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ORIGINAL ARTICLE

WILEY Congenital Heart Disease

Building a comprehensive team for the longitudinal care of single ventricle heart defects: Building blocks and initial results

Karen Texter, MD[1,2] | Jo Ann M. Davis, RN, MS, CPNP-AC[1] | Christina Phelps, MD[1,2] | Sharon Cheatham, PhD, ACNP[1,2] | John Cheatham, MD[1,2] | Mark Galantowicz, MD[1,3] | Timothy F. Feltes, MD[1,2]

[1]Division of Cardiology, Nationwide Children's Hospital, Columbus, Ohio, USA

[2]Department of Pediatrics, The Ohio State University, Columbus, Ohio, USA

[3]Division of Cardiothoracic Surgery, Nationwide Children's Hospital, Columbus, Ohio, USA

Correspondence
Karen Texter, MD, The Heart Center, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH, USA.
Email: karen.texter@nationwidechildrens.org

Abstract

Introduction: With increasing survival of children with HLHS and other single ventricle lesions, the complexity of medical care for these patients is substantial. Establishing and adhering to best practice models may improve outcome, but requires careful coordination and monitoring.

Methods: In 2013 our Heart Center began a process to build a comprehensive Single Ventricle Team designed to target these difficult issues.

Results: Comprehensive Single Ventricle Team in 2014 was begun, to standardize care for children with single ventricle heart defects from diagnosis to adulthood within our institution. The team is a multidisciplinary group of providers committed to improving outcomes and quality of life for children with single ventricle heart defects, all functioning within the medical home of our heart center. Standards of care were developed and implemented in five target areas to standardize medical management and patient and family support. Under the team 100 patients have been cared for. Since 2014 a decrease in interstage mortality for HLHS were seen. Using a team approach and the tools of Quality Improvement they have been successful in reaching high protocol compliance for each of these areas.

Conclusions: This article describes the process of building a successful Single Ventricle team, our initial results, and lessons learned. Additional study is ongoing to demonstrate the effects of these interventions on patient outcomes.

KEYWORDS

care coordination, hypoplastic left heart, quality improvement

1 | INTRODUCTION

Hypoplastic left heart syndrome (HLHS) and other types of single ventricle congenital heart defects remain some of the most difficult congenital heart lesions that face patients, families, and providers in the pediatric cardiology community. Despite decades of advancements in surgical palliation, the lifetime risks of morbidity and mortality remain high.[1–8] With improving surgical survival there has been emerging data on the additional comorbidities of congenital heart disease, particularly neurodevelopmental, growth, thromboembolic, and quality of life for the patient and family.[9–22] Variability in the care of HLHS has been studied in the recent efforts of The Joint Council on CHD and the National Pediatric Quality Improvement Collaborative (NPC-QIC) and others, looking at variability in surgical and medical management of these patients.[23–30] The NPC-QIC has successfully established best practice guidelines for the medical management of infants with HLHS following Stage I palliation, which has resulted in practice change at our institution and others across the nation, to improve interstage mortality for infants with HLHS.[31]

As pioneers of alternative hybrid management strategies for complex single ventricle patients, in 2013 the leadership of The Heart Center at Nationwide Children's Hospital charged a multidisciplinary team with redefining how we delivered care to our patients with single ventricle anatomy, including HLHS. The goals of the charge were to

improve outcomes and quality of life in single ventricle patients across their lifetimes, from the initial diagnosis to adulthood. This charge by Heart Center leadership ultimately led to a Heart Center wide initiative to institute standardized protocols for delivery of care to patients with single ventricle heart disease. A comprehensive longitudinal Single Ventricle Team was established to develop standardized practice guidelines for the care of single ventricle patients, oversee all aspects of their care and coordination, and provide consistency in family support and education. This article details the steps toward successfully establishing a comprehensive Single Ventricle Team, initial results, and lessons learned.

2 | METHODS

2.1 | Step 1—gaining "buy-in"

Establishing this team represented a paradigm shift in how we have historically managed single ventricle patients. Thus, for this initiative to be successful it was necessary to first gain support from the Heart Center as a whole. In 2013 the Heart Center leadership held an all-day faculty retreat as a call for change, and to examine how we cared for patients with single ventricle heart defects. This was a multidisciplinary review of patients' experience and outcomes, and included input from all providers within our Heart Center—physicians, nurses, nurse practitioners, and social workers. The longitudinal patient experience was broken into five time periods representing different point in their care—(i) Fetal, (ii) Stage I Hospitalization, (iii) Interstage Period, (iv) Stage II up to Fontan, and (v) Fontan and beyond. Multidisciplinary working groups were established for each time period, led by a physician–nurse team from across the Heart Center. Parents were represented in the committees and working groups. Working groups met to identify the most important issues facing patients at each time period, and reported back to the Heart Center at a follow-up retreat. As each group presented their findings, there were common areas of need identified that spanned across all points in time. Variability in care was common throughout the different stages of palliation, including timing of interventions, medical management, and interstage care for the patient with HLHS. Families received varying levels of support at the time of diagnosis and throughout the interstage period depending on the timing and location of a prenatal versus postnatal diagnosis and individual practitioner preferences. Despite growing literature on the neurodevelopmental needs of children with significant congenital heart disease there was significant variability in utilization of neurodevelopmental resources. There was generalized agreement that to address these concerns a new framework of care was going to be necessary, and the Single Ventricle Team initiative was created.

2.2 | Step 2—building the team

For the initiative to be successful, it was clear that a dedicated longitudinal team of providers was necessary, and a multidisciplinary Single Ventricle Team was established. The team included a small group of cardiologists, nurses, and a Single Ventricle Team Nurse Practitioner (NP). Additional team members were necessary with areas of expertise in neurodevelopment, psychology, feeding and nutrition; a developmental pediatrician, feeding specialists and therapists, social work, and a psychologist were included in the team. All new patients with single ventricle types of congenital heart disease, including but not limited to HLHS, were followed by the team. Each patient was assigned a primary outpatient cardiologist within the Single Ventricle team (SV). Each week one of the SV physicians served as the on call SV physician; this was a group of five cardiologists with expertise in fetal cardiology, non-invasive imaging, and cardiac intensive care. A full time position was created to allow for a dedicated Single Ventricle team NP. All other practitioners (MDs, RN) absorbed the added clinical time commitment within their current job scope. The NP was the nucleus of the team, coordinating and overseeing care of all inpatient and outpatient single ventricle patients, and providing consistent communication to team members and families. The medical team designed and implemented care protocols for the different stages in care over the first year of life. During hospital admissions, the team worked together with the primary inpatient care providers to ensure compliance with care protocols, provide communication and support to families, and ensure seamless transfers in care between the outpatient and inpatient setting. The Single Ventricle NP, SV cardiologist on call, and SV nurse rounded daily with the inpatient team to discuss each patient's progress, family concerns, and next steps. Patient management issues were discussed by the team at twice monthly multidisciplinary clinical care meetings. Consultants with expertise in neonatology, feeding and gastrointestinal issues, psychology, and neurodevelopment were included in the management. Patients were followed closely by the Single Ventricle team from diagnosis (either fetal or postnatal) in this manner until after they were home and had recovered from the Glenn/Stage II procedure. After discharge from the Glenn/Stage II procedure care continued with the primary outpatient Single Ventricle cardiologist. Figure 1 is a process map that shows the flow of clinical care from diagnosis until the discharge from the Glenn/Stage II procedure.

Standard of care protocols were created and implemented by the team addressing the initial fetal diagnosis and delivery planning, management of the Stage I and Stage II palliation and inpatient hospital stay, and interstage monitoring protocols. A neurodevelopmental protocol was established to ensure regular developmental testing, developmental intervention, and family support. Parental feedback was incorporated routinely into initiatives within the team.

Presentations to the heart center leadership team were given on a regular basis where feedback was provided, and information was disseminated widely at faculty and town hall meetings. Key driver diagrams were used in development of initiatives and goals. Control charts and pareto charts were used to monitor protocol compliance quarterly to identify areas of noncompliance.

3 | RESULTS

Our comprehensive Single Ventricle Team assumed care responsibility of our single ventricle patients in 2014. The team cared for all patients diagnosed with single ventricle physiology from the initial diagnosis onward, a total of 100 patients since the beginning of the program.

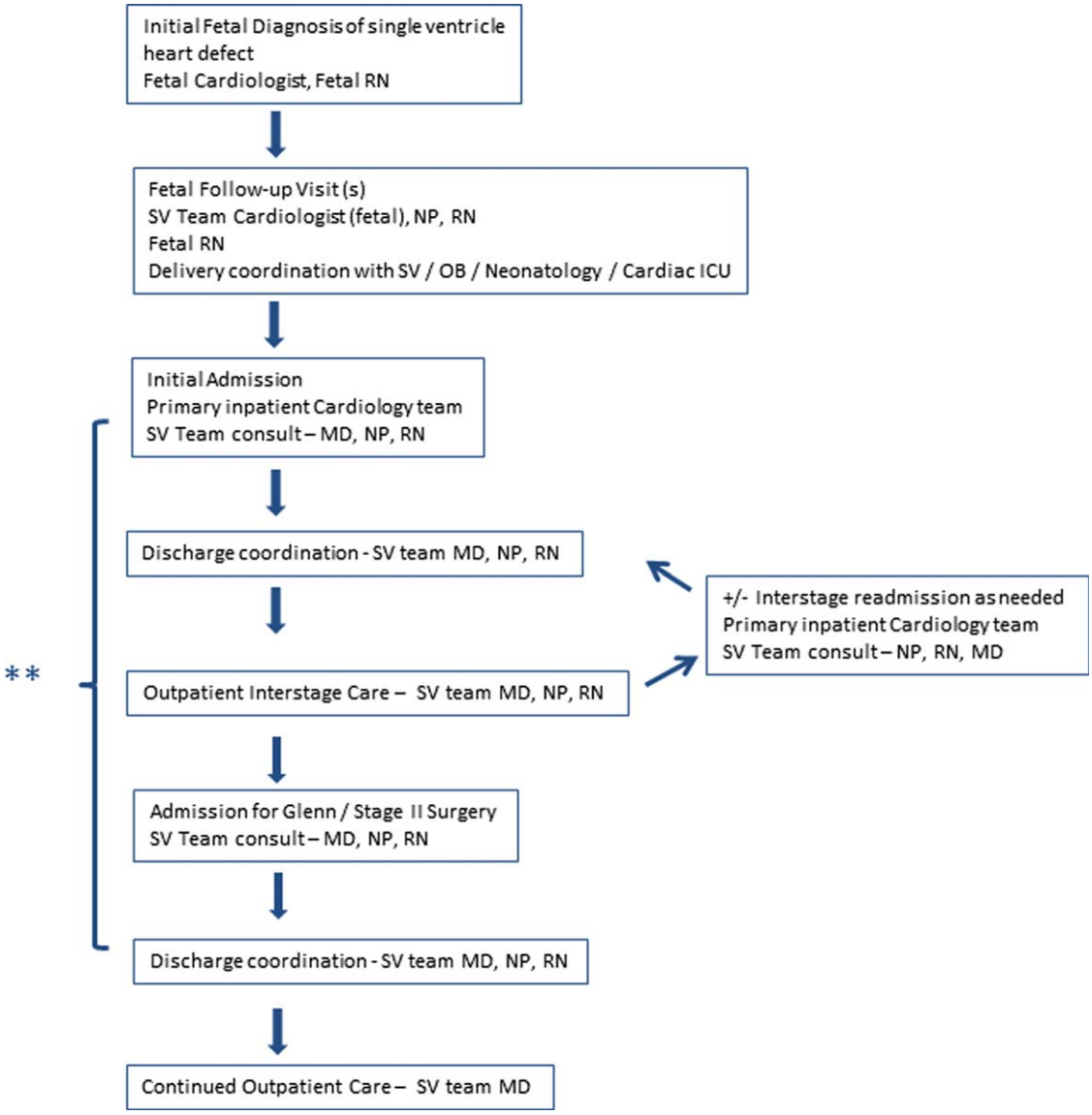

FIGURE 1 Flow diagram illustrating care for the single ventricle patient. SV, Single Ventricle. ** denotes time period of biweekly team review of clinical progress

The team's initial focus was on standardizing protocols for the first year of life, given the highest risks for morbidity and mortality for these patients during this time frame. The team decided to focus on four goals for the first set of protocols—decreasing mortality and morbidity, improving neurodevelopment support and quality of life, and improving coordination of care. Standard of care protocols to address these goals were designed and implemented within five areas—(i) Fetal Diagnosis, (ii) Stage I Management, (iii) Interstage Management, (iv) Stage II Management, (v) Neurodevelopmental and family support.

3.1 | Management protocols

3.1.1 | Fetal

The majority of single ventricle patients in our center are diagnosed prenatally. From parent specific feedback we learned that most parents in our heart center wanted to meet the caregivers for their child prior to the birth of their baby. Prenatal counseling starts with the initial consultation with a fetal cardiologist, along with our fetal nurse coordinator. At subsequent fetal visits each family then also meets the Single Ventricle team NP and Single Ventricle cardiologist, and cardiothoracic surgeon. Expectations of care are discussed, including the birth, initial hospitalization, and long term issues including neurodevelopmental follow-up. A neonatologist is present during the final delivery planning consult to discuss additional issues around the birth and transfer of the baby, and provide a direct handoff to the neonatology team who will be attending the delivery. Each case is then discussed prior to the birth in a multidisciplinary conference involving cardiology, maternal fetal medicine, cardiac intensive care, and neonatology.

3.1.2 | Stage I management

For patients with HLHS or similar variants, Hybrid Stage I palliation (patent ductus arteriosus stent placement, bilateral pulmonary artery

TABLE 1 Compliance of individual stage I protocol components

	% Compliance
Timing of initial surgical palliation	75%
Echocardiographic monitoring postoperatively	93%
Balloon atrial septostomy timing	88%
Medication compliance at discharge	100%
Discharge bundle	95%

banding, balloon atrial septostomy) is predominantly performed at our center as the initial palliative surgery.[32,33] The Stage I protocol was designed around standardization of care of the hybrid patient, consisting of: (i) timing of initial surgical palliation within seven days of life, (ii) timing of the balloon atrial septostomy within 1 week after Hybrid Stage I surgery, (iii) weekly echocardiography surveillance post Hybrid Stage I while the patient remains hospitalized, (iv) standard medications at discharge, and (v) standard discharge processes, consisting of family rooming in, appointment coordination, and discharge conference call with the pediatrician and primary cardiologist. At baseline all measures varied from 30 to 80%, but compliance with each of the components improved significantly under the Single Ventricle Team model, ranging from 75 to 100% (Table 1, Figure 2).

3.1.3 | Interstage care

Our Interstage processes were largely established with our Home Monitoring Program in place since 2008. In our prior Home Monitoring Program daily oxygen saturations, weight gain, and oral intake using home a home scale and home pulse oximetry were recorded daily for infants with HLHS during the interstage period by their families at home, and reviewed by dedicated Heart Center Home Monitoring nurse on a once weekly phone call. Each family was given criteria with which to call the Home Monitoring team in between weekly calls if there was breach of predetermined criteria in oxygen saturation or weight gain. The data was reviewed weekly with the primary outpatient cardiologist to decide on any changes in management. A nutritionist was involved in the outpatient clinic visit to help with poor weight gain. Although the Home Monitoring Program positively affected patient outcomes,[34] there remained a need for improvement in standardization of care and family support. Specifically, patients were followed by a large number of different cardiologists, and there were no standardized protocols for responding to breech criteria or other clinical concerns. For patients followed outside of our heart center, there was no standard communication between the primary home cardiologist and the surgical center if interstage concerns developed. Under Single Ventricle Team, new Home Monitoring protocols were developed to standardize the management for the patient with HLHS after hybrid procedure during the interstage period. Each patient was assigned a primary cardiologist within the Single Ventricle team. Algorithms were developed addressing use of routine outpatient testing, response to home monitoring red flags, and when to consider cardiac catheterization. Specific echocardiographic protocols were developed for the single ventricle patient after hybrid procedure, along with direct feedback to sonographers to enhance study quality. Feeding protocols were developed to treat oral feeding failure and poor weight gain. The Single Ventricle NP met routinely with families during clinic visits to standardize interstage and pre Stage II education. As a dedicated full time position, the Single Ventricle NP was available for urgent outpatient assessment of any patient with a breach identified in Home Monitoring, together with the Single Ventricle cardiologist on call or the patient's primary cardiologist. For patients followed outside of our heart center the Single Ventricle NP served as a direct line of communication for any clinical concerns noted during the interstage period. The

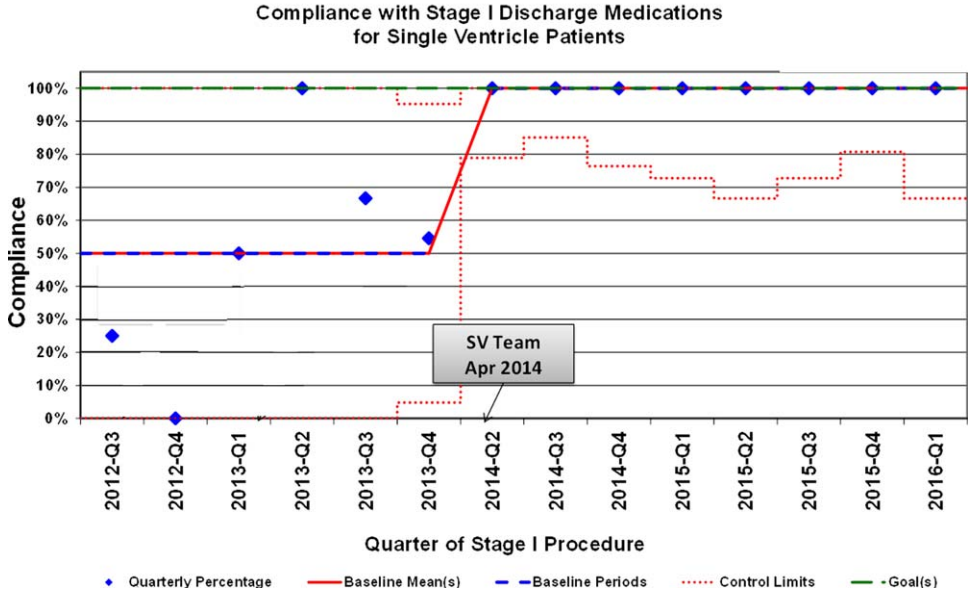

FIGURE 2 Control chart/p chart showing compliance with recommended medications at discharge for Stage I patients shows 100% compliance since starting Single Ventricle (SV) team in April 2014. Baseline data starting in 2012 shows significant variability prior to the start of Single Ventricle team

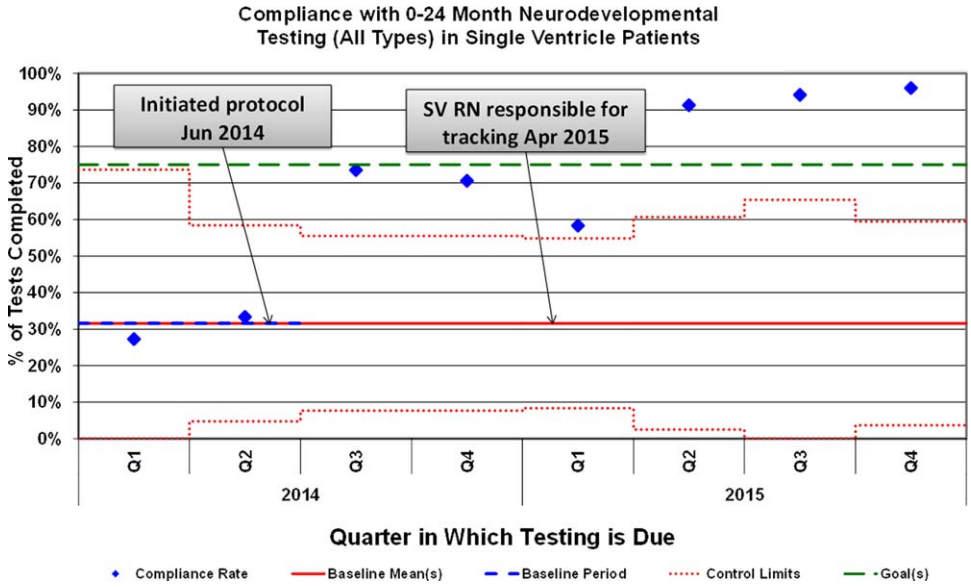

FIGURE 3 Control chart/p chart showing compliance with multiple components of the Neurodevelopmental Protocol, described in text. Compliance improved with dedicated tracking from Single Ventricle (SV) team nurse and nurse practitioner

Single Ventricle NP and cardiologist met together on the discharge conference call with the home primary cardiologist to establish open lines of communication for the interstage and review our Heart Center's protocols for catheterization. This was of particular importance for HLHS patients after Hybrid Stage I who may need timely evaluation with catheterization during the interstage period to address concerns of retrograde arch obstruction, PDA stent obstruction, or residual atrial septal restriction. All HLHS patients in the interstage period who breach home monitoring protocol, or require admission for other concerns, are routinely admitted to the cardiothoracic ICU for an initial assessment and a minimum of twenty four hour observation before being deemed stable for the cardiology step-down unit. Since 2014 with Single Ventricle team our interstage mortality rate for HLHS has decreased to 8% (13% year 1, 6% year 2, 0% year 3), compared with the 4 years prior (17%).

3.1.4 | Stage II management

Review of our outcomes after the Comprehensive Stage II procedure in single ventricle patients (removal of the ductus arteriosus stent and pulmonary artery bands, bidirectional Glenn, aortic arch reconstruction, atrial septectomy, Damus Kaye Stansel)[32,33] identified that acute and chronic pulmonary artery thrombosis is a significant contributor to postoperative mortality. In 2010 a new protocol was begun to treat all post Stage II patients with anticoagulation,[35] which resulted in improvement in mortality. Within the Single Ventricle team, additional risk factors for chronic thrombosis were identified. This resulted in development of an additional care protocol addressing pulmonary artery thrombosis in the postoperative Stage II patient. The components were: (i) intraoperative angiography of the cavopulmonary anastomosis and pulmonary arteries, (ii) intraoperative treatment of significant pulmonary artery stenosis, (iii) 6 weeks of anticoagulation therapy postoperatively, (iv) identification and communication of higher risk patients needing additional imaging with either cardiac catheterization or magnetic resonance imaging (MRI) postoperatively prior to stopping anticoagulation. Compliance with the protocol included closed loop communication such that all team members are aware of the anticoagulation and imaging plan for a specific patient. Since initiation of this protocol in 2015, compliance has been 100%, with no episodes of thrombosis for patients following the protocol.

3.1.5 | Neurodevelopmental protocol

As the literature expands about the potential for neurodevelopmental issues in these patients later in life,[13,14,22,36–40] neurodevelopmental outcomes and support is a significant focus of the efforts of our Single Ventricle Team. Our neurodevelopmental support protocol starts at the initial birth hospitalization with occupational and physical therapy consults, family psychology consult, and outpatient developmental referrals. Standardized developmental testing is performed on all patients at three months of age using the Test of Infant Motor Performance, the Bayley Scales of Infant and Toddler Development, 3rd edition at 12 and 24 months, and a Speech evaluation at 18 months. Occupational, physical, and speech therapists are part of the Single Ventricle Team and perform the developmental evaluations during regular cardiology clinic visits, allowing for closed loop communication with the primary cardiologist about the results and any need for developmental intervention. Following Fontan completion, older children are referred for evaluation by a developmental pediatrician. Scheduling of all of the developmental visits is coordinated by a dedicated Single Ventricle Team nurse and nurse practitioner. All families are evaluated at the initial Stage I hospital admission, as well as all subsequent hospital admissions, by a psychologist and social worker to assess family coping and stress. With the addition of dedicated RN and NP tracking, compliance with the Neurodevelopmental Support protocol from birth to 2 years of life has risen to greater than 90%, shown in Figure 3.

Rates of appropriate referral to developmental services have been 100% since the start of the program.

4 | DISCUSSION

With the implementation of our Single Ventricle program in 2014, we have established a dedicated Single Ventricle Team of providers to direct the care of patients with single ventricle types of congenital heart disease. The driving force of heart center leadership, coupled with commitment and support of a Single Ventricle Team approach, was integral to successfully developing and implementing standardized management protocols. We were able to reach high rates of compliance for multiple complex protocols by building a multidisciplinary team to represent patients' complex care needs, integrating closed loop communication into each protocol, and using quality improvement tools to regularly monitor compliance. Key points include the engagement and support of all providers within the heart center, valuing patient and family input as equal team members, and keeping the team aligned to the common goal of patient/family centered protocol driven care.

Home monitoring for HLHS during the interstage period was first introduced in 2003 showing a decrease in interstage mortality for HLHS.[41] Since then many centers have developed similar type programs. Such programs frequently have clustered the primary cardiology care to a core group of cardiologists providing care during the interstage and have demonstrated improvement in interstage mortality and growth.[42–48] Our Single Ventricle team is similar in that we also have a dedicated group of providers caring for high risk single ventricle infants. However, our Single Ventricle team has broadened goals to start care for the single ventricle patient and family during fetal life, bridge the inpatient and outpatient experience, and extend through the Glenn/Stage II procedure. The team addresses goals of mortality, morbidity, family support, and neurodevelopment. Future plans will allow us to extend further to the Fontan procedure and beyond. With a dedicated team and NP involved from fetal diagnosis until home and recovered from the Stage II/Glenn, we are able to have a presence for inpatients on the floor and ICU, in addition the outpatient management, and provide consistent support for families throughout their journey during this high risk period. This, together with regular use and review of our results using quality improvement tools, has also allowed us to reach high rates of protocol compliance.

Standardizing management of care and care coordination has demonstrated near 100% compliance, and has eliminated patients "falling through the cracks" for important aspects of their care. We have seen important decreases in our interstage mortality for HLHS and in the complication of PA thrombosis after Stage II procedure. Caring for children with HLHS and other single ventricle types of heart disease is challenging due to the complexity of their medical needs, involvement of multiple subspecialists, and frequent transitions in care between the inpatient and outpatient settings. Establishment of a comprehensive Single Ventricle team has allowed for implementation of care protocols with excellent compliance. Long-term studies will be necessary to evaluate outcomes of these protocol changes on patient outcomes.

5 | CONCLUSIONS

The creation of a comprehensive multidisciplinary Single Ventricle Team has been a positive change in our heart center to help manage longitudinal care needs for patients with single ventricle types of congenital heart defects. Assessing the effects of our protocols on key outcome measures of mortality, morbidity, neurodevelopmental outcomes, and quality of life is ongoing.

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CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest with the contents of this article.

DISCLOSURES

None

AUTHOR CONTRIBUTIONS

Karen Texter: concept/design of the article, data collection, analysis, and interpretation, drafting and approval of the article.
Jo Ann Davis: concept/design of the article, data collection, analysis, and interpretation, editing and approval of the article.
Christina Phelps: concept/design of the article, editing and approval of the article.
Sharon Cheatham: concept/design of the article, editing and approval of the article.
John Cheatham: concept/design of the article, data analysis and interpretation, editing and approval of the article.
Mark Galantowicz: concept/design of the article, data analysis and interpretation, editing and approval of the article.
Timothy Feltes: concept/design of the article, data analysis and interpretation, editing and approval of the article.

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