## ORIGINAL ARTICLES

# Use of a Learning Network to Improve Variation in Interstage Weight Gain after the Norwood Operation

Jeffrey B. Anderson, MD,*† Robert H. Beekman, III, MD,* John D. Kugler, MD,‡ Geoffrey L. Rosenthal, MD, PhD,§ Kathy J. Jenkins, MD,¶ Thomas S. Klitzner, MD, PhD,** Gerard R. Martin, MD,†† Steven R. Neish, MD,‡‡ Lynn Darbie, MS,§§ Eileen King, PhD,§§ and Carole Lannon, MD† for the National Pediatric Cardiology Quality Improvement Collaborative

*The Heart Institute, §§Division of Biostatistics and Epidemiology, †The James M. Anderson Center for Clinical Excellence, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; ‡Children's Hospital & Medical Center, Omaha, Neb, §University of Maryland School of Medicine, Baltimore, Md, ¶Boston Children's Hospital Medical Center, Boston, Mass, **Mattel Children's Hospital at UCLA, Los Angeles, Calif, ††Children's National Medical Center, Washington, DC, and ‡‡University of Texas Health Center, San Antonio, Tex, USA

**ABSTRACT**

***Background.*** Growth failure is common in infants with single ventricle. This study evaluated the use of a learning network, the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), to spread optimized nutritional practices and improve infant growth.

***Methods.*** A previously identified Nutritional Bundle was spread among NPC-QIC sites. Primary outcome: interstage weight-for-age z-score change (ΔWAZ) between discharge from stage 1 palliation (S1) and stage 2 surgical palliation (S2). Variation among sites in interstage ΔWAZ was evaluated before (Period 1) and after (Period 2) spread of Nutritional Bundle. We performed an analysis of NPC-QIC registry infants presenting for S2 at sites previously shown to have significant variation in interstage patient growth.

***Results.*** Four hundred seven infants from 15 sites underwent S2 between 2008 and 2013: 158 in Period 1 (December 2008–December 2010) and 249 in Period 2 (December 2010–April 2013). Median age at S2 was 4.9 months (2.6–12.8) with no difference between periods. There was significant variation in interstage ΔWAZ among sites in Period 1 ($P = .01$) but not in Period 2 ($P = .39$). More patients had an interstage ΔWAZ <0 in Period 1 (43%) than Period 2 (32%) ($P = .03$). In Period 1, the median interstage ΔWAZ was <0 in six sites while in Period 2 no site had median interstage ΔWAZ <0. Sites with the worst patient growth in Period 1 had marked improvement in Period 2 ($P = .02$, .06, and .06, respectively).

***Conclusions.*** Spread of optimal nutritional practices led to decreased variation in interstage growth with most improvement observed at sites with the worst baseline growth outcomes.

***Key Words.*** Nutrition; Hypoplastic Left Heart Syndrome; Variation; Quality Improvement

## Introduction

The past several decades have seen dramatic increases in survival in infants born with single ventricle anatomy. The typical staged surgical course for infants with hypoplastic left heart syndrome (HLHS) begins with the Norwood operation, followed several months later by superior cavopulmonary anastomosis (SCPC) with an ultimate goal of Fontan-type circulation.[1–3] Improvement in surgical and postoperative man-

**Funding**: This study was supported in part by a grant from the Cincinnati Children's Heart Association, and in part by cooperative agreement #HS016957 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

**Financial disclosure**: The authors have no financial relationships relevant to this article to disclose.

| NPC-QIC Nutrition Bundle |
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| Interstage weight monitoring with home scales |
| Use of "Red Flags" for interstage weight monitoring |
| Regular contact with families at home regarding weight gain and feeding |
| Availability of a Dietician to manage interstage nutrition questions |
| Standardized evaluation of feeding ability post-Norwood prior to discharge to interstage |

**Figure 1.** Nutritional Bundle. Specific practices associated with improved weight gain in the interstage period. "Red Flags" refers to specific cutoffs for poor daily weight gain.

agement has led to considerable improvement in early post-Norwood survival in the recent era.[4–7] Following the Norwood procedure and prior to SCPC, a time period termed "interstage," infants remain high risk, with mortality across many centers approximately 10–15%.[8–10]

Along with high mortality rates, adequate growth and nutrition are often difficult to attain in infants with HLHS. Poor growth is commonly seen in infants with congenital heart disease, and malnutrition is even more prominent in patients with complex congenital heart disease, such as HLHS.[11] This poor nutrition is associated with infection risk, increased hospital stay and mortality following cardiac surgery.[12–14] Several studies have suggested that a strict regimen of interstage nutrition and weight monitoring may improve survival among patients with HLHS; nonetheless, variation in outpatient nutrition and management in these infants is still common.[8,9,15] Large multicenter studies evaluating the efficacy of specific practices are lacking.

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is the first multicenter quality improvement collaborative within pediatric cardiology.[16] NPC-QIC's mission is to improve the outcomes of care for children with congenital heart disease through a national quality improvement collaborative network of multidisciplinary clinical teams and families, working together to collect longitudinal data and conduct quality improvement to accelerate the development and transition of new knowledge into practice. The collaborative network currently comprises 54 pediatric cardiology centers in North America that contribute data to a registry of infants with HLHS. This collaborative provides the infrastructure to better define optimized practices and outcomes in this relatively rare condition. Using NPC-QIC registry data, we previously demonstrated significant variation in the nutritional practices *and* growth patterns of infants with a single ventricle across surgical centers. Centers with better growth performance used nutritional practices that differed from practices used at other centers, and that allowed early identification of feeding difficulties and very close monitoring for early signs of growth problems. These optimal nutritional practices (home scales, outpatient dietician, weekly interstage contact with family, standardized post-S1 feeding evaluation) comprised a "Nutritional Bundle" demonstrated in Figure 1.[17]

The purpose of this study was to describe the effect on growth patterns of infants with HLHS enrolled in NPC-QIC after quality improvement techniques were used to educate participating surgical centers regarding these optimal nutritional practices and to spread these practices. We sought to describe variation in growth patterns among surgical centers before and after these optimized practices were disseminated.

## Methods

### *Study Design*

The aim of this project was to spread the use of a previously identified Nutritional Bundle of care among surgical site participating in NPC-QIC. The components of this Nutritional Bundle have been previously reported and can be seen in Figure 1.[17] In our previous analysis, we looked at combinations of individual nutrition practices used at NPC-QIC centers with better growth to find the most significant "bundle" of nutritional interventions affecting interstage weight gain. The combination of standard postoperative feeding evaluation before Norwood discharge and close weight monitoring in the interstage period with the use of home scales and specific weight gain/loss red flags resulted in the greatest effect, with an increase of interstage change in weight-for-age z-score (WAZ) of 0.98, compared with sites that did not use these monitoring interventions.[17] Sites received information via two methods: (1) at semiannual learning sessions, during which representatives from each site gather for face-to-face quality improvement and education meetings; and

(2) monthly action period calls, where teams learn and share clinical practices via phone conferences. Study data were collected from the NPC-QIC registry database. Teams were not required to report specific changes they made in clinical practice over the time of the study. Interstage growth of patients was compared at these sites before and after information about the Nutritional Bundle was disseminated to surgical sites.

We performed a retrospective analysis of patients enrolled in the NPC-QIC registry who had presented for their SCPC. Registry eligible patients are required to have a univentricular heart requiring a Norwood procedure and to be discharged home following their Norwood admission. Families consented to be enrolled in the registry and individual institutional review boards at each participating site approved enrollment. The initial study demonstrating growth and practice variation included 16 surgical sites for analysis; their patients completed the interstage and underwent SCPC between December 2008 and December 2010 (Period 1).[17] Patients from these same sites who completed their interstage care between December 2010 and April 2013 (Period 2), after implementation of the "Nutritional Bundle" within NPC-QIC, were included for analysis in the present study. The purpose of choosing these two time periods was to allow comparison of intersite variation before and after spread and implementation of components of the Nutritional Bundle.

### *Data Collection*

#### Demographic Data

Demographic data collected included gender, gestational age, race, and age at presentation for Norwood and SCPC. In addition, cardiac diagnosis and Norwood length of stay were also collected.

#### Anthropometric Measures

Anthropometric measures included birth weight and absolute weight and WAZ at the following three discrete time points: initial neonatal hospital admission, discharge following Norwood, and admission for SCPC. The change in WAZ between Norwood discharge and SCPC admission (i.e., the interstage WAZ change) was calculated for each patient. Zero change in WAZ was considered adequate growth, a WAZ change >0 was considered positive growth, and a WAZ change <0 was considered negative growth. WAZ scores were calculated using the Centers for Disease Control Epi-Info program (Centers for Disease Control, Atlanta, GA, USA).

#### Statistical Methods

Patient characteristics were summarized and compared between the two periods using percentages and chi-square tests for categorical data and mean with standard deviation and Wilcoxon rank sum tests for continuous variables.

The *primary outcome variable* was interstage WAZ change between neonatal discharge following the Norwood procedure and admission for the SCPC. Variation among centers in interstage WAZ changes was evaluated before (Period 1) and after (Period 2) implementation of the Nutritional Bundle using analysis of variance (ANOVA) with period, center, and period-by-center interaction. The growth patterns of patients who died or underwent cardiac transplantation in the interstage period were analyzed. In the cases of those patients who died or underwent cardiac transplantation, the most recent clinic or admission weight/WAZ prior to these events was used and compared with their Norwood discharge WAZ. ANOVA by period with Tukey–Kramer adjustment was used for multiple comparisons. Chi-square tests were used to compare percentages. $P$ values <.05 were considered statistically significant. All statistical analyses were performed using SAS version 9.3 (SAS Institute Inc., Cary, NC, USA).

## Results

### *Demographic Data and Group Comparisons*

During Period 1, a total of 158 infants successfully completed the interstage and presented for SCPC from 15 surgical centers (among the 16 surgical centers in the original analysis, one center enrolled only one patient in the registry during Period 2, so this site was excluded from the overall analysis). During the same time period, there were 14 patients who experienced interstage mortality and no patients underwent interstage transplantation. During Period 2, a total of 257 infants completed the interstage. During the same time period, there were 33 patients who experienced interstage mortality and six patients who underwent interstage transplantation. Eight patients for whom a valid change in WAZ could not be calculated were excluded from the analysis. All were from Period 2; three patients had a missing weight at Norwood or SCPC and five patients had inconsistent birth, Norwood or SCPC dates. There were no differences between groups in gender, race, diagnosis of

**Table 1.** Patient Characteristics

| Characteristic | Period 1 ($n$ = 158) | Period 2 ($n$ = 249) | $P$ Value |
|---|---|---|---|
| Female gender | 35% | 39% | 0.36 |
| Race | | | |
| Caucasian | 74% | 78% | 0.09 |
| African American | 13% | 16% | |
| Other | 13% | 7% | |
| Cardiac diagnosis | | | |
| HLHS | 64% | 71% | 0.17 |
| Gestational age, wk | 38.5 (1.4) | 38.4 (1.4) | 0.56 |
| Birth weight, kg | 3.21 (0.48) | 3.16 (0.52) | 0.51 |
| Norwood age, d | 7 (7) | 7 (8) | 0.81 |
| Norwood LOS, d | 38 (22) | 41 (27) | 0.39 |
| WAZ at Norwood discharge | –1.55 (0.9) | –1.61 (1.0) | 0.72 |
| Genetic abnormality | | | |
| Any syndrome | 11 (7%) | 18 (7%) | 0.92 |
| Down syndrome | 2 (1%) | 1 (0.4%) | 0.56 |
| Turner syndrome | 0 | 1 (0.4%) | 1 |
| CHARGE | 0 | 0 | — |
| 22q11 deletion | 0 | 0 | — |
| Heterotaxy syndrome | 3 (2%) | 7 (3%) | 0.75 |
| VACTERL syndrome | 0 | 1 (0.4%) | 1 |
| Other syndrome | 6 (4%) | 8 (3%) | 0.78 |

CHARGE, coloboma of the eye, heart defects, atresia of the nasal choanae, retardation of growth and/or development, genital and/or urinary abnormalities, and ear abnormalities and deafness; VACTERL, vertebral anomalies, anal atresia, cardiac defects, tracheoesophageal fistula and/or esophageal atresia, renal and radial anomalies and limb defects; WAZ, weight-for-age z-score; HLHS: hypoplastic left heart syndrome.

HLHS, gestational age, birth weight, presence of chromosomal abnormalities, age at Norwood, Norwood length of hospital stay, or WAZ at Norwood discharge (Table 1).

### *Nutritional Management*

At the time of Norwood discharge, 74% of the infants were being fed with any oral feeds, 44% were being supported with a nasogastric or nasojejunal tube, and 14% had a gastrostomy tube in place. The majority of patients were fed with human milk formula with only 19% being fed with breast milk alone. There were more patients fed with any oral feeds at time of Norwood discharge in Period 1 (83%) than in Period 2 (68%), and there were fewer patients with a gastrostomy tube at the time of Norwood discharge in Period 1 (10%) than in Period 2 (17%). There were no significant differences between Period 1 and Period 2 with regard to number of patients being fed via nasogastric or nasojejunal tube or whether feeds were formula, breast milk, or a combination of the two at the time of neonatal discharge.

### *Outcomes: Weight-for-Age Z-Score Changes*

As shown in Figure 2, during Period 1 there was significant variation in change in WAZ during the interstage period in patients cared for at each of the surgical sites ($P$ = .01). Figure 3 demonstrates WAZ changes for the same 15 sites in Period 2 after the nutrition bundle was disseminated throughout the collaborative. After dissemination of these optimized practices, there was no longer significant variation in patient growth among clinical sites. Within site, variation in patient growth persisted, but there were no surgical sites with median interstage WAZ changes <0 in their group of patients, whereas the median interstage WAZ change was <0 in six sites (40%) in Period 1. More patients had an interstage WAZ change <0 in Period 1 (43%) than Period 2 (32%)($P$ = .03). There were centers in this study where interstage growth worsened from Period 1 to Period 2, although not statistically worse, and no sites worsened to the point that patients' median WAZ was <0.

Figure 4 includes the interstage WAZ change for all patients at all 15 centers over both periods. The sites with the most significant improvement were those with the worst outcomes prior to the intervention. The three worst performing sites from Period 1 had the most impressive improvement in interstage weight gain. Site 1 had the most dramatic shift, with all but one patient experiencing an interstage WAZ <0 prior to Nutritional Bundle implementation and the majority of their patients with positive interstage growth afterward ($P$ = .02). Sites 2 and 3 also trended toward overall improved growth of their patients following implementation of these practices ($P$ = .06).

The growth patterns of patients who died or underwent cardiac transplantation in the inter-

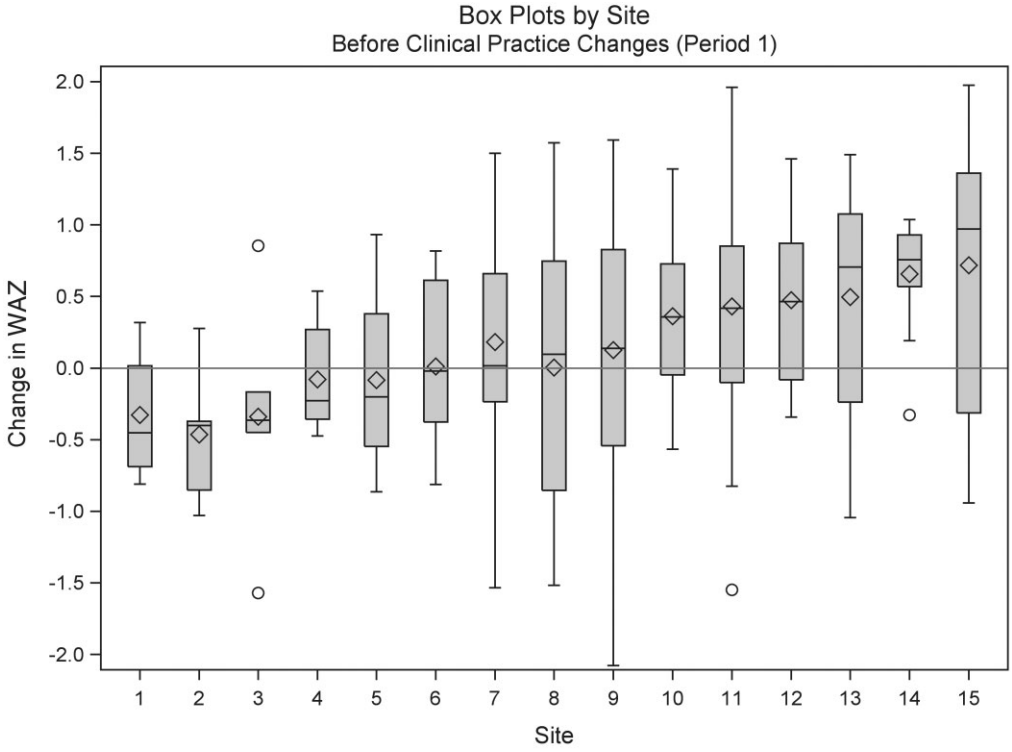


**Figure 2.** Weight-for-age z-score (WAZ) changes between Norwood discharge and SCPC, Period 1. WAZ, weight-for-age z-score; SCPC, superior cavopulmonary connection.

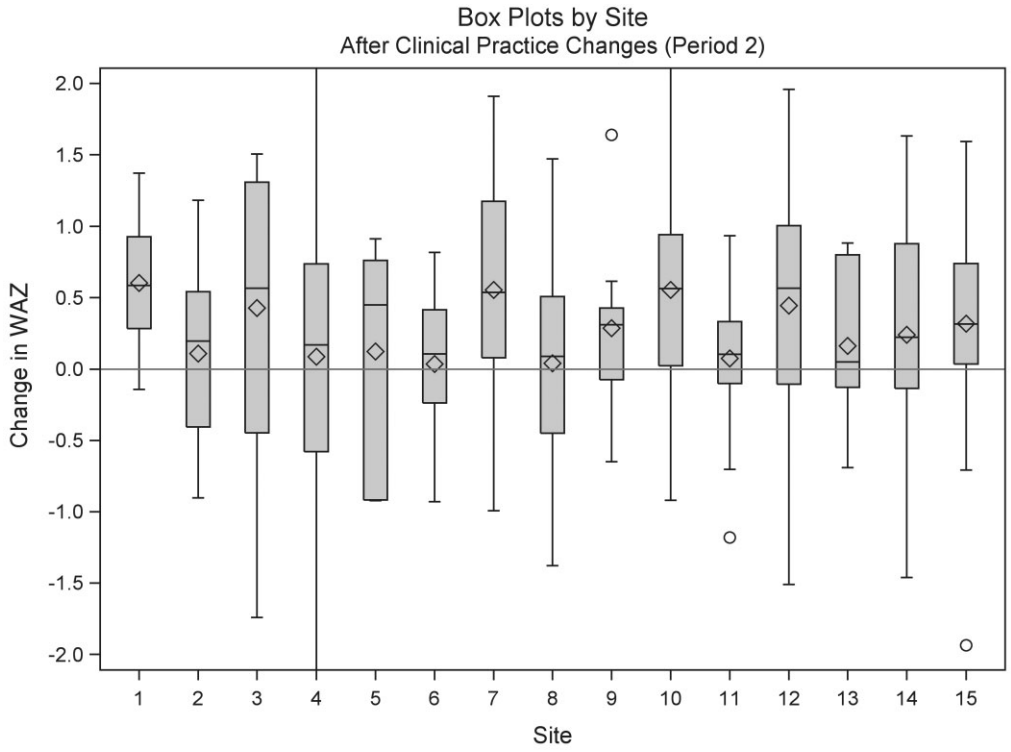


**Figure 3.** Weight-for-age z-score changes between Norwood discharge and SCPC, Period 2. WAZ, weight-for-age z-score; SCPC, superior cavopulmonary connection.

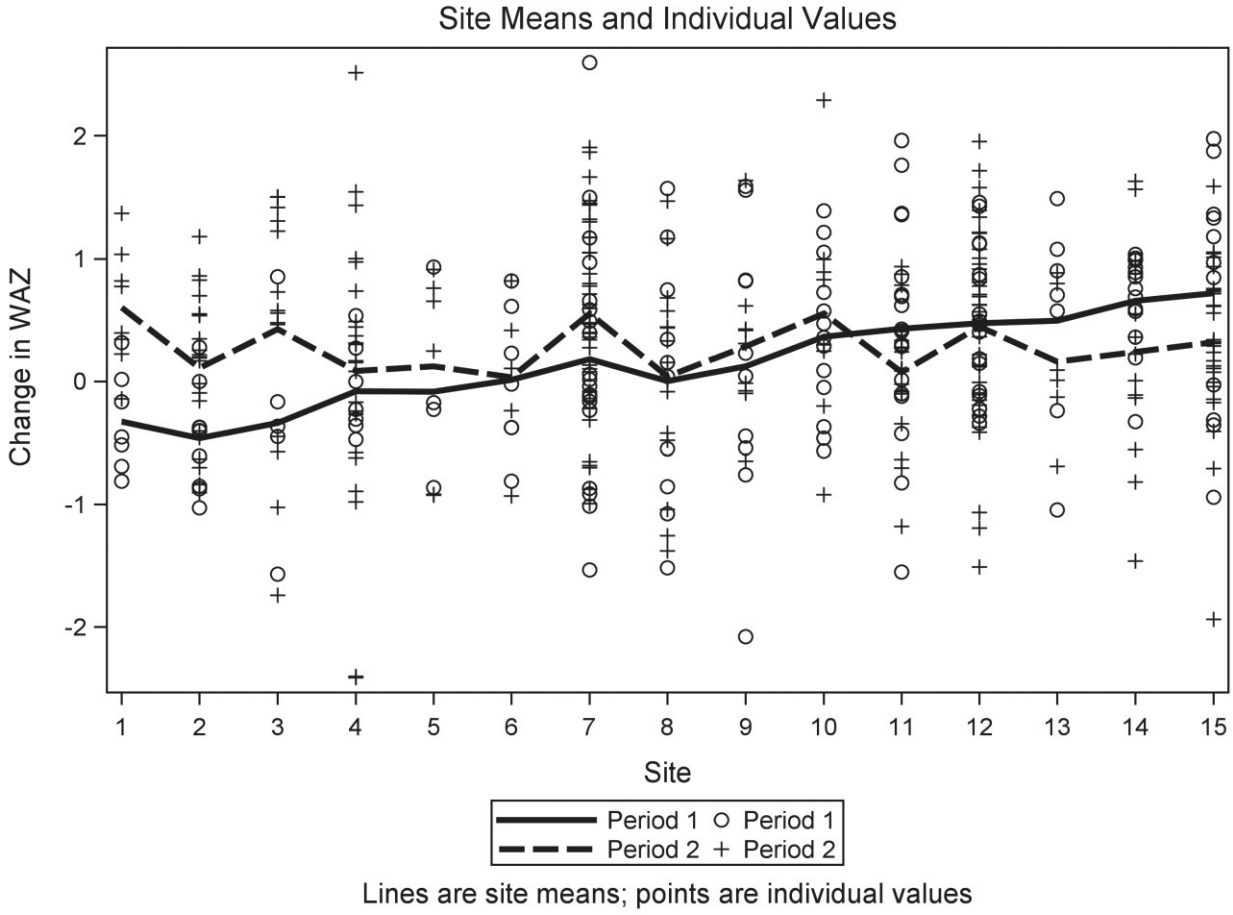


**Figure 4.** Weight-for-age z-score changes between Norwood discharge and SCPC, Periods 1–2. WAZ, weight-for-age z-score; SCPC, superior cavopulmonary connection.

stage period were analyzed. In Period 1, there were no transplants. There was no difference in change in WAZ between those who died and those who underwent SCPC ($P = .34$). In Period 2, there was a significant difference among the groups. Those who died had significantly different change in WAZ than those who underwent SCPC (–0.22 vs. 0.30; $P = .009$). There was no difference between those who underwent transplant and those who underwent SCPC or between those who died and those who underwent transplant. ANOVA by period with Tukey–Kramer adjustment in period 2 was used for multiple comparisons among died, Glenn, and transplant groups. There was no need for multiple comparison adjustment in Period 1 because there was no transplant group and we had only two groups. I did not have change in WAZ for 9 of the 33 patients who died. I did have change in WAZ for all patients who had a transplant.

## Discussion

As has been previously reported, we found considerable variation in interstage patient growth among surgical sites caring for infants with a single ventricle after the Norwood operation.[17] We demonstrated the effectiveness of using a learning network to identify practice variation, isolate optimal practices at sites with superior outcomes, and disseminate these practices with resultant improvement in patient outcomes. This study showed that implementation of standard nutritional practices can improve interstage growth, most prominently in centers with poorer baseline patient outcomes. This improved growth was in the face of more patients supported with gastrostomy tube feeding during the follow-up period but no statistically significant increase in use of nasogastric or nasojejunal tube feeding. Even in a complex patient population, there can be reduc-

tion in variation in care and improvement in outcomes through sharing and implementing standard practices.

Infants with single ventricle heart disease are among the most complex patients within the field of congenital heart disease. Over several decades, improvement in surgical and postoperative management has reduced early mortality in this population.[7] Despite surgical and medical improvements, variation in practice is common among individuals and institutions caring for children with congenital heart disease and, importantly, this variation in practice has been associated with variation in patient outcomes.[17–20] Reduction in variation is known to lead to safer practices, improved quality outcomes, and a reduction in cost in medical practices as well as in other industries.[21–25]

There has been a long-held belief among those who care for infants with complex congenital heart disease that their complex medical problems prohibit normal growth. While this study does not explain the individual patient factors that affect growth, it does demonstrate that the overall incidence of growth failure in this high-risk population may be reduced through standardization of specific identified nutritional practices. This standardization is more important and more effective in sites that have poor baseline performance.

The primary driver of most of the components of the nutrition bundle that was identified and disseminated is attention to early signs of growth failure in this fragile population that is so prone to this problem. Early identification allows for earlier changes in nutritional management to potentially correct this deviation. Certain components of the growth bundle are resource intensive (e.g., equipment needed to check daily weights or services of a dietician as part of the team caring for these infants). Some of the teams involved in this analysis had difficulties convincing hospital or divisional leadership to invest in these resources. These data demonstrate that investment in these resources can result in real improvement of patient outcomes. Furthermore, while the relationship between better interstage growth and later surgical outcomes warrants further study, it has been noted that there is a relationship between better early growth and more favorable later surgical outcomes, including reduction in hospital length of stay.[14,26]

Understanding variation and identification of optimal practices is crucial. This is especially true in areas of medicine where evidence-based practices have not been established and where drivers of outcomes are still poorly understood. Infants with single ventricle congenital heart disease, most commonly HLHS, are one of these populations that, while we have a much clearer understanding of their management than two decades ago, still present caregivers with clinical and outcome conundrums. Growth problems are only one of the issues that infants with HLHS face early in life. Despite best efforts, mortality in the first several months of life in this group of patients is still unacceptably high.[27] One of the first steps to understanding variation and drivers of outcomes in an unclear clinical scenario is to standardize processes using best or at least the most "sound" clinical practices. Standardization of practices reduces process variation and provides a foundation on which new approaches can be tested more effectively.

While this study demonstrated the effectiveness of dissemination of nutritional practices on growth of patients, it is limited by its retrospective nature. Only patients who were eligible and consented were enrolled in the NPC-QIC registry. Self-audits by participating sites indicate that over 95% of eligible infants are included in the registry. Nevertheless, there may have been clinical differences between patients enrolled in the registry and those who were not enrolled in the registry. The NPC-QIC registry includes site- and patient-specific data deemed important to understanding the clinical course of this high-risk group of infants and to offer a foundation for starting to reduce variation and perform quality improvement work. Information about the Nutritional Bundle was shared with sites via in-person meetings and over webinars. The NPC-QIC registry does not ask specifically about each of the elements of the nutrition bundle and we did not require additional tracking of specific practices at individual sites. Therefore, it is unknown whether these nutritional practices were applied uniformly to all patients at each site or what practice patterns changed at individual sites. Because individual practice elements were not recorded, we cannot exclude some component of a Hawthorne effect in these changes as well. Future work in this area will include tracking of these specific nutritional practices and better understanding the effect of each of these practices on growth patterns. It is also important that we gain a better understanding of the economics of these changes and their effect on future health care expenditures. Finally, while there was improved variation among centers, there

are still individual patients who experience growth failure. We need to continue to pursue specific etiologies for growth failure in this population to continue to reduce the incidence of growth failure.

The findings in this study were made possible because of the cooperation among multiple clinical centers involved in the NPC-QIC. When caring for infants and children with rare conditions, it is difficult to determine optimal practices because of the limited number of patients an individual provider or center cares for. As we seek to find and implement practices that will lead to improved outcomes in our patients, it is imperative that we cooperate and share practices and outcomes among caregivers through patient registries and collaborative groups. The importance of these activities has been recognized by the American Board of Pediatrics. In fact, requirements for maintenance of certification now emphasize assessing quality of care and demonstrating systematic improvement of care for children, a requirement that can be met by involvement in these types of groups.[28]

## Conclusion

Variation exists in the nutritional practices and growth patterns of infants with a single ventricle when these factors are compared across surgical centers. Dissemination of optimal nutritional practices leads to reduced variation and improvement in patient growth, especially in sites with poor baseline outcomes. In this case, optimal practices included home scales during the interstage period, utilizing an outpatient dietician as part of the team caring for these patients, weekly interstage contact with family regarding growth, and a standardized post-Stage 1 feeding evaluation prior to Stage 1 discharge. Understanding this variation and the suggestion of optimal growth monitoring practices is the first step in standardizing nutritional monitoring and moving toward elimination of growth failure in this high-risk group of infants. The involvement in national collaborative and registries makes it possible to answer clinical questions about patients with uncommon disease processes.

## Author Contributions

Dr. Anderson conceptualized and designed the study, drafted the initial manuscript, and approved the final manuscript as submitted. Dr. Beekman is the Chair of the Governing Council of the National Pediatric Cardiology Collaborative. He assisted in the conception of the research and significantly contributed to writing the manuscript. He approved the final manuscript as submitted. Drs. Kugler, Rosenthal, Jenkins, Klitzner, Martin, and Neish comprised the Governing Council of the National Pediatric Cardiology Collaborative and directed the research. They significantly participated in writing the initial manuscript and editing the manuscript, and approved the final manuscript as submitted. Ms. Darbie and Dr. King carried out the analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted. Dr. Lannon is the quality improvement lead for the National Pediatric Cardiology Collaborative, assisted in the conception of the research and significantly contributed to writing the manuscript, and approved the final manuscript as submitted.

**Corresponding Author:** Jeffrey B. Anderson, MD, MPH, MBA, The Heart Institute, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, ML 2003, USA. Tel: 513-636-3865; Fax: 513-636-3952; E-mail: jeffrey.anderson@cchmc.org

*Conflict of interest:* The authors have no conflicts of interest relevant to this article to disclose.

*Accepted in final form: October 2, 2014.*

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