long-Term Activity Recommendations

Resources	Patient-Related Factors
Published Guidelines	Health-related factors
36th Bethesda Guidelines	Patient hemodynamics
2015 *AHA/ACC* Guidelines	Patient symptoms
2012 *EACPR* Guidelines	Testing
2012 *ECHLEG* Guidelines	6-minute walk test
2012 *APEC* Guidelines	ECG exercise test
Institutional Guidelines	Stress test with VO2
Colleague or expert opinion	Stress echocardiogram
Personal judgment	Non-health related factors
	Social benefits
	Long-term health benefits
	Quality of life
	Family or patient preference
	Long-term viability of sport
	Perceived parental over-protectiveness
	Parent/patient ability to understand and adhere to guidelines

NOTE *Cardiovascular care providers indicated whether each factor impacted their recommendations, "not at all," or to a "minimal," "moderate," or "significant" degree.*

Immediate post-operative recommendations: Participants were asked to type in the number of weeks they recommend patients wait prior to re-engaging in a series of age appropriate activities (**Table 1**) and how the age of the patient influences those recommendations. They could also indicate that they do not make any recommendations for a particular activity.

Long-term activity recommendations: Participants were asked to rate how heavily they weighted existing resources, health-related patient factors, and non-health related patient factors in making exercise recommendations to their post-surgical patients using a series of Likert scale questions (**Table 2**). Participants who indicated they used published guidelines or exercise testing in formulating their recommendations were asked which resources or testing they used in a multiple-choice format.

Vignettes: All participants were asked to read a series of six vignettes, each describing an eight-year-old child with a different surgically-repaired cardiac defect or no known cardiac defect, and indicate how they would counsel the family regarding the child's participation in 12 different categories of physical activity to maximize health (**Table 3**). The sequence of scenarios and activity choices were randomized within each participant's survey. Responses were given in Likert format ranging from "Avoid at all costs" to "Encourage participation."

Study Procedures

In March of 2018 a standardized survey was sent to all members. Members who did not respond to the initial mailing were sent a reminder email two weeks later.

Analysis

Immediate post-operative recommendations: Histograms were created reflecting the distribution of activity restriction duration for each activity and means and standard deviations were calculated. Percentage of respondents who varied their advice depending on the age of the patient was calculated.

Long-term activity recommendations: Participant's Likert responses to questions regarding resources used in making activity recommendations and weight given to both health and non-health related patient factors were collapsed into two categories (more important: moderate or significant weight; less important: minimal, not at all). Percent of participants who felt each factor was important was calculated.

TABLE 3

Physical Activities Clinicians Were Asked to Recommend or Restrict

Type of Activity	Examples of this Activity Type
Unstructured play	rough and tumble play, tree climbing, sword fighting
Unsupervised recess	swings, kickball, pickup football, slides, play structures
Physical education class	
Supervised lessons	swimming, tennis, dance
Recreational activities with limited collisions	ice skating, horseback riding, bicycling
Recreational activities with risk of collision	trampoline, downhill skiing
Competitive sports with limited collisions	soccer, basketball, tennis, softball
Competitive sports with risk of collision	football, hockey, wrestling
Motor sports	ATV, motorcycle, water skiing
Amusement park activities	roller coaster, water slide, bounce house
Isometric sports	wrestling, weight lifting, gymnastics
Aerobic sports	running, swimming

NOTE *Clinicians were asked to recommend or discourage each of the following types of activity for a series of six children, each with a different cardiovascular lesion or no lesion at all.*

Participant's Likert response to questions regarding types of activities encouraged in patients with various surgical histories was also collapsed into two categories (encourage participation: "encourage" and "benefits outweigh the risks"; avoid: "not the best idea" and "avoid at all costs"). Percentage of clinicians encouraging each type of activity for each clinical scenario was then calculated. Graphs were created allowing for a qualitative comparison of exercise recommendations in various clinical scenarios.

Results

Demographics: Response rate from the initial invitation of *MWPCS* members was 9.4% (45/477 invitees) with an overwhelming majority being male physicians (**Table 4**).

Immediate post-operative recommendations: Most providers indicated they recommend a waiting period prior to resuming bathing, lifting a child under the arms, wearing a backpack, returning to daycare or school, participating in physical education classes, participating in unsupervised recess or resuming all pre-surgical activities. While there was some variability in the timing of each of these milestones, more than 80% of all providers who gave recommendations indicated that all post-surgical restrictions would be complete by six weeks after surgery. Recommendations on when to return to school or daycare were more variable. While 75% of providers recommended a return to school at one to two weeks following surgery, providers were split on care for younger children, with just over 30% recommending a return to daycare at two weeks, another 22% recommending waiting until four weeks after surgery, and another 16% giving no recommendation at all. Complete data for the recommended timing of return to these and other activities of daily living can be found in **Figure 1.**

Long-term activity recommendations: Clinicians indicated that, when formulating activity recommendations, they place most weight on their personal judgment (92% of clinicians give moderate or significant weight to this factor), patient symptoms (95%), hemodynamics (100%), and considerations of patient quality of life (97%) as well as to the long-term health (93%) and social (90%) benefits of exercise. Full data on factors influencing recommendations can be found in **Table 5.**

Certain types of activities were considered appropriate for all children. More than 90% of clinicians recommended aerobic sports, gym class, supervised lessons or recreational activities with limited collisions to patients regardless of diagnosis. Motor sports, on the other hand, were recommended by fewer than 30% of clinicians to individuals with any diagnosis.

Clinicians recommended the widest range of activities for children with no cardiac diagnosis and Tetralogy of Fallot with good hemodynamic repair and no known arrhythmias. Greater than 90% of clinicians recommended 10 categories of activity for children with no known defect; only motor sports and competitive sports with risk of collision did not meet this threshold. For children with repaired Tetralogy of Fallot, recreational sports with risk of collision also fell below the 90% recommendation rate.

TABLE 4
Demographics

Characteristics	Percent	Average	SD	Number Total
Degree				
MD/DO	89%			40/45
NP/PA	9%			4/45
Other	2%			1/45
Specialty				
Non-Interventional Cardiology	82%			37/45
Interventional Cardiology	7%			3/45
Surgery	7%			3/45
PICU	2%			1/45
Multiple specialties	2%			1/45
Years in practice		12.818	10.6	
Gender				
Male	69%			31/45
Female	31%			14/45
High school or college sports (yes)	67%			30/45
Hours of exercise per week		3.4	2.4	

The narrowest range of activities was recommended for children with a mechanical aortic valve anticoagulated on Coumadin, a repaired VSD with surgical heart block and epicardial pacemaker, and with a single ventricle after Fontan. Full data can be found in **Table 6**.

Discussion

While there are some areas of consensus regarding both post-surgical and long-term activity recommendations in young children after cardiac surgery, there is also substantial variation. In formulating activity recommendations for children under the age of twelve, clinicians consider multiple factors; however, guidelines and evidence to inform these recommendations are lacking. Despite overall variability, there is some agreement regarding which activities are safe to resume two weeks (daycare attendance, school attendance, and bathing) and six weeks after surgery (lifting under the arms, participation in physical education, unsupervised recess, and wearing a backpack). In the long term, children with single ventricle physiology, pacemakers, and systemic anticoagulation are recommended to limit their long-term activity level the most frequently and to the greatest extent.

TABLE 5
Weight Given to Factors Used to Formulate Activity Recommendations

Factor	Percent	Number/ Total Responses
Personal Judgment	92%	39/42
Published Guidelines	76%	32/42
2005 Bethesda	39%	14/36
2015 *AHA/ACC*	75%	27/36
EACPR	8%	3/36
ECHLEG	8%	3/36
AEPC	8%	3/36
Colleague/Expert Opinion	73%	30/41
Institutional Guidelines	67%	28/42
Hemodynamics	100%	41/41
Symptoms	95%	39/41
Testing	59%	24/41
ECG exercise test	51%	19/37
Stress test with VO2 max	46%	17/37
Stress echo	11%	4/37
6-minute walk	5%	2/37
Quality of Life	98%	40/41
Long-term Health Benefits	93%	38/41
Social Benefits	90%	37/41
Patient and Parent Preferences	83%	37/41
Long-term Viability of Sport	83%	37/41
Ability to Understand and Adhere	63%	26/41
Parental Over-protectiveness	46%	19/41
Exposure to Litigation	20%	8/40

NOTE *Clinicians giving moderate or significant weight to a factor reported as a percent of those responding to the question. For specific published guidelines and testing, clinicians using a particular resource or test are reported as a percentage of those using any published guidelines or testing.*

Currently, pediatric cardiovascular providers, general pediatricians, and other individuals caring for young patients who have had cardiac surgery have limited data and guidelines to shape their recommendations regarding physical activity. This has led to issuing inconsistent recommendations to patients and their families, and may inadvertently contribute to the disproportionate burden of physical and neurocognitive deficits in this population. This survey of active providers offers insight into current practices, from which more consistent guidelines can be designed.

Study Limitations

While multi-institutional, this study had a small geographic catchment area and a low response rate. Both of these limitations constrain the degree to which these findings can be generalized across the United States and beyond. It is unclear whether those providers who responded to this survey differ in any substantial way from those providers who did not respond. It is also unclear whether the recommendations offered by providers in the Midwest will differ in any significant way from those offered by providers in other parts of the United States or in other countries. There will certainly be some activities about which providers in the Midwest will be asked, such as snowmobiling, that may be less prevalent in other geographic regions. For these reasons, we recommend the collection of additional data from providers in other geographic regions as part of the process of developing a more robust set of recommendations regarding return to full (or partial) activity after cardiac surgery in young children.

Acknowledgments

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	Type of Cardiac Defect					
Type of Activity	No Heart Defect	Repaired Coarctation	Repaired Tetralogy	Single Ventricle Fontan	Epicardial Pacemaker	Coumadin
aerobic sports	100	100	100	100	100	100
gym class	100	100	100	100	100	100
supervised lessons	100	100	100	100	100	100
recreational activities with limited collisions	100	100	96	96	91	92
competitive sports with limited collisions	100	100	100	96	96	58
unsupervised recess	100	100	100	92	82	80
unstructured play	96	95	96	88	73	50
amusement park activities	96	96	92	71	65	60
recreational activities with risk of collision	92	79	92	63	59	20
isometric Sports	96	63	80	33	64	44
competitive sports with risk of collision	76	58	60	29	4	0
motor sports	26	23	22	18	4	0

TABLE 6

Percent of Clinicians Encouraging Various Types of Activity

NOTE *Percent of clinicians encouraging specific activities[1] in otherwise healthy 8-year-olds with various cardiac defects.[2] For ease of interpretation, "safe" activities recommended by 90-100% of clinicians were coded green; "questionable" activities recommended by ≤50% of clinicians were coded red; all other activities were considered "controversial" and coded yellow.*

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JESSE M. BOYETT ANDERSON, MD, MS

Corresponding Author
Pediatrics Resident, PGY-2
Department of Pediatrics
University of Wisconsin Hospitals and Clinics
600 Highland Ave.
Madison, WI, USA
608.262.8785
jboyettanderson@uwhealth.org

MEGAN A. MORENO, MD, MSED, MPH

Professor of Pediatrics
Division Chief of General Pediatrics and Adolescent Medicine Vice Chair of Digital Health
University of Wisconsin School of Medicine and Public Health
Madison, WI, USA

JOHN S. HOKANSON, MD

Professor of Pediatrics
Division of Pediatric Cardiology
University of Wisconsin School of Medicine and Public Health
Madison, WI, USA

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Pediatric Interventional Cardiology Coding Work Group Part Two: The Pre-Procedure Segment in a RUC Assessment of Total Procedural Time

Sergio Bartakian, MD, FSCAI, FAAP; Sarosh P. Batlivala, MD, MSCI; Gurumurthy Hiremath, MD, FACC, FSCAI; Mark H. Hoyer, MD, FSCAI; Frank F. Ing, MD, FACC, MSCAI

Abbreviations
AMA - American Medical Association
CCCHD - Cardiac Catheterization for Congenital Heart Disease
CMS - Centers for Medicare and Medicaid Services
CPT® - Current Procedural Terminology
NCCI - National Correct Coding Initiative
PICCW - Pediatric Interventional Cardiology Coding Work Group
RUC - Relative value scale Update Committee
RVU - Relative Value Units
SCAI - Society of Cardiovascular Angiography and Interventions

This is the second article in a series from the Pediatric Interventional Cardiology Coding Workgroup (PICCW) designed to educate providers on coding/billing practices for Cardiac Catheterization for Congenital Heart Disease (CCCHD), as well as to update the community regarding ongoing projects. Importantly, the reader must understand these topics cover only one component of reimbursement, the physician work Relative Value Units (RVUs). The other two components of the RVU system, practice expense RVU and professional liability RVU, are beyond the scope of this work.[1]

As mentioned last month, once a code application is accepted by the Current Procedural Terminology (CPT®) Panel, a Relative Value Scale Update Committee (RUC) survey is distributed to stakeholder society members via email. The aim of the survey is to gather data on the time and intensity required to perform the proposed work. In the survey, respondents are initially provided a list of existing CPT® codes, from which they are to pick the one that most closely resembles the new code with respect to time, complexity, and intensity. This comparison code is referred to as the Key Reference Service (KRS). Respondents are then asked a series of questions comparing the proposed procedure to that of the KRS. Whereas any questions regarding the technical skill or mental intensity required are purely subjective, time allocation is a very objective means of comparison. The survey will direct respondents to be very precise with respect to how much time they allocate to each segment, and to not simply round off times.

In order for the physician work RVU for procedures to be accurately and fairly presented to Centers for Medicare and Medicaid Services (CMS), it is imperative that survey recipients take the time to carefully and thoughtfully complete them. In order to do so, the respondent must have an understanding about what is included in the different segments of physician work. The physician work captured by each CPT® code is broken down into three segments: the pre-procedure, intra-procedure, and post-procedure times. This month, we discuss the first element of the RUC assessment of total procedural time, specifically pre-procedure work.

The pre- and post-procedure times can best be understood by first delineating the intra-procedure time. Simply stated, intra-procedure time is essentially the meat of the procedure, described historically as the "skin-to-skin" time. Therefore, pre-procedure entails work performed leading up to the intra-procedure, and post-procedure being the work following the intra-procedure.

The pre-procedure time is designed to capture any time required of the provider for a given procedure, before the actual start of the procedure. For most typical catheterization labs in Children's Hospitals, the pre-procedure work can further be broken into three categories:

1. Work performed in consultation for a procedure referral
   a) Time spent discussing a case with a referring provider.
   b) Time spent evaluating chart/EMR including other provider notes, prior results such as chest x-rays (CXR), electrocardiogram (EKG), labs, echocardiograms, computed tomography (CT), mitral regurgitation (MR), etc. With increasing complexity of patients, in the current era, this may even include evaluation and planning with 3D printed/virtual models of the heart.
   c) Time spent confirming all potential components required for the procedure are available, plus contingencies and backups.

2. Work performed typically on the day of the procedure with the family/patient
   a) Time spent performing and documenting a complete and/or interval history and physical exam.
   b) Time spent providing a description of the procedure and expected results to the parents/caregivers of the patient, a description of potential hazards and signature of informed consent for the procedure.
   c) Time spent acquainting the patient or parents with the catheterization laboratory.
   d) Time spent supervising the administration of anxiolysis, when necessary.

3. Work performed in the immediate preparation prior to starting the procedure
   a) Time spent conducting final procedural coordination with technicians, nurses, and the anesthesiology team (aka "pre-cath huddle").
   b) Time spent setting up a sterile table with all necessary sheaths and catheters, syringes, bowl with sterile heparinized flush, contrast, and any other necessary sterile equipment.
   c) Time spent connecting sterile tubing to flush system and pressure transducers and ensure the hemodynamic recording system is properly zeroed.
   d) Time spent positioning the patient.
   e) Time spent prepping, scrubbing, draping and waiting.
   f) Time spent donning surgical scrubs and lead.

There are typically two main aspects providers fail to recognize in estimating time for pre-procedure work. First, any work done in preparation for the case, either the day before or the day of the case, is considered pre-procedure work. This includes, for example, the items listed in **1) a, b, and c** above. Second, providers often fail to account for time spent on certain tasks by subordinates for which the physician is responsible. This may include a fellow or advanced practitioner performing the interval H&P and obtaining informed consent. It is not merely the work the provider performs him/herself, but also work done by surrogates for whom the physician provides oversight and needs to be factored in.

Failure to place appropriate priority and attention to completing the surveys has been an ongoing problem. It is imperative for as many providers to respond to these surveys in order to capture the great variability in practice across the country. As an example, bear in mind, of the roughly 150 centers providing congenital cardiac catheterization services across the United States, only 62 have a Pediatric Cardiology fellowship program.[2] This contributes greatly to the variability in available resources, staff, and fellows

from institution to institution. No single provider should assume the work they perform is the same as everyone else. In fact, the only way to ensure your work is captured and represented in the valuation is to fill out the survey.

1	Straightforward Patient	Straightforward Procedure	No anesthesia care
2	Difficult Patient	Straightforward Procedure	No anesthesia care
3	Straightforward Patient	Difficult Procedure	General anesthesia
4	Difficult Patient	Difficult Procedure	General anesthesia

TABLE 1 *Pre-procedure packages for facility setting*[5]

Additionally, there are inherent problems with the survey process, which place our community at an even greater disadvantage in receiving appropriate valuation. Currently, the RUC has four pre-procedure service packages for those performed in the hospital setting (**Table 1**). The first two levels are for patients undergoing conscious sedation, and two more for those under general anesthesia. The total time associated with these levels ranges between 19 to 63 minutes. Since the standard for the majority of CCCHD procedures is for use of general anesthesia, all of the codes developed for our specialty will fall into one of the latter two packages. Although the concept seems straightforward, it is far from so for our specialty. These packages were derived on the basis of the far greater number of procedures performed in the adult patient population. There are no pediatric-specific packages designed to capture the increased time requirements of working in a children's hospital setting with limited resources. Additionally, none of these packages allow for sufficient time for pre-procedure evaluation of the complex prior studies that have become the norm in our field. In fact, the most complex level for a difficult patient having a difficult procedure under general anesthesia allows only 15 minutes for evaluation of prior studies and results. This same 15 minutes is also supposed to cover performance of a history and physical exam. Consider how much time you actually spend in reviewing outside imaging on a referral for possible transcatheter pulmonary valve implant. How about the amount of time you spend at the bedside evaluating a newborn with Transposition of the Great Arteries, while trying to decide if a septostomy is needed or not? This latter scenario often requires up to an hour of direct emergent bedside evaluation in making the determination to proceed with the cardiac catheterization. The inpatient consultation evaluation and management (E/M) billing would normally capture this work. However, because our specialty does not have a distinct specialty taxonomy code, as Non-congenital/Adult Interventional Cardiologists do, we are unable to submit E/M billing. CMS does not allow for more than one clinician in the same specialty to submit for E/M services on the same date of service. For Pediatric Cardiology, our general Pediatric Cardiology colleagues performing the admission consult report the E/M, even though their consult does not specifically capture the work we perform in our evaluation. This is, however, a topic for another day.

All of these issues highlight the importance of providers educating themselves on the RUC survey and then taking the appropriate time to thoughtfully and carefully complete an accurate survey. A detailed video and PowerPoint describing the RUC survey and how to correctly fill one out is available from the American Medical Association (AMA)[3,4] and should be reviewed by everyone prior to each survey until they are completely comfortable with the process.

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SERGIO BARTAKIAN, MD, FSCAI, FAAP

Children's Hospital of Michigan
AMA CPT Advisor for SCAI
dctrbar@gmail.com

SAROSH P. BATLIVALA, MD, MSCI

Associate Professor, Pediatric Cardiology
University of Cincinnati College of Medicine
Cincinnati Children's Hospital Medical Center

GURUMURTHY HIREMATH, MD, FACC, FSCAI

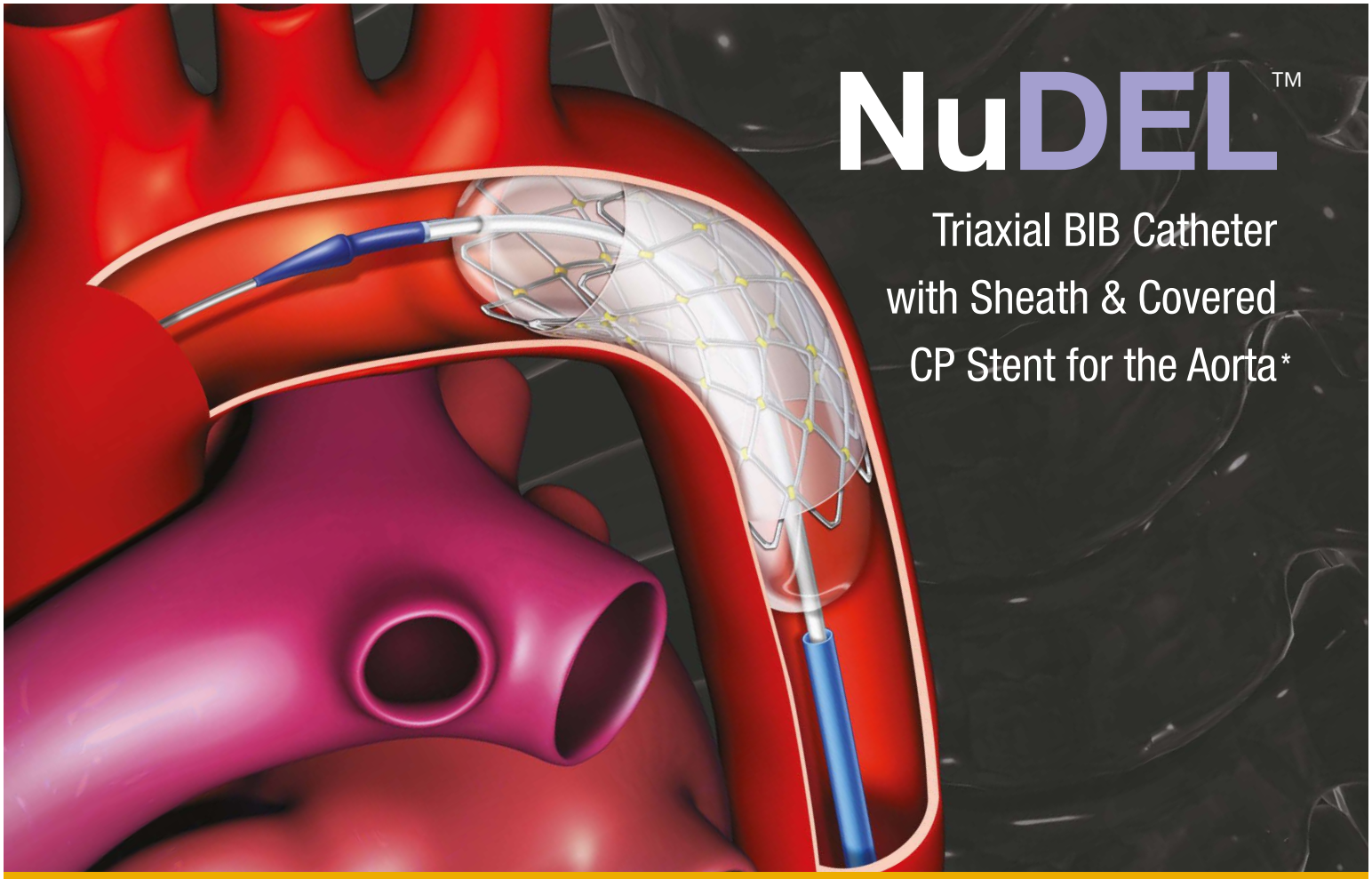
Pediatric Cardiologist and Director,
Congenital Cardiac Catheterization
Research VP, Pediatric Interventional
Cardiology Early Career Society
University of Minnesota Masonic Children's Hospital

MARK H. HOYER, MD, FSCAI

Professor of Clinical Pediatrics and Medicine
Director, Pediatric and Congenital Interventional Cardiology
Riley Hospital for Children
Indiana University School of Medicine

FRANK F. ING, MD, FACC, MSCAI

Professor of Pediatrics
UC Davis School of Medicine
Chief, Pediatric Cardiology
Co-director, Pediatric Heart Center
UC Davis Children's Hospital



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Sudden Cardiac Death in the Young in Ohio: The Postmortem Investigation: An Educational Symposium Sponsored by Akron Children's Hospital and the Cleveland Clinic

Ira B. Taub, MD, FACC, FAAP

The sudden death of a young person is a twofold tragedy, with the unheralded loss of a young life compounded by uncertainty about its cause. Families must manage both their own grief and concern for the well-being of other loved ones. Anxiety often spreads to the community and can trigger a cascade of diagnostic testing that is expensive and of questionable clinical value. On February 7, 2020, Akron Children's Hospital hosted a symposium for professionals who are involved in the difficult process of investigating sudden cardiac death in the young. Co-sponsored by Cleveland Clinic Children's, the event targeted physicians on the front lines of the process as well as allied professionals who interact with bereaved families.

The day began with a Grand Rounds talk given by Barbara Sampson, MD, PhD, Chief Medical Examiner of the City of New York. Dr. Sampson's office, tasked with investigating deaths in a city of over 8 million people, operates the largest DNA laboratory in the nation. She has developed a protocol that allows for meticulous gross, microscopic and genetic testing of all decedents in whom a cardiac cause of death is suspected. Where a genetic abnormality is identified, appropriate follow-up with genetics and cardiology is arranged for all family members. This has allowed for the identification and treatment of clinically silent but potentially dangerous conditions in many family members. Variants of uncertain significance and novel mutations can be investigated as part of an ongoing research effort.

Keynote speaker Barbara Sampson, MD, PhD, Chief Medical Examiner of the City of New York

Dr. Sampson explains NYC's molecular autopsy protocol to the audience

For the first plenary session, "When A Child Dies," the audience heard powerful accounts from two mothers whose own children were the victims of sudden cardiac death. Stephanie Kornet shared the story of her 17-year-old son, Alec, who died after collapsing during a high school hockey practice. Christa Poole's, LISW-S, son, Devin, a senior at Kent State University, collapsed and died suddenly during a pickup basketball game. In both cases, the initial shock of the loss was compounded by a lengthy process beset by communication difficulties and unanticipated financial and insurance barriers.

The next session focused on the "Victim, Family and Social Environment" and began with a talk by intensivist, Michael Forbes, MD, who discussed the initial medical response to a potential cardiac death. Dr. Forbes provided evidence-based guidance for the appropriate length of resuscitation attempts, and shared his experiences in dealing with families during these highly charged moments. Sarah Friebert, MD, a specialist in Palliative Medicine, gave an enlightening talk on how medical providers can manage the spread of anxiety and misinformation via social media. Laura A. Markley, MD, a pediatric psychiatrist, offered insight into the bereavement process and the long-term psychological impact of a sudden death on surviving family members. These sessions were moderated by Joy Burt, MSN and Nancy Carst, both of Akron Children's Hospital.

The pathological and genetic postmortem investigations were addressed in the next plenary session, moderated by Lisa J. Kohler, MD, Chief Medical Examiner for Summit County, Ohio. E. Rene Rodriguez, MD, Director of Cardiovascular Pathology at Cleveland Clinic, gave an in-depth presentation on the postmortem examination of the heart and shared several fascinating cases where careful investigations helped his team clarify difficult diagnoses. Rocio Moran, MD, Medical Director of Genetics at MetroHealth Medical Center, discussed postmortem genetic testing and the "molecular autopsy," emphasizing that retention of a blood specimen from the decedent is invaluable in the investigation. Genetic counsellor Diane Clements, MS, addressed the role of the geneticist in counselling the surviving family and the financial impact of genetic testing in the current era.

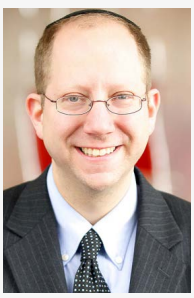
The afternoon plenary session, moderated by cardiologist Grace Smith, MD, focused on specific cardiac conditions that may cause sudden death. Peter Aziz, MD, Director of the Inherited Arrhythmia Clinic at the Cleveland Clinic, provided an overview of the yield of the postmortem investigation and shared the caveat that, even with exhaustive testing, current investigations do not reveal a definitive cause of death in most cases. Dr. Aziz and fellow electrophysiologist John Clark, MD, Director of the Arrhythmia Center at Akron Children's Hospital, reviewed Arrhythmias and Cardiac

Conduction Disease as a cause of sudden death. Dr. Clark shared his experiences with Automatic External Defibrillators (AEDs) as an invaluable resource in preventing sudden death and advocated for wider availability of AEDs throughout the community.

A session on Structural Heart Disease and Cardiomyopathies followed, with a panel of experts moderated by cardiologist Stephen Manu, MD and pathologist Carmela Tan, MD. Brandon Smith, MD, began the session with a discussion of Hypertrophic Cardiomyopathy, highlighting the imaging and pathological aspects of this disease. Francine Erenberg, MD, reviewed coronary artery anomalies and the problem of distinguishing benign anatomic variants from potentially lethal forms. Shahnawaz Amdani, MD, a specialist in pediatric heart failure, discussed myocarditis and cardiomyopathies, including how these common but often poorly understood entities generate the substrate for unexpected cardiovascular collapse. Kenneth Zahka, MD, reviewed Marfan's Syndrome and other connective tissue disorders as a cause of catastrophic aortic rupture. He shared his perspective on risk stratification and exercise restrictions, emphasizing how shared decision making can be used to balance patient autonomy and safety. Ashish Saini, MD, whose clinical focus is Adult Congenital Heart Disease, discussed the risk of sudden death in the growing population of young adults with repaired lesions, including the unique problems seen in the single ventricle patient.

The final plenary session, moderated by cardiologist Christine Tracy, MD, addressed Special Situations and Future Directions. Genetic counsellor Kimberly Wallis, LGC, shared her perspective on how to manage the postmortem genetic clinic visit. Malek Yaman, MD, a congenital cardiovascular imaging specialist, introduced the audience to the fascinating topic of Postmortem Cardiac Imaging, including CT, MRI and 3D Modeling. Chaplain Matthew Tweddle, MDiv, addressed Religious and Cultural Perspectives on Autopsies, allowing providers to interact sensitively with families from diverse traditions. Pediatric cardiologist Ira Taub, MD, then discussed the growing field of For-Profit Cardiac Screening and Testing, which often uses fear-based marketing tactics to attract business from the families of student athletes.

Those who are responsible for the investigation of a sudden death in the young must have access to the latest scientific information regarding congenital and acquired heart disease that may lead to such events. It is our hope that this symposium helped equip those professionals with the tools needed to fulfill their responsibilities.



IRA B. TAUB, MD, FACC, FAAP
Pediatric Cardiologist
Akron Children's Hospital
Considine Professional Building
215 W Bowery, Suite 5200
Akron, OH, USA
ITaub@akronchildrens.org

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- PCLC and ACHD Fellow core curriculums with associated testing
- A developing ICD-11 imaging atlas highlighting the consensus terminology under the leadership of the ***International Society for Nomenclature of Paediatric and Congenital Heart Disease***

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Catheter-Based Options for Valve Problems for ACHD Patients

Webinar, 7:00 pm EST

https://zoom.us/webinar/register/WN_XJ0y1oVRQlKB8F8bt1_-cQ

13-16

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19

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24th World Congress on Heart Disease – International Academy of Cardiology

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The Latest in Pediatric Heart Disease: Benefits of Skin-to-Skin Care, Nurse-Initiated PIV Training and Improving Cholesterol Screening in High-Risk Patients

CHOP's *Cardiology 2020* Conference Research Highlights

PRNewswire - Experts in pediatric heart disease from across the country shared the latest findings from their research at a large national conference hosted by the Cardiac Center at Children's Hospital of Philadelphia (CHOP). The *23rd Annual Update on Pediatric and Congenital Cardiovascular Disease*, **https://chop.cloud-cme.com/default.aspx?P=5&EID=928**, "Vision 20/20: Lessons from the Past, a Bold Look Toward the Future," took place from February 12 to February 16 in Lake Buena Vista, Florida. Experts presented research focusing on improving the quality and duration of life for those with Pediatric and Congenital Cardiovascular Disease.

CHOP research highlights include:

Skin-to-Skin Care Reduces Stress in Mothers and Infants Before Neonatal Cardiac Surgery

Researchers demonstrated that Skin-to-Skin Care (SSC) is a low-cost, low-risk, nurse-led intervention that reduces maternal stress and anxiety, promotes infant comfort, and supports stable vital signs before and after neonatal cardiac surgery. Following 30 mother-infant pairs, the team of researchers placed the infants in SSC with their biological mothers at two time points for one hour each: once before surgery and once after surgery. They measured mothers' stress and anxiety and infant pain and vital signs immediately before SSC, 30 minutes into SSC, and 30 minutes after SSC had ended. They found that both before and after surgery, mothers' anxiety scores were significantly lowered during and after SSC, and their cortisol levels – indicators of physiological stress – also decreased. Infant pain scores dropped during SSC before and after surgery, and infants were sleepier when compared to baseline. Infant heart and respiratory rates decreased during SSC before surgery, and systolic blood pressure increased. Both before and after surgery, infant cortisol remained stable before and during SSC, but cortisol increased after SSC. Researchers noted that infants with higher baseline cortisol after surgery saw significantly lower cortisol during SSC. Researchers say more research is needed to identify factors that lead to higher infant baseline cortisol and how SSC could be used to reduce stress in infants with Congenital Heart Disease (CHD).

Amy Lisanti, PhD, RN, CCNS, CCRN-K, et al. "Stress Reduction In Mother-Infant Dyads Through Skin To Skin Care."

Training Nurses in the Cardiac Preparation and Recovery Unit to Insert Peripheral Intravascular Catheters Reduced Procedure Delays

Pediatric cardiac patients admitted to CHOP's Cardiac Preparation and Recovery Unit (CPRU) require peripheral intravascular catheters (PIVs) prior to their procedure. However, historically only nurses in CHOP's Vascular Access Service (VAS) were the ones responsible for PIVs for all patients. The procedure monopolized VAS resources every morning and led to scheduling delays in services offered by the unit. To streamline the process and avoid delays in procedures, CPRU nurses developed a program to train their staff in PIV insertion in order to offload that responsibility from VAS nurses. In a two-phase project between 2017 and 2019, CPRU nurses received initial training by the VAS team and then underwent an immersion experience with the VAS team to practice PIV placement for a minimum of two hours. The two teams also developed a partnership so that in difficult cases, the VAS team could support the CPRU nurses. In addition, the team trained three unit-based "Qualified Observers" to help train and mentor other Cardiac Center nurses in PIV placement. Using this two-phase process, the CPRU nursing team was able to increase rates of successful PIV placement by CPRU nurses from 83% success after phase one to 89% after phase two and decrease the number of delayed procedures from 4.6% after phase one to 1.8% after phase two. Overall PIV management and care also improved over the course of the project.

Jamie Fitzgerald, RN, BSN, CPHQ, et al. "Pivoting to a New Approach: Building Unit-Based PIV Competency in a Procedural Area."

Jack Rychik, MD, Director of the Fetal Heart Program at Children's Hospital of Philadelphia and Course Director of Cardiology 2020

Patients at High Risk for Early Atherosclerosis Not Sufficiently Screened for High Cholesterol

CHOP researchers examined how often children in different risk categories had their cholesterol and triglycerides checked. Doctors recommend screening for atherosclerosis – the narrowing of arteries due to plaque buildup – twice during childhood through a universal lipid panel because the condition typically begins in childhood. For patients with congenital and acquired heart conditions, including cardiomyopathy and coronary artery anomalies, the recommendation is to screen early because those patients are at higher risk for developing atherosclerotic heart disease. Researchers reviewed commercial and Medicaid insurance claims databases to assess the rates of lipid screening in children with high-risk cardiac diagnoses, as well as those with Congenital Heart Disease and the general population. Analyzing more than five million records, they found that lipid screening in children with high-risk conditions predisposing them to early atherosclerosis was about the same as screening in low-risk cardiac patients (28% vs. 26%, respectively) and only slightly higher than the 19% screening rate for the general population. Patients who had undergone a heart transplant were screened at a higher rate (70%), as were those with cardiomyopathy (41%). However, only 28% of patients with complex two-ventricle or single-ventricle disease were screened. The research team suggests factors

like testing access, practice variation and family choice could explain why many high-risk patients are not being screened, but that more research is needed to understand the phenomenon and increase screening rates.

Justin H. Berger, et al. "Congenital Heart Disease patients at High Risk for Early Atherosclerosis are not Adequately Lipid Screened."

Changes in Ventricular Function Over Time After Fontan

CHOP researchers studied changes in ventricular function over time in patients with single-ventricle disease who had undergone Fontan, a surgical procedure that redirects blood flow from the lower body to the lungs. Although numerous indicators have been developed to measure ventricular function in patients with single-ventricle disease, little data exists on how the parameters change over time. Examining 141 echocardiograms from 18 unique patients between 2006 and 2017, the team found that although measures of ventricular function after Fontan operations were consistently different from what one would expect in a population without Congenital Heart Disease, there was no significant change to these measures over a decade of follow-up. The team suggests that the failure of the Fontan circulation is likely multifactorial and may occur without decline in systolic ventricular function.

Matthew J. Campbell, MD, et al. "Longitudinal Changes in Echocardiographic Measures of Ventricular Function after Fontan."

Links Found Between Post-Operative Outcomes in Tetralogy of Fallot and Serum Biomarkers, Length of Hospital Stay

Infants with Tetralogy of Fallot (TOF), a combination of four congenital heart conditions that often causes oxygen-poor blood to flow out of the heart and into the rest of the body, have worsening right ventricular strain after surgery, which improves over the next one to two years. Given that blood serum biomarkers of myocyte stretch and fibrosis might also be associated with postoperative outcomes, CHOP researchers followed a group of 64 TOF patients between 2014 and 2018 to see if such an association existed. Serum biomarkers were drawn before surgery, and research echocardiograms were performed two and five days after surgery. Patients were divided into two groups: those whose hospital stay was more than seven days, and those whose stay was less than seven days. Patients in the study also had echocardiograms and biomarker measurements one and two years after surgery. Researchers found a longer hospital stay after TOF repair is associated with worse right ventricular strain and higher levels serum biomarker MMP1 one year after surgery, suggesting the length of time a patient spends in the hospital after surgery may correspond with poorer outcomes in the initial months following TOP repair.

Andrea Jones, MD, et al. "Association of Serum Biomarkers and Right Ventricular Strain with Post-Operative Outcomes in Tetralogy of Fallot."

Monitoring Blood Oxygen Levels in the Delivery Room May Help Determine the Need for Catheterization Procedure in Infants with Transposition of the Great Arteries

Researchers studied 76 infants diagnosed at the CHOP Fetal Heart Program and born in CHOP's Garbose Family Special Delivery Unit (SDU) between 2012 and 2017 who had Transposition of the Great Arteries (D-TGA), the most common congenital heart defect to present in the first week of life that results in low blood oxygen levels. Looking at the infants' complete medical records, the researchers investigated the association between the infants' blood oxygen levels in the delivery room and whether or not they later underwent balloon atrial septostomy (BAS), a catheterization procedure in which a small hole is created between the upper two chambers of the heart to increase the flow of oxygen-rich blood. They found that about two-thirds of infants with D-TGA followed in the study were intubated and exposed to 100% oxygen in the delivery room, both interventions that were significantly associated with the infants subsequently undergoing BAS. All patients who were unable to attain a blood oxygen saturation of 74% or higher in the delivery room ultimately underwent BAS, while those who achieved blood oxygen saturation of 85% or higher had a lower likelihood of BAS. The research team concluded that the blood oxygen saturation levels observed as early as the delivery room may help determine whether or not BAS will be needed.

Russell Kesman, MD, et al. "Associations Between Delivery Room Management and Balloon Atrial Septostomy in D-Transposition of The Great Arteries."

Identifying Fetal Characteristics and Postnatal Outcomes of Patients with Absent Ductus Venosus

Researchers in CHOP's Fetal Heart Program studied infants with absence of the ductus venosus (ADV), a congenital anomaly of the fetal circulatory system with two subtypes: extrahepatic, in which the umbilical venous drainage bypasses the liver, and intrahepatic, in which the flow enters the liver. Based on limited published and anecdotal data, extrahepatic ADV patients are thought to have an increased risk of developing volume overload while in the womb, and intrahepatic ADV patients may have more genetic syndromes and other non-cardiac congenital anomalies. To better understand the clinical characteristics and outcomes of these patients, researchers reviewed maternal prenatal medical records and fetal echocardiogram images of nearly 200 mothers who were part of CHOP's Fetal Heart Program between 2008 and 2019. Pediatric medical records were also examined when available. They found that patients with extrahepatic ADV had higher incidence of prenatal volume overload, as well as issues like enlarged heart, umbilical venous pulsations and tricuspid regurgitation. These patients also tended to have longer hospital stays during their initial hospitalizations. ADV patients who had concurrent congenital heart disease had a higher rate of postnatal death, a finding that the research team says warrants further study. The research may lead to better prenatal counseling, targeted postnatal management, and improved outcomes.

Somya Shankar, BS, et al. "Clinical Characteristics of Absent Ductus Venosus in the Fetus and Associated Postnatal Outcomes."

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