#### **ORIGINAL PAPER**



# Initial Experience with Telemedicine for Interstage Monitoring in Infants with Palliated Congenital Heart Disease

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Received: 16 May 2022 / Accepted: 17 August 2022 / Published online: 1 September 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

### Abstract

Infants with staged surgical palliation for congenital heart disease are at high-risk for interstage morbidity and mortality; home monitoring programs have mitigated these risks. In 2019, we instituted telemedicine (TM) in our established Infant Single Ventricle Monitoring Program. All consecutive patients discharged following neonatal operation/intervention were monitored until subsequent stage 2 surgical palliation. We offered TM (synchronous video) visits as part of regularly scheduled follow-up, replacing at least one in-person primary care visit with a TM cardiologist visit. We tracked emergency department (ED) visits, hospitalizations, how TM identified clinical concerns, and whether use of TM prevented unnecessary ED visits or expedited in-person assessment. We assessed caregiver and clinician satisfaction. Between 8/2019 and 5/2020, we conducted 60 TM visits for 29 patients. Of 31 eligible patients, 2 families (6.9%) declined. Median monitoring time was 199 days (range 75–264) and median number of TM visits/patient was 2 (range 1–5). In 6 visits (10%), significant clinical findings were identified which avoided an ED visit. Five TM visits led to expedited outpatient assessments, of which 1 patient required hospitalization. There were no missed events or deaths. Median ED visits/patient/month were significantly lower compared to the same calendar period of the prior year (0.0 (0–2.5) vs. 0.4 (0–3.7), p = 0.0004). Caregivers and clinicians expressed high levels of satisfaction with TM. TM for this high-risk population is feasible and effective in identifying clinical concerns and preventing unnecessary ED visits. TM was particularly effective during the COVID-19 pandemic, allowing for easy adaptation of care to ensure patient safety in this fragile cohort.

Keywords Single ventricle · COVID-19 · Telemedicine · In-home monitoring · Interstage outcomes · Quality improvement

# Introduction

Infants with single ventricle heart disease requiring staged palliation are at high risk for interstage morbidity and mortality and account for high use of healthcare resources. They require complex care coordination and monitoring which involves extensive family effort, community support, and medical resources. Care is frequently fragmented between specialists and primary care physicians (PCPs), and even minor illnesses commonly result in emergency department

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<sup>2</sup> Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA (ED) visits often prompting hospitalization. The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) reported that 66% of infants with hypoplastic left heart syndrome (HLHS) experienced an unanticipated interstage readmission. Most hospitalizations were prompted by a minor clinical change; only 6% occurred secondary to a major adverse event [1]. For infants between stage 1 palliation (S1P) and stage 2 palliation (S2P), the use of in-home monitoring programs, in addition to frequent, scheduled, in-person physician evaluations, has decreased interstage mortality from 20% to as low as 2% [2, 3]. Since 2010, the Cardiac Center Infant Single Ventricle Monitoring Program (ISVMP) at Children's Hospital of Philadelphia has cared for approximately 770 such patients with a low incidence of interstage morbidity and mortality, with no deaths over the past 6 years in infants with HLHS (unpublished data).

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Although asynchronous transfer of monitoring data (i.e., weights, oxygen saturation, red flags) by caregivers via electronic means, including tablet-based programs [4], is increasingly being used, few studies have evaluated the use of telemedicine (TM) (synchronous video visits) in the infant single ventricle population. A comparison of videoconferencing to telephone-based care in children with congenital heart disease (CHD) showed high levels of family satisfaction, decreased use of health care resources, and greater levels of provider confidence around decision-making with videoconferencing [5]. A more recent study corroborates the feasibility of TM in these patients [6]. TM eliminates travel time and expenses, avoids wait times, minimizes potential infectious exposures, and can potentially reduce caregiver burden and physical stress for infants related to equipment needs and transport to in-person appointments. Moreover, TM can be deployed quickly and minimizes family disruption, particularly associated with hospitalization. Finally, it creates medical homes that promote continuity as care is received from trusted clinicians with access to the child's electronic medical record (EMR).

Given the rates of intercurrent illness, geographic and sociodemographic disparities in access to care, and significant family stressors in this patient population, we investigated adding TM (synchronous video visits) to the ISVMP. Our goals were to provide a feasible method of care delivery that would reduce stressors for families, support clinical decision-making, and identify significant clinical concerns before they escalated. We hoped to increase caregivers' confidence regarding the clinical management of their children and decrease ED visits and secondary hospitalizations as well as associated costs [7]. This article was written according to Standards for Quality Improvement Reporting Excellence (SQUIRE) guidelines [8].

# Methods

#### Context

The ISVMP is a multidisciplinary collaborative group which consists of a nurse practitioner (NP), 9 designated cardiologists, nutritionists, case managers, and individuals with expertise in quality improvement. We create, implement, and continually reassess standardized protocols, innovate, and incorporate caregivers as part of the healthcare team by providing necessary education and ongoing support. The ISVMP monitors all infants in the interstage period (defined as discharge from S1P and admission for S2P). It includes infants who have shunt-dependent single ventricle physiology (surgical shunt placement or PDA stenting as part of staged palliation), patients with single ventricular physiology and a pulmonary artery band, patients with aortopulmonary shunts or PDA stents in anticipation of eventual biventricular repair as well as patients with stable neonatal physiology with either single ventricle physiology or those with undetermined candidacy for biventricular repair with the above interventions. On average, we follow approximately 70 patients (62–89) per year after they have undergone the above interventions; roughly 50% are infants with HLHS.

The ISVMP entails a standardized approach to discharge criteria, daily home monitoring by caregivers, and frequent, regularly scheduled follow-up (in-person and telephone). In the days approaching discharge, caregivers are provided with equipment (digital baby scales, pulse oximeters) and receive standardized education, including instructions with specific parameters to prompt communication to the ISVMP team. Caregivers receive weekly telephone calls from the ISVMP NP, and patients are seen regularly in-person, at intervals based upon diagnosis. Patients with HLHS attend weekly visits with their cardiologist alternating with their PCP. Patients who required an isolated aortopulmonary shunt or patent ductus arteriosus (PDA) stent attend monthly cardiology and PCP visits. According to the established protocol, if concerns are raised during the NP or a caregiver telephone contact, an "urgent" consultation with a cardiologist is conducted to determine the appropriate course of management. Moreover, caregivers can call the ISVMP NP or come to the hospital with their infant at any time.

## Intervention

With this initiative, we replaced at least one in-person PCP visit with a TM Cardiology visit; this increased to biweekly for our HLHS population during the COVID-19 pandemic. The TM team consisted of the ISVMP NP, a pediatric cardiologist (ISVMP team member) and/or the patient's primary cardiologist, including cardiology fellows. This initiative was led by one of the cardiologists (TJP), who trained clinicians to perform TM encounters through a narrated slide presentation, tutorials, and one-on-one training including a simulated encounter. In August 2019, TM visits were instituted in our standard ISVMP protocol for neonates with HLHS following discharge after S1P and later expanded to include all patients within the ISVMP. TM was not available on nights and weekends; calls from caregivers during these times were addressed through the on-call team.

We provided oral and written information regarding our TM program to caregivers during their child's hospitalization. Participating caregivers were provided instructions to download the patient portal application required for TM visits. We verified that caregivers had internet access and a device (e.g., smartphone, iPad) and provided an iPad for those who did not have access to a device. Initially, caregivers recorded and communicated daily home monitoring data (through email, text or phone) to the ISVMP NP. We subsequently implemented the Epic Care Companion app in MyChart where caregivers could upload monitoring data using their device. This allowed monitoring data to be accessible to all care providers. The upcoming appointment was scheduled prior to discharge; then, at each appointment, the subsequent one was scheduled. To allow time for troubleshooting, caregivers were instructed to log on to the portal 15 min before the appointment. If caregivers did not successfully connect within 5 min of the appointment time, staff contacted caregivers to assist. Interpreter services were provided for families with limited English proficiency.

Clinicians used software embedded in the EMR (Epic Systems Corporation; Verona, Wis.) to conduct TM visits. The TM visit protocol included: tracking of clinical concerns and ED visits or hospitalizations, visual assessment of color, activity, work of breathing and respiratory rate, oxygen saturation and heart rate (via direct visualization of the pulse oximeter). It also included discussion of daily weights, nutrition, and medications (including need for refills), identification of equipment malfunction, confirmation of immunizations status including palivizumab, and identification of health-associated social and developmental needs and additional subspecialty evaluations. Clinicians documented the TM visit through a templated note with a modified physical examination and new fields to document need for the visit, identification of visit participants, and appointment duration. Clinicians also noted the action that would have occurred had a TM encounter not taken place (e.g., prevented or expedited a clinic or ED visit). All findings were communicated to the patient's PCP and primary cardiologist if not in attendance. After each TM visit, clinicians completed a questionnaire assessing perceptions of caregiver receptiveness, clinical effectiveness, and experience with technical difficulties. They also were queried for overall satisfaction, whether their perception of TM changed, follow-up plans using TM, and potential impact on their well-being. Caregivers completed a comparable questionnaire at the end of the interstage period.

#### Study of the Intervention

We prospectively tracked clinical findings, recommended interventions based on patient observations, and monitored their impact on patient care. Data for diagnosis, discharge and visit dates, weight at discharge, and occurrence of ED visits and hospitalizations were extracted from the EMR, as were number and duration of TM visits. We assessed significant clinical findings identified through TM that resulted in avoiding ED visits as well as expedited in-person evaluations/assessments. Additionally, we tracked non-urgent issues identified at TM visits, such as equipment or medication concerns, nutrition, education, and additional required subspecialty referrals. We compared the monthly frequency of ED visits per patient occurring during the period when TM was introduced in August 2019 through May 2020 (ISVMP with TM cohort) with the same calendar period of the year prior (August 2018–May 2019, ISVMP cohort).

Two independent reviewers (TJP, AS) retrospectively evaluated each hospitalization occurring in both cohorts through chart review, and based on our accumulated TM experience, deemed as potentially avoidable had telemedicine been available. For all hospitalizations, there was no discrepancy between reviewers.

### Analysis

We compared the monthly frequency of ED visits per patient between the ISVMP and ISVMP with TM cohorts using the Wilcoxon rank sum test. We estimated the savings associated with decreased ED visits based on a median ED charge for children with CHD of \$1266 (2014 USD) [9] and updated to \$1509 (2021 USD) using the Bureau of Labor Statistics consumer price index calculator (http://data.bls.gov). The reimbursed cost of a hospitalization was estimated from costs of respiratory syncytial virus (RSV) hospitalizations in CHD [10].

# Results

Sixty TM visits were conducted for 29 patients (Table 1). Thirty-one patients were eligible; two families (6.9%) declined due to their preference not to use new technology, neither due to lack of a device or internet access. The three most common diagnoses for patients in these cohorts were HLHS, double outlet right ventricle variants (DORV) and tetralogy of Fallot with pulmonary stenosis or pulmonary atresia (TOF/PS, vs PA). Only two (3.2%) scheduled visits were canceled, which were due to illness in other family members. All attempted TM visits were completed, with a successful audiovisual connection made at first attempt in 59 visits (98%). The average length of TM visits was 20 min.

In 6 TM visits (6 patients), significant clinical findings (e.g., decreased saturations, tachypnea, poor feeding) were identified which led to therapeutic changes and avoided ED visits and/or hospitalizations. Prior to implementing our TM program, such findings would have resulted in ED visits and/or hospitalizations. Expedited follow-up TM visits were subsequently performed in 3 of these 6 patients. Avoiding 6 ED visits saved an estimated \$9054 in direct charges not including possible decreased hospital admissions and incremental indirect expenses (e.g., missed work, travel). Five other TM visits (4 patients) prompted expedited in-person Cardiology assessments; of these, 1 patient was hospitalized. Two additional urgent TM Table 1Characteristics ofpatient cohorts before and afterintegration of TM (synchronousvideo visits) in the ISVMP

Table 2Comparison ofoutcomes before and afterintegration of TM (synchronousvideo visits) in the ISVMP

	ISVMP August 2018–May 2019 (N=43)	ISVMP with TM August 2019–May 2020 (N=29)
HLHS (%)	19/43 (44.2)	16/29 (55.2)
Monitoring time <sup>a</sup> , days (median, range)	206 (28–365)	199 (75–264)
Weight <sup>b</sup> , kg (median, range)	3.1 (2.0–5.8)	3.4 (2.3–5.4)

ISVMP infant single ventricle monitoring program, HLHS hypoplastic left heart syndrome, TM telemedicine

<sup>a</sup>Monitoring time is number of days in the interstage monitoring period, defined as discharge from stage 1 palliation through admission for stage 2 palliation

<sup>b</sup>Weight at time of discharge from stage 1 palliation

	ISVMP August 2018–May 2019 ( <i>N</i> =43)	ISVMP with TM August 2019–May 2020 ( <i>N</i> =29)
ED visits avoided via TM	_	6
ED visits no./patient/month (median, range)	0.4 (0–3.7)	0.0 (0-2.5) p = 0.0004
ED visits	62	20
ED visits resulting in hospitalization no., (%)	41 (66)	14 (70)
Potentially avoidable hospitalizations no., (% of hospitalizations)	19 (46)	6 <sup>a</sup> (43)

*ISVMP* infant single ventricle monitoring program, *TM* telemedicine, *ED* emergency department <sup>a</sup>Reflects 6 hospitalizations in 2 patients who were sent to the ED during times when TM was unavailable

consultations (2 patients) were requested by the patient's cardiologist. There were no missed events or deaths.

Median monthly ED visits/patient were significantly lower compared to the 2018–2019 period (Table 2). The 19 patients in the ISVMP cohort during the 2018–2019 period admitted for isolated fever, emesis, transient desaturation/breathing problems, fussiness, and/or feeding concerns were felt to potentially have been avoidable had TM been available during this period (Table 2). During the 2019–2020 period, 6 hospitalizations occurred in 2 patients who were unable to be seen via TM during nights/ weekends (when TM was not available) and were sent to the ED.

In all TM visits, patient visualization was helpful, especially in those with greater urgency where a continuous image of the patient significantly impacted the clinical plan. In these cases, the patient's appearance, especially respiratory rate and effort, either caused concern for an expedited in-person evaluation or reassured the clinician that the patient was stable and/or responding appropriately to an intervention without requiring escalation of care. All TM visits identified at least one non-urgent issue (Table 3). Notably, the discovery of equipment malfunction, primarily

Issue	Total TM visits $(N=60)$		
	N	%	
Equipment troubleshooting	5	8.3	
Titration of feedings	10	16.7	
Medication adjustments/refills	9	15.0	
Education/anticipatory guidance	60	100.0	
Referred to primary care physician	2	3.3	
Referred to cardiologist	3	5.0	
Referral to other subspecialty	6	10.0	

TM telemedicine

of pulse oximeters, is something that would not have been determined by an in-person visit.

Caregivers were extremely positive about TM with 97% of caregivers reporting they were satisfied (response rate: 100%). They felt the technology was easy to use with overall high audio and video quality. Technical difficulties were reported by 17% of caregivers, the most common being poor audio (e.g., transient interruptions from caregiver incoming calls or background noise) (Table 4). Families felt confident that their child was assessed by a health professional familiar with their infant. All 8 clinicians who conducted TM visits completed at least one visit survey (86% response rate) (Table 5). Clinicians reported occasional technical problems, but these decreased with increased TM use. Clinicians expressed overall satisfaction, including ability to provide effective care, and interest in ongoing TM visits. TM was felt by clinicians to be superior to in-person visits regarding the ability to observe patients for a prolonged period in their home environment allowing for contextual care, to understand how the family was coping, and to evaluate medical equipment functionality, the latter of which would not be assessed during an in-person visit.

# Discussion

We report a large comprehensive initiative on incorporating exclusively synchronous video visits in our established home monitoring program for this high-risk population [11]. TM for these infants was feasible, sustainable, and effective in identifying clinical concerns. It allowed rapid identification of potentially serious issues prompting expedited care which may have averted major adverse events. It also enabled successful management of non-acute problems which previously would have resulted in ED visits and/or hospitalizations. There were no deaths or missed events. Despite

 Table 4
 Responses to caregiver surveys

some initial technical difficulties, caregivers and clinicians expressed high levels of satisfaction with TM. TM proved to be an efficient care model, facilitating prompt resolution of non-urgent issues. In addition to reducing inconvenience and travel-related time and expenses for families, TM enabled contextual care and provided an excellent opportunity for caregiver education, creating an integrated medical home. During the COVID-19 pandemic, the TM program was particularly effective at adapting care to ensure patient safety in this fragile cohort.

Importantly, the opportunity for providing caregiver education became increasingly evident. The quantity of information caregivers receive prior to and at hospital discharge can be overwhelming. TM was essential in reinforcing concepts, resolving concerns, including how to properly use and troubleshoot equipment, and ensuring coordination of complex care in a less stressful environment.

Incorporating TM necessitated logistical and staffing considerations. It required reliable technical and scheduling support, especially for families with low digital literacy, and integration of interpreter services. Motivation and training were required for caregivers and healthcare staff. We also required quality assurance resources to assess effectiveness. Additionally, TM visits initially were not reimbursed. However, the COVID-19 pandemic effected relaxation of licensing restrictions and stipulations about telehealth use, as well as expanded payor coverage. Our findings highlight the benefits and demand for the ongoing use of telemedicine and

Item	Caregivers in ISVMP with TM cohort $n=29$	
	Responses	n (%)
How satisfied were you with the quality of care you received during your TM visit?	Satisfied	28 (97)
	Neutral	1 (3)
	Dissatisfied	0
Do you feel your medical concerns were appropriately addressed during your TM visit?	Yes	28 (97)
	Somewhat	1 (3)
	No	0
Did you experience any technical difficulties <sup>a</sup> during your TM visit?	Yes	5 (17)
	No	24 (83)
Did TM improve your ability to keep your appointment?	Yes	29 (100)
	No	0
How much money on average does one round trip visit to your cardiologist's office cost?	\$10-\$25	18 (62)
	>\$25	11 (38)
Are you interested in TM visits in the future?	Yes	28 (97)
	Unsure	1 (3)
	No	0

#### TM telemedicine

<sup>a</sup>Categories of technical difficulties included poor video, poor audio, difficulty logging in, interruption of communications, and unfamiliarity with the process. Caregivers could report more than 1 category

#### Table 5 Responses to clinician surveys

Visit-specific surveys $n = 52$		
Item	Responses	n (%)
What was your perception of the caregiver's receptiveness to the TM visit?	Very receptive	50 (96.2)
	Somewhat receptive	2 (3.8)
	Not at all receptive	0
How often did you experience technical difficulties <sup>a</sup> during the TM visit?	Never	47 (90.4)
	Sometimes ( $< 50\%$ of the time)	4 (7.7)
	Often ( $\geq$ 50% of the time)	1 (1.9)
a. Did it prevent you from completing the visit?	Yes	0
	No	5 (100)
b. How did you proceed?	Reconnected	4 (80.0)
	Transitioned to telephone	1 (20.0)
	Visit ended	0
Did you find TM appropriate for effective patient assessment?	Yes	51 (98)
	Unsure	1 (2)
	No	0

Item	Responses	n (%)
How satisfied are you overall with your experience with TM visits?	Satisfied	8 (100)
	Neutral	0
	Dissatisfied	0
How has your perception of TM changed over the course of the past year?	Improved	8 (100)
	No change	0
	Worsened	0
Would you like to continue incorporating TM into your clinical practice post-Covid 19?	Yes	7 (87.5)
	Unsure	1 (12.5)
	No	0
How has TM impacted your lifestyle/well-being?	Positively	7 (87.5)
	No impact	1 (12.5)
	Negatively	0

All 8 clinicians who conducted TM visits completed at least one visit survey

TM telemedicine

Overall surveys<sup>b</sup>

<sup>a</sup>Categories of technical difficulties included poor video, poor audio, difficulty logging in, interruption of communications, and unfamiliarity with the process

<sup>b</sup>Indicates clinicians' responses based on overall experience with TM

remote patient monitoring. An essential component to the success and future of telehealth is advocating for modification and enhancement of the licensure and reimbursement obstacles that currently exist.

There were several limitations. Some of the TM period included the onset of the pandemic when some caregivers may have been hesitant to seek in-person care. However, this period was brief (approximately 2 months) compared to the overall duration of the TM period, and in our experience with this high-risk patient population, the pandemic did not impact caregivers' willingness to seek in-person care. We also did not alter the timing of our procedures or interventions (i.e., cardiac MRI, cardiac catheterization, surgery) for this cohort during the pandemic. Second, TM was not available during nights and weekends which was a factor in some potentially avoidable ED visits and hospitalizations. Our intention is to expand these services. Next, while we ensured all of our families had internet access, devices, and language interpreter services, ongoing disparities in access to care persist both with in-person as well as telehealth care. The successful incorporation of synchronous telecardiology requires reliable, secure technical support ensuring needed equipment, internet access, education, and integration of interpreter services for caregivers, especially for those with low digital literacy. Improving the financial, educational, technological and infrastructure resources such as highspeed broadband internet availability in many areas that also lack pediatric specialty care is critical to achieving equity in access to TM. Fortunately, many new programs and policies are addressing this inequity through federal and state programs. Although we report on a highly monitored cohort, we are assessing the effect of disparities in access to care in this population. Lastly, we did not evaluate caregivers' psychosocial stressors. The AHA recently published guidelines highlighting the importance of psychological factors in the care of patients with CHD [12]. It is essential that the extensive challenges and impact on the daily lives of these infants' caregivers be recognized [13]; using patient-reported outcomes, we intend to assess these challenges and the benefit TM psychological support can potentially provide.

Our model can be adopted by multiple medical specialties, particularly for patients requiring complex care, including other high risk cardiac populations (e.g., ventricular assist devices, post-cardiac transplant, pulmonary hypertension) and those requiring home mechanical ventilation. An area for further study is TM's ability to promote population health, as in many chronic illnesses, low rates of follow-up result in poor medication adherence and outcomes. In this capacity, it may decrease costs by promoting regular assessments with decreased wait times, optimizing medication management, and addressing social determinants of health potentially reducing subsequent clinic, ED visits, and hospitalizations [14]. Through improved care coordination and management of chronic medical conditions, we anticipate decreased downstream costs and increased care satisfaction. Ultimately, a hybrid model may allow for practice flexibility in optimizing in-person visits (including diagnostic testing) and virtual care to maintain clinician-family relationships, ensure earlier escalations of care prior to decompensation, and preserve the successes of the medical home while integrating emerging technologies that support detailed home assessments. We are conducting research in remote monitoring and diagnostic technologies (e.g., digital stethoscopes) to optimize decision-making and demonstrate TM to be even more valuable in this population and in additional subspecialties in our Cardiac Center.

Acknowledgements The authors would like to thank the families and our colleagues who participated in this initiative. We would also like to acknowledge the statistical input provided by the Cardiac Center Clinical Research Core and Kristin McNaughton, MHS for assistance with editing. We are grateful for the support of the Cardiac Center Innovation Grant and the Digital Health Program at Children's Hospital of Philadelphia.

Author Contributions AS, TJP, TMG, BFO, and KMF conceptualized and designed the project, AS, TJP, SSN, DAH, ALS, JJR, and CR contributed to acquisition of data, BLL analyzed data, and AS, TJP, TMG, and MMG contributed to interpretation of data. TJP drafted the initial manuscript and all other authors critically reviewed for important intellectual content. All authors read and approved the final manuscript and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding Cardiac Center Innovation Grant, Children's Hospital of Philadelphia.

# Declarations

Conflict of interest TJP is on the editorial board of Journal of Pediatrics and World Journal of Pediatric and Congenital Heart Surgery. TMG is Invited Editor-in-Chief for a 17-article supplement in Pediatric Critical Care Medicine: Critical Treatment Strategies for Acute Pulmonary Hypertension in Infants and Children: Pediatric Cardiac Intensive Care Society Scientific Statement, guest editors: Giglia TM, Bronicki RB, Checchia PA, Laussen PC. Pediatr Crit Care Med;11(2 Suppl):S3-S90, 2010, and a manuscript reviewer for: Journal of the American College of Cardiology, Intensive Care Medicine, European Journal of Heart Failure, Clinical and Applied Thrombosis/Hemostasis, Cardiology in the Young, The Journal of Pediatrics, Pediatric Critical Care Medicine, and World Journal for Pediatric and Congenital Heart Surgery. CR is a manuscript reviewer for Congenital Heart Disease, Journal of Pediatrics, International Journal of Artificial Organs, Cardiology in the Young, Journal of Thoracic and Cardiovascular Surgery, Artificial Organs, World Journal for Pediatric and Congenital Heart Surgery, Journal of American College of Cardiology, Circulation, European Journal of Clinical Nutrition, Critical Care Nursing, Italian Journal of Pediatrics, European Journal of Clinical Nutrition, and Journal of the American Heart Association. JJR is Guest Editor, Progress in Pediatric Cardiology-Transcatheter Treatment of Congenital Heart Defects and a reviewer for: Annals of Thoracic Surgery, Catheterization and Cardiovascular Interventions, Journal of Thoracic and Cardiovascular Surgery, Circulation, Journal of the American College of Cardiology, Journal of Pediatrics, and American Journal of Cardiology, Chest. AS, ALS, BFO, KMF, MMG, DAH, BLL, SSN: none.

**Ethical Approval** This quality improvement initiative was reviewed and determined to not meet the criteria for Human Subjects Research by the Children's Hospital of Philadelphia Institutional Review Board.

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