Improvement in Interstage Survival in a National Pediatric Cardiology Learning Network

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Goals and Vision of the Program

Infants with univentricular congenital heart disease (CHD), including those with hypoplastic left heart syndrome (HLHS), regularly pose dilemmas in decision-making because their anatomy and physiology are often unique and variable. The typical staged surgical course for infants with complex univentricular anatomy with systemic outflow obstruction begins with the Norwood (stage 1) operation or variant shortly after birth, followed several months later by superior cavopulmonary anastomosis (stage 2 palliation) with an ultimate goal of a Fontan-type operation several years later.[1–3] Improvement in surgical and postoperative management has led to considerable improvement in early post-Norwood survival in the recent era.[4–7] However, after the Norwood procedure and before stage 2 palliation, a high-risk time period termed interstage, mortality has been previously been reported at 10% to 15%.[8–10] The rare nature of this disorder has limited robust learning about successful strategies to improve survival undertaken by single-surgical centers, and a gap exists in our ability to further improve mortality in this population.

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), the first multicenter learning network within pediatric cardiology,[11] was established with the goal of improving care and outcomes for children with univentricular heart after the Norwood operation and specifically to (1) improve interstage mortality, (2) decrease interstage growth failure, and (3) reduce interstage hospital readmissions for major medical events.

Local Challenges in Implementation

There were several perceived challenges to success in changing clinical outcomes before starting the NPC-QIC collaborative. A primary challenge in collaboration among multiple sites can be agreement on best practices that should be implemented. This is especially true for rare diseases, such as univentricular heart disease, where evidence-based clinical guidelines are not available to clinicians. As noted above, major variation persists in management practices among individuals and institutions caring for children with HLHS and other forms of univentricular CHD.[8,12–16] Although NPC was designed as a learning collaborative, it was unclear whether teams of caregivers would be willing or interested in changing practices or whether there would continue to be persistent variation. A second challenge was the linkage between process measures and clinical outcomes. Although expert opinion and literature (where available) were used to design clinical practices expected to be related to reduction in mortality, it was unclear at the onset of the collaborative, whether adherence to these specific practices would indeed move mortality. We expected challenges in measuring adherence to processes and measuring outcomes in a learning network that would have rolling enrollment with new centers joining each year. Finally, it was felt to be essential that clinical care teams actively participate in the collaborative, including attending face-to-face NPC-QIC meetings. There was some concern that it would be difficult to gain institutional buy-in locally, so clinical teams would have support to do this work. The challenges of team buy-in and implementation of change practices were primarily addressed building the program with engagement of national leaders in the field of congential heart disease. We addressed the measurement challenges by working closely with experts in statistical process control (SPC) from the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center and the consultant firm Associates in Process Improvement.

Received December 30, 2014; accepted May 5, 2015.

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The Data Supplement is available at http://circoutcomes.ahajournals.org/lookup/suppl/doi:10.1161/CIRCOUTCOMES.115.001956/-/DC1.

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(*Circ Cardiovasc Qual Outcomes.* 2015;8:428-436. DOI: 10.1161/CIRCOUTCOMES.115.001956.)

Table 1. Key Metrics Reported on Each Patient in the NPC-QIC Registry

Measure	Goal	Data Definitions
Mortality	0%	Numerator: cumulative no. of deaths between discharge after Norwood repair and completion of stage 2 repair (ie, the interstage)
		Denominator: cumulative no. of parents who had a Glenn, died, or had a heart transplant
Mortality G-chart	***	No. of patients who were admitted for glenn surgery between patients who died
Major event readmission	0%	Numerator: no. of interstage readmissions for a major event
		Denominator: no. of patients who had at least 1 interstage day n the month/100
Major event G chart	***	No. of patients who were admitted for Glenn surgery between patients who had a major event readmission
Average daily weight gain	90%	Numerator: number achieving a minimum age-appropriate daily weight gain between Norwood discharge and Glenn admission
		Denominator: no. of patients admitted for Glenn surgery
Weight for length achievement	***	No. of patients with adequate growth between patients with growth failure events. A growth failure event is defined as decreasing ≥2
		Weight for length percentile bands over the course of the interstage (Norwood discharge to Glenn admission)
Proportion of discharges with identified discharge coordinator	100%	Numerator: no. of discharges with identified discharge coordinator
		Denominator: no. of patients discharged alive after Norwood
Proportion of discharges with complete preventative care plan	100%	Numerator: no. of discharges with documented immunization status at discharge, and plan for RSV and influenza prevention discussed
		Denominator: no. of patients discharged alive after Norwood where site indicates that routine immunizations are recommended during the interstage
Proportion of discharges with written medication list	100%	Numerator: no. of discharges with written medication list provided
		Denominator: no. of patients discharged alive after Norwood
Proportion of discharges with written Red-Flag Action Plan	100%	Numerator: no. of discharges with written red-flag action plan provided to families
		Denominator: no. of patients discharged alive after Norwood
Proportion of discharges with written nutrition plan	100%	Numerator: no. of discharges with written nutrition plan provided to families
		Denominator: no. of patients discharged alive after Norwood
Proportion of discharges with follow-up plan with PCP and primary cardiologist	100%	Numerator: no. of discharges with identified PCP, identified primary cardiologist, and scheduled appointments or contact information for self-scheduling
		Denominator: no. of patients discharged alive after Norwood
Proportion of clinic visits with identified postclinic care coordinator	100%	Numerator: no. of clinic visits with an individual or group identified for coordinating the outpatient management of the patient
		Denominator: total no. of clinic visits for interstage population that month
Proportion of clinic visits with updated preventative care plan	100%	Numerator: no. of clinic visits with documented immunization status and plan for RSV and influenza prevention discussed
		Denominator: no. of clinic visits during the month where site indicates that routine immunizations are recommended during the interstage
Proportion of clinic visits with updated written medication list	100%	Numerator: no. of clinic visits with updated written medication list provided
		Denominator: total no. of clinic visits for interstage population that month
Proportion of clinic visits with updated written red-flag action plan	100%	Numerator: no. of clinic visits with updated red-flag action plan provided
		Denominator: total no. of clinic visits for interstage population that month
Proportion of clinic visits with growth parameter documentation	100%	Numerator: no. of clinic visits where weight, weight for age percentile, average daily weight gain and current caloric intake is documented
		Denominator: total no. of clinic visits for interstage population that month
Proportion of clinic visits with updated nutrition plan	100%	Numerator: no. of clinic visits with updated nutrition plan provided
		Denominator: total no. of clinic visits for interstage population that month
Proportion of clinic visits where clinic visit information was communicated to PCP	100%	Numerator: no. of clinic visits with documented communication to PCP of clinic visit information
		Denominator: total no. of clinic visits for interstage population that month

PCP indicates primary care physician; and RSV, respiratory syncytial virus.

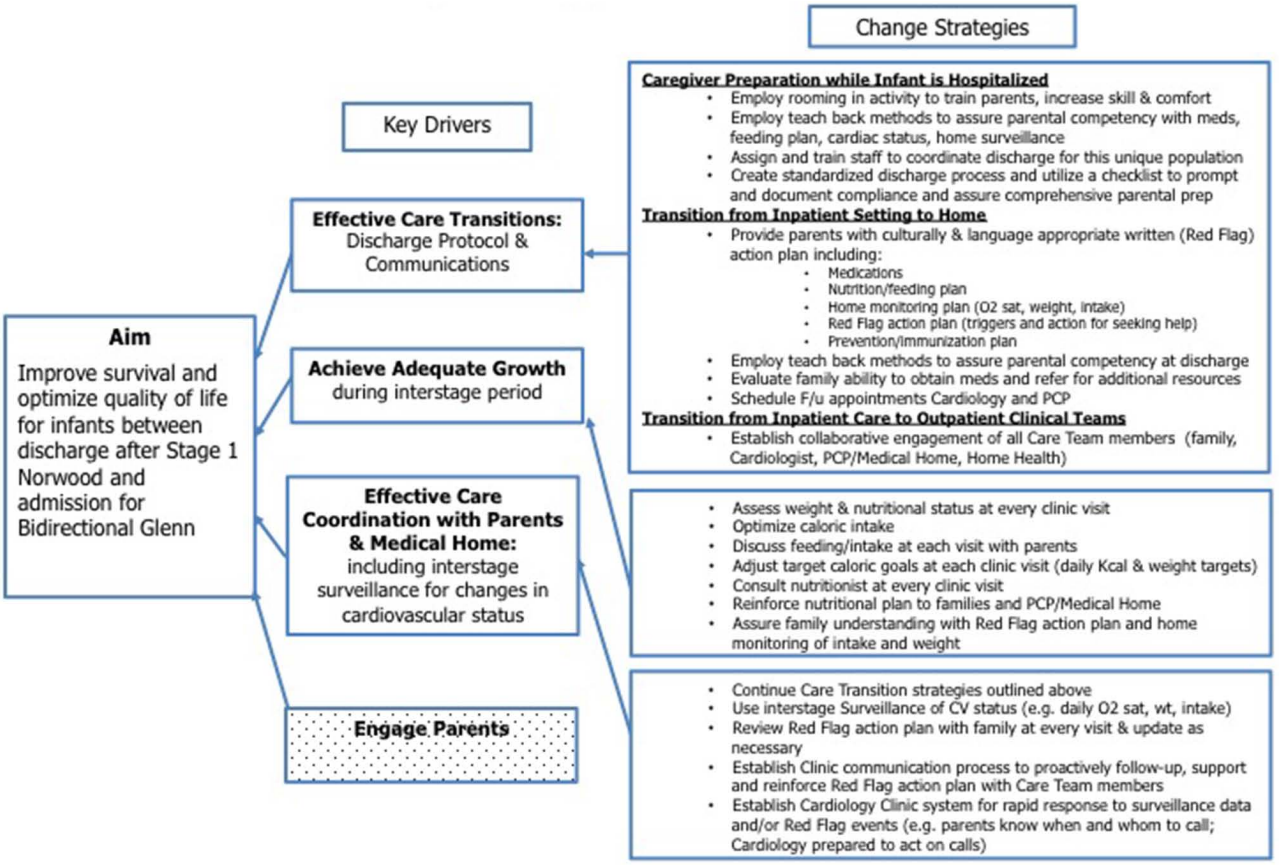

Figure 1. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) key driver diagram.

Design of the Initiative

Conceptual Model

NPC-QIC is a longitudinal learning community modeled after the Institute of Medicine learning healthcare system framework.[17] These networks are multisite collaborations that focus on both improvement and research and engage patients, families, clinicians, and researchers in working together to improve outcomes. They provide a resource for understanding variation in clinical care and opportunities to test changes in clinical practice to improve care. Large networks with registries provide the infrastructure to gather information on patients across treatment centers and to understand differences in care processes and clinical outcomes and to reduce unnecessary variation.[18–20] Learning networks may be especially useful in rare medical problems, such as complex CHD, where no one center is able to care for enough cases to learn about potential optimal practices. Regional and national networks and databases have also been established to better understand care of pediatric cancer, inflammatory bowel disease, neonatal management, and cystic fibrosis.[21–24]

Improvement Methodology

NPC-QIC's improvement method is based on an adapted Institute for Healthcare Improvement's Breakthrough Series Model, which incorporates knowledge about dissemination and behavior change to support practice change.[25] Pediatric cardiology centers participate through local teams comprised of a physician champion, nursing, nutrition, and family representatives. Each month, teams submit data on patient status and care processes; postreports of their progress; participate in webinars and a listserv; and test changes to improve their systems. Teams receive monthly reports from NPC-QIC demonstrating results of their local clinical processes and outcomes, as well as those of the entire network for benchmarking (Table 1). Semiannual learning session workshops bring teams and parents together to share lessons learned about clinical process changes.

Theory for Mortality Improvement

Evidence (literature, where available) and expert opinion were used to identify clinical practices expected to be related to improvement in interstage mortality (key driver diagram: Figure 1). These care processes are grouped into 4 domains or key drivers: (1) care coordination, (2) care transitions, (3) interstage growth, and (4) engaging families. Example processes include applying standard Norwood discharge procedures, providing families with a written action plan for acting on clinical Red Flags that may arise in the interstage and communicating the care plan to the infant's primary care physician at the time of discharge after stage 1 palliation and when updated at interstage clinic visits.

To address concerns for buy-in from local teams and institutions, several steps were taken. The leadership of NPC-QIC was made up of a group of national experts in CHD. The Joint Council on Congenital Heart Disease (JCCHD) was formed

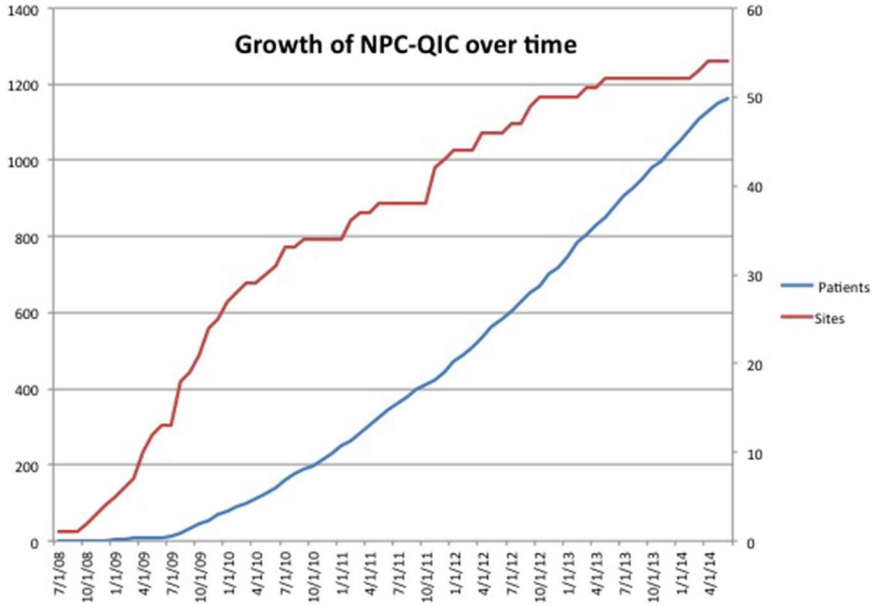

Figure 2. Growth of National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC). Growth in number of NPC-QIC teams (red) and patients enrolled (blue).

in 2003 as an alliance between pediatric cardiologists, congenital cardiothoracic surgeons, and adult CHD specialists. This group founded NPC-QIC in 2006. This leadership at the national level gave instant clinical credibility to the collaborative. At the local team level, NPC-QIC leadership made a point to encourage local teams to include clinician and parent involvement, allowing parental voice to push teams for improvement. NPC-QIC leadership also worked with US News and World Report to add involvement in NPC-QIC as a line item point on the scoring system for Cardiac and Cardiothoracic Surgery Programs, increasing the value to institutions. In addition, the American Board of Pediatrics Maintenance of Certification Part 4 credit was made available to participating physicians. The engagement of clinical leaders and parents, as well as the alignment with US News and the American Board of Pediatrics, helped drive the involvement of institutions and teams and buy-in to quality improvement activities.

Table 2. Demographic Data

	n (%); Mean (25%–75%)
Female sex	440 (37%)
Race	
White	860 (74%)
Black	165 (14%)
Other	138 (12%)
Cardiac diagnosis	
HLHS	781 (67%)
Gestational age, wk	38.4 (38–39)
Birth weight, kg	3.2 (2.9–3.5)
Norwood age, d	6.3 (4–7)
Norwood LOS, d	42 (24–53)

HLHS indicates hypoplastic left heart syndrome; and LOS, length of stay.

Data Collection

The NPC-QIC registry captures information about infants with a univentricular CHD who undergo a Norwood procedure or variant with ultimate plan for a stage 2 palliation. Institutional Review Boards at all participating sites approved their participation. Infants become eligible for registry inclusion when they are discharged home from their Norwood surgery; patients who are eligible and consented are enrolled in the registry. Patients who spend their entire interstage hospitalized are not eligible and are not included in the registry. At the time of this discharge, data from their surgery and initial hospitalization are captured. Additional clinical information is then collected from each outpatient visit and readmission to the hospital during the interstage and information about each interstage transplantation or mortality. Finally, data are collected on admission for stage 2 surgical palliation and the hospitalization that follows this surgery. Data are collected at the site level and entered into an electronic registry using the Research Electronic Data Capture system.

Statistical Methodology

NPC-QIC uses SPC methods and charts to measure and report progress. This is a novel approach in the fields of pediatric cardiology and cardiac surgery. As with all rare diseases, the low incidence of HLHS presents a challenge to the ability to measure changes in care process or outcome performance using traditional statistical methods.[26] Combining data from individual sites improves the statistical power to measure differences and the effects of changes over time. SPC methods combine rigorous time series analysis methods with graphical presentation of data, allowing meaningful interpretation of data despite the relatively small numbers of patients in the population of interest.[27–29] SPC charts document statistical changes to a system using control limits, which define 3 SDs above and below the mean. Statistical rules determine when there has been a significant change to the system and identify

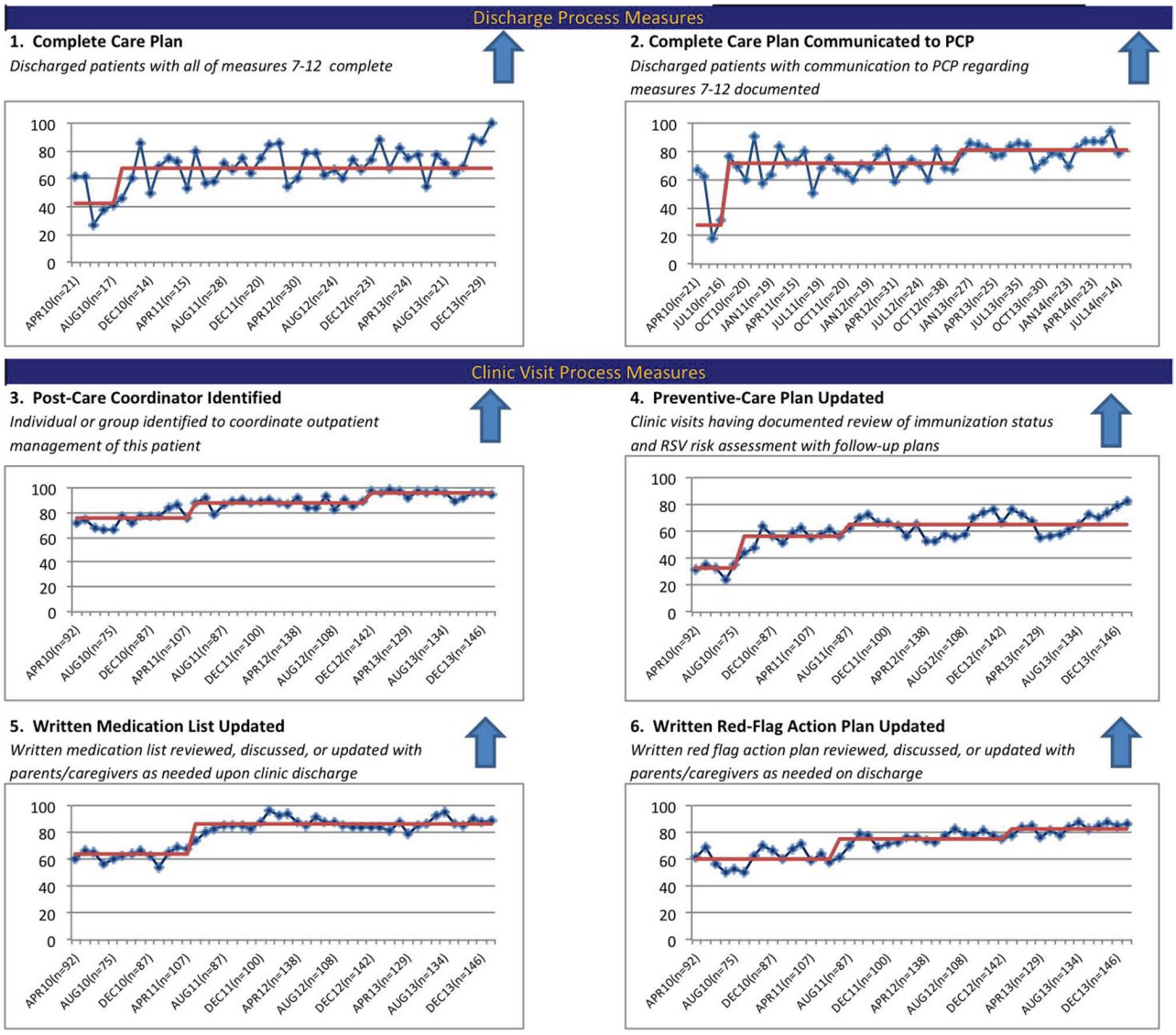

Figure 3. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) primary clinical process measure improvement. Network-wide improvement in care processes measures. Each point indicates the network-wide compliance with the specific measure, as a percentage of patients who received that measure. The red line indicates the network-wide average. The line is moved when rules for special cause are met, indicating a statistical change to the system. PCP indicates primary care physician; and RSV, respiratory syncytial virus.

measurement points that fall outside the statistical control limits. Several SPC charts are used by NPC-QIC to identify system changes. These include G charts, P charts, and cumulative sum (CuSum) charts. G charts track time and distance between rare events. In this case, NPC-QIC tracks the number of infants who successfully complete the interstage between mortalities. P charts document percentage of events, here tracking the percentage of mortalities per interstage patient for the collaborative on a monthly basis. Finally, a CuSum chart determines the accumulation of small changes to a system over time.

Implementation of the Initiative

The NPC-QIC interstage project was implemented in 2008 with a group of 6 pilot sites. Since then, the network has grown to 55 sites (Figure 2; Appendix A in the Data Supplement) with a rolling onboarding system, and now, it includes the majority of centers that perform staged palliation for univentricular CHD in the United States. Since 2008, there has been steady growth of the number of infants enrolled in the registry. However, since October 2012 when the 50th surgical site joined the network, only 4 additional surgical sites have been added, leading to a fairly stable system of surgical centers since late 2012. Self-audits by participating sites twice yearly indicate that >95% of eligible infants at participating centers are consented and included in the registry. Over half (54%) of centers report regularly involving parents of HLHS patients in their local improvement work. We have had few barriers in engaging care teams at local sites, but it has been a challenge to get each team to find and engage parents in the teams in a meaningful way. We have worked closely with a parent group, Sisters By Heart, to identify parents that would like to be involved at each center. However, working with parents on this type of project is not something that many clinicians

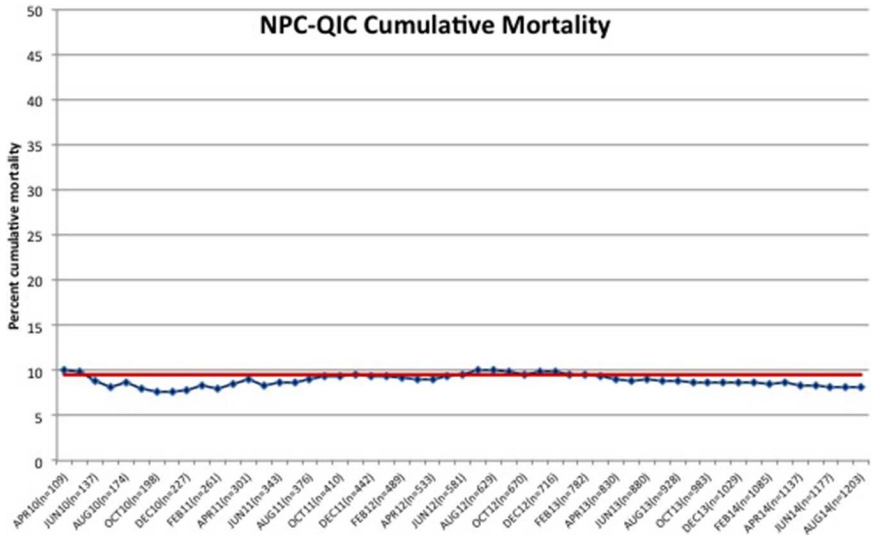

Figure 4. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) cumulative mortality. Network-wide cumulative mortality. Total number of interstage deaths divided by the total number of infants enrolled in the registry (all infants who completed the interstage with stage 2 palliation or experienced interstage mortality/transplant). Figure starts in 2010 when metric was stable within the collaborative.

have done before. However, with education and shared practices among sites, we have had steady improvement in parent involvement at the local level over time.

Success of the Initiative

To assess the effect on care and outcomes, we analyzed data for all infants enrolled in the NPC-QIC registry that completed the interstage (ie, underwent stage 2 palliation, transplant, or died in the interstage) between July 2008 and July 2014. This analysis included data for 1163 infants from 52 surgical centers; 1050 (90.2%) completed the interstage with Stage 2 palliation, 18 (1.5%) underwent transplantation during the interstage, and 95 (8.1%) experienced interstage mortality. The demographic makeup of these patients can be found in Table 2.

Care Process Measures

Significant improvement has occurred over time in many of the care processes identified as having potential to affect mortality (Figure 3). In addition to improvement in these processes, several additional practices have been developed by and spread among participating sites over the course of the past several years, including (1) having caregivers rooming-in with the infant for 24 hours before discharge; (2) conducting a call or meeting among the cardiology team, referring primary care physician and family caregivers before discharge with an intent of facilitating transition; (3) establishing a single ventricle clinic (with a focused, dedicated clinical team) for outpatient follow-up of these infants; and (4) connecting families at diagnosis with Sisters by Heart, a nationwide parent support group.

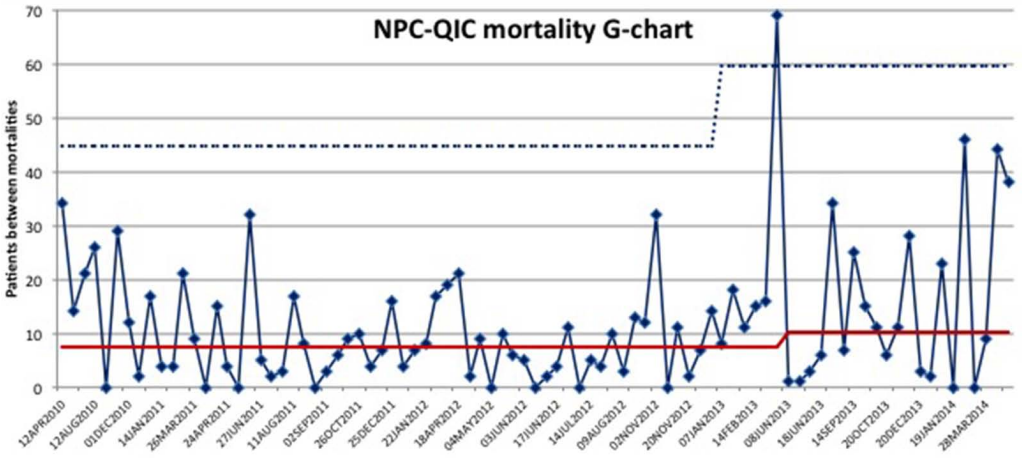

Figure 5. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) mortality G chart. Each point indicates an interstage mortality on the date the mortality occurs. The *y* axis indicates the number of infants successfully completing the interstage between each mortality. The red line indicates the median number of infants completing the interstage between each mortality, and the blue dotted line denotes the statistical upper control limit. Figure starts in 2010 when metric was stable within the collaborative.

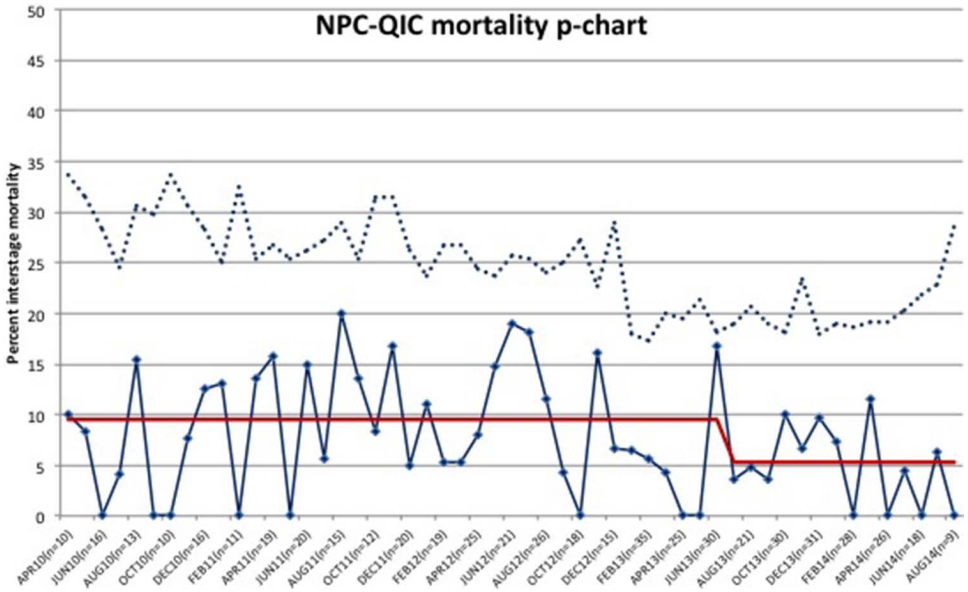

Figure 6. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) mortality P chart. Each point indicates monthly interstage mortality rate within the network. The solid red line is the median monthly mortality percentage, and the dotted black line is the upper control limit. Figure starts in 2010 when metric was stable within the collaborative.

Interstage Mortality

Before NPC-QIC's inception, interstage mortality had been reported by multiple single-center studies to be 10% to 15%.[8–10] It was recognized early in the network that cumulative interstage mortality, defined as the total number of interstage deaths divided by all infants who were discharged after stage 1 palliation and completed the interstage (stage 2 palliation or interstage mortality/transplant), was lower among participating centers than previously reported, being consistent between 8% and 10%, as seen in the NPC-QIC cumulative mortality chart (Figure 4). However, a cumulative mortality chart becomes increasingly insensitive over time to identify changes in a system.

Therefore, to identify potential signals of improvement in network interstage mortality, we turned to the more sensitive G chart. As noted in Figure 5, the system of interstage mortality was stable until a point of special cause above the statistical upper control limit occurred in June 2013 when a total of 68 infants completed the interstage between mortalities. A shift in the pattern of the chart was also noted after the point of special cause. We confirmed this improvement in mortality using a P chart and CuSum chart. The P chart (Figure 6) demonstrated

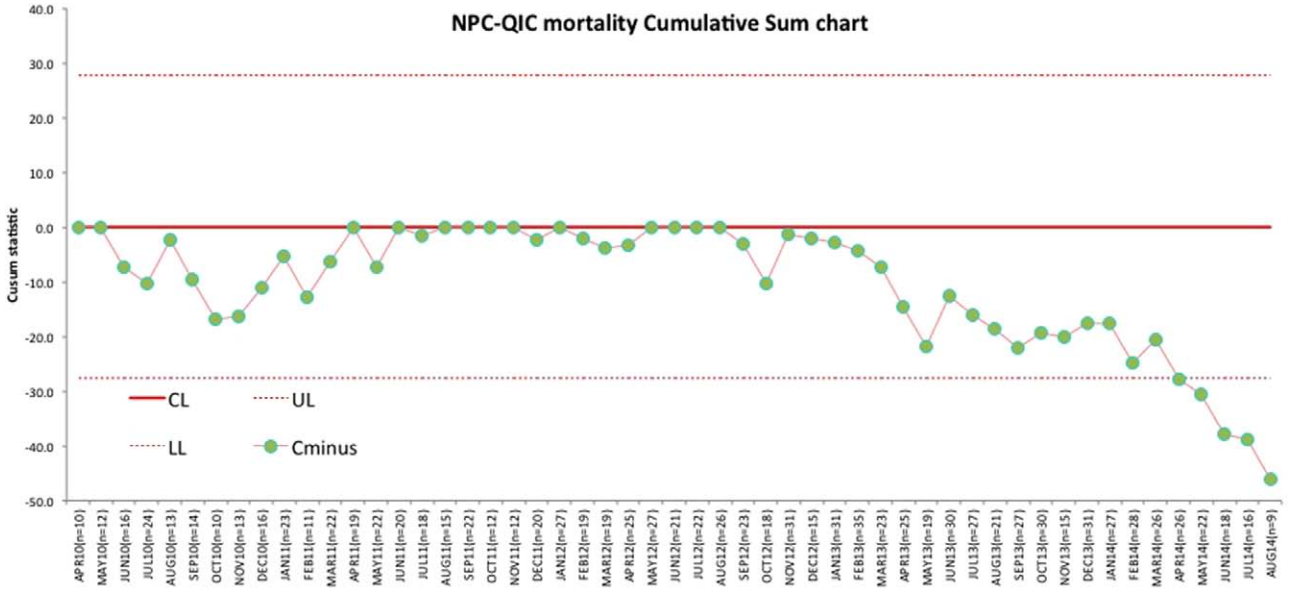

Figure 7. National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) cumulative sum (CuSum) chart. Each point indicates the cumulative deviation from a historic mortality level. The green line demonstrates cumulative deviation from a target of 9.5% mortality, the NPC-QIC cumulative mortality from 2008 to May 2013. A significant change was first noted in April 2014 with continued reduction in mortality thereafter. Figure starts in 2010 when metric was stable within the collaborative. CL indicates center line (median); LL, lower control limit; and UL, upper control limit.

a shift in mortality from 9.5% to 5.3% beginning in June 2013. The P-chart analysis helped to confirm the suspicion that the interstage mortality system had shifted. Second, we analyzed the system using a CuSum chart (Figure 7), which used the network's mean mortality from 2008 to May 2013 (9.5%) and subtracted each month's mortality percentage from this value, therefore cumulating these deviations. The slope of the change indicates the significance in the cumulative deviation, as did the fact that the measure crossed the statistical lower control limit of the chart in April 2013 and continued on the same negative slope thereafter. This analysis (Figure 7) provided additional support for a conclusion that there was a decrease in mortality across the network, beginning in early 2013.

Using the mortality G chart as the initial indicator of a change in our system and supporting this finding with additional analysis using the P chart and CuSum charts, we recalculated the NPC-QIC cumulative mortality chart starting June 2013. Cumulative aggregate mortality between 2008 and May 2013 in NPC-QIC centers was 9.5%, lower than published previously. From June 2013 to August 2014, cumulative aggregate mortality was 5.3%, a relative reduction of 44%.

Summary of the Experience, Future Directions, and Challenges

Although there had been considerable improvement in postoperative Norwood mortality in infants with HLHS in the past 2 decades, the most recent literature would suggest continued moderate rates of early mortality in this population, including during the interstage period. We have demonstrated a reduction in interstage mortality for infants cared for in centers participating in the NPC-QIC collaborative quality improvement network. Although this improvement is certainly multifactorial in cause, we think that increased reliability in important care processes thought or known to be associated with mortality (Appendix A in the Data Supplement) is a significant factor as we are unaware of any new medications or other therapies introduced during the program period. It is not possible, nor was it our objective, to identify singular changes in care that led to the reduction in mortality. However, this improvement in outcome was achieved at pediatric cardiac centers actively participating in NPC-QIC, a learning healthcare system applying quality improvement methodology. We do not know, however, the level of changes in mortality seen in control centers not involved in the NPC-QIC collaborative, over the same time period. NPC-QIC's activities facilitate the identification of practice variation, isolation of optimal clinical practices, and rapid dissemination of these practices across centers to improve care and outcomes.

Infants with single ventricle heart disease are among the most complex patients within the field of CHD and, indeed, within the healthcare system as a whole. Wide variation in care practices persists among individuals and institutions caring for children with CHD, and this variation has been tied to variation in patient outcomes.[12–14,30] Furthermore, numerous reports demonstrate that reduction in variation leads to safer practices, improved quality outcomes, and a reduction in cost.[22,24,31–33] One of the primary aims of a learning healthcare system, such as NPC-QIC, is to identify areas of variation, identify best or promising care practices, and to provide a forum to share and spread those practices. In a complex system, such as that needed to care for children with univentricular CHD, cooperation and sharing of practices accelerate the discovery of new information and the spread of that information.

A major obstacle to improving care for infants with HLHS is the rare nature of the condition; no one center alone can have the experience or expertise to define optimal care and outcomes. These limitations can be overcome in part by collaboration among centers. Furthermore, our experience demonstrates that improvements can be identified in rare populations by applying SPC methods to monitor changes in metrics. Simply monitoring the cumulative mortality within the network did not identify changes in mortality (despite real changes in the system) because cumulative mortality becomes increasingly insensitive to change over time as the denominator increases. The addition of the G chart, P chart, and CuSum chart analyses, classic SPC methods, allowed for identification of changes that had recently occurred within the system.

Although parents and clinicians have been thrilled with the reduction in mortality seen thus far in NPC-QIC, it is clear that more work needs to be done to achieve further reductions. Future work in this collaborative will focus on understanding of variation and identification of best surgical and postoperative management surrounding stage 1 palliation in an effort to further improve outcomes.

Sources of Funding

Current funding sources for National Pediatric Cardiology Quality Improvement Collaborative include (1) a grant supporting partial infrastructure funding from the Children's Heart Association of Cincinnati; (2) a federal grant to the pediatric Center for Education and Research in Therapeutics at Cincinnati Children's Hospital Medical Center, funded by the federal Agency for Healthcare Research and Quality; and (3) participation fees from enrolled centers.

Disclosures

None.

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KEY WORDS: collaborative ■ hypoplastic left heart syndrome ■ mortality ■ outcomes research ■ quality improvement

Circulation
Cardiovascular Quality and Outcomes

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Circ Cardiovasc Qual Outcomes. 2015;8:428-436; originally published online June 9, 2015;
doi: 10.1161/CIRCOUTCOMES.115.001956
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231

Print ISSN: 1941-7705. Online ISSN: 1941-7713

Centers participating in NPC-QIC as of July 2014

Hospital Name	City	State
Advocate Hope Children's Hospital	Oak Lawn	IL
All Children’s Hospital	Saint Petersburg	FL
Ann and Robert H. Lurie Children's Hospital of Chicago	Chicago	IL
Arizona Pediatric Cardiology Consultants	Phoenix	AZ
Arkansas Children's Hospital	Little Rock	AR
Arnold Palmer Children’s Hospital	Orlando	FL
Batson Children’s Hospital-University of Mississippi	Jackson	MS
Children’s Hospital and Research Center Oakland	Oakland	CA
Boston Children’s Hospital	Boston	MA
Children’s Hospitals and Clinics of Minnesota	Minneapolis	MN
Children’s Medical Center Dallas	Dallas	TX
Children’s National Medical Center	Washington DC	
Children's Healthcare of Atlanta	Atlanta	GA
Children's Hospital and Medical Center, Omaha	Omaha	NE
Children's Hospital Colorado	Aurora	CO
Children's Hospital Los Angeles	Los Angeles	CA
Children's Hospital of Philadelphia	Philadelphia	PA
Children's Hospital of Wisconsin	Milwaukee	WI
Children's Mercy Hospitals and Clinics - Kansas City	Kansas City	MO
Cincinnati Children's Hospital and Medical Center	Cincinnati	OH
Cleveland Clinic Children’s Hospital	Cleveland	OH
Doernbecher Children’s Hospital	Portland	OR
Duke University Medical Center	Durham	NC
Inova Fairfax Hospital for Children	Falls Church	VA
Joe DiMaggio Children's Hospital	Hollywood	FL
Johns Hopkins Hospital	Baltimore	MD
Le Bonheur Children's Hospital – Memphis	Memphis	TN
Levine Children’s Hospital - Sanger Heart and Vascular Institute	Charlotte	NC
Lucile S. Packard Children’s Hospital at Stanford	Palo Alto	CA
Mattel Children’s Hospital UCLA Pediatric Cardiology	Los Angeles	CA
Mayo Clinic- Rochester	Rochester	MN
Medical University of South Carolina	Charleston	SC
Miami Children's Hospital	Miami	FL
Nationwide Children's Hospital	Columbus	OH
Nemours A.I. Dupont Hospital for Children	Wilmington	DE
New York Presbyterian - Morgan Stanley Children's Hospital	New York	NY
NYU Medical Center	New York	NY
Penn State Hershey Children's Hospital	Harrisburg	PA
Primary Children's Medical Center	Salt Lake City	UT
Riley Hospital for Children	Indianapolis	IN

Hospital Name	City	State
Seattle Children's Hospital	Seattle	WA
St Louis Children’s Hospital	St. Louis	MO
Texas Children’s Hospital	Houston	TX
The Children’s Hospital of Montefiore	Bronx	NY
UC Davis Children’s Hospital	Sacramento	CA
University Hospitals Case Medical Center - Rainbow Babies & Children's Hospital, Pediatric Heart Center	Cleveland	OH
Children’s of Alabama	Birmingham	AL
University of Florida Pediatric Cardiovascular Center at Wolfson Children's Hospital	Jacksonville	FL
University of Iowa Children's Hospital	Iowa City	IA
University of Louisville – Kosair Children’s	Louisville	KY
University of Maryland Children's Hospital	Baltimore	MD
University of Michigan Congenital Heart Center	Ann Arbor	MI
University of Texas Health Science Center, San Antonio at University Hospital	San Antonio	TX
UVA Children's Hospital	Charlottesville	VA
Yale New Haven Children’s Hospital	New Haven	CT