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Power of a Learning Network in Congenital Heart Disease

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Abstract

Background: The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) formed to improve outcomes in infants with hypoplastic left heart syndrome. The collaborative sought to (1) decrease mortality, (2) reduce growth failure, and (3) reduce hospital readmissions due to major medical problems during the interstage period between discharge following stage 1 palliation (S1P) and admission for stage 2 palliation (S2P). **Methods:** The NPC-QIC is a learning network, coproduced by parents and clinicians, of 65 pediatric cardiology centers that contribute clinical data on care processes and outcomes to a shared registry. The adapted Breakthrough Series Model structure brings teams together regularly to review data, share lessons, and plan improvements. Outcomes are monitored using statistical process control methods. **Results:** Between 2008 and 2016, interstage mortality decreased by >40%, from 9.5% to 5.3%. Identification and use of a nutrition bundle led to improved infant growth, with a 28% reduction in interstage growth failure. The rate of serious hospital readmissions was low and did not significantly change. Importantly, a formed partnership with the parent group Sisters by Heart fostered the coproduction of tools and strategies and an emphasis on data transparency and outcomes. **Conclusions:** The NPC-QIC's initial efforts led to improvements in interstage growth and mortality. The NPC-QIC has modeled the use of data for improvement and research, the value of coproduction with parents, and the concept "all teach, all learn," demonstrating the power of the learning network model.

Keywords
nutrition, Norwood, hypoplastic left heart syndrome, quality improvement

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Introduction

Improving Care for Children With Rare Disease

Pediatric cardiologists treat children with rare disorders, yet large studies to guide care advances are few. In 2003, several congenital heart disease leaders formed the Joint Council on Congenital Heart Disease (JCCHD) to lead overarching efforts in the field. Shortly after formation, the JCCHD worked with the American Board of Pediatrics to create the first nationwide quality improvement project in pediatric cardiology, proposing a network of pediatric cardiology teams that would contribute data to a shared longitudinal registry and identify and test changes in clinical care that could improve care processes and patient outcomes. The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) was therefore formed, beginning with six sites in 2006.

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Abbreviations

BTS	Breakthrough Series
HLHS	hypoplastic left heart syndrome
IRB	institutional review board
JCCHD	Joint Council on Congenital Heart Disease
NPC-QIC	National Pediatric Cardiology Quality Improvement Collaborative
S1P	stage 1 palliation
S2P	stage 2 palliation

Focus on Infants With Hypoplastic Left Heart Syndrome

The leadership of NPC-QIC chose to focus on improving care and outcomes for infants born with single ventricle congenital heart disease, which includes babies with hypoplastic left heart syndrome (HLHS). Hypoplastic left heart syndrome is a complex and high-risk heart defect that requires intensive early intervention. It is also rare, affecting an estimated 1 in every 4,344 babies born in the United States each year, according to the Centers for Disease Control and Prevention. Most infants with HLHS undergo a series of three palliative cardiac surgeries: a stage I Norwood palliation (S1P) within a few days of birth, a stage II palliation (S2P) at four to six months, and a stage III (Fontan) procedure at two to four years, and outcomes in this population have been studied by several single-center and multicenter studies over time, the most robust of which has been the work done by the Pediatric Heart Network.[1] The NPC-QIC's phase I goal was to improve care and outcomes for infants during the interstage period—the period between discharge following S1P and admission for S2P.

The NPC-QIC proposed three goals: (1) decrease interstage mortality, which was reported at 10% to 15% at the initiation of the collaborative; (2) reduce interstage growth failure, also well-documented at the time; and (3) reduce the number of infants readmitted to the hospital during the interstage period due to major medical problems. Work began in 2008 and enrollment in this initial phase ended in 2016. This article describes the results of this multiyear effort to improve outcomes.

Methods

The NPC-QIC adopted a collaborative improvement approach that was novel at that time in pediatric cardiology. A collaborative approach, as opposed to a competitive approach, facilitates the open sharing of insights and harnesses the collective intelligence of a large group of individuals focused on the same goal and can speed problem-solving (eg, Linux, Wikipedia, Human Genome Project). Cardiology centers were unaccustomed to the routine sharing of both data and implementation challenges, as well as partnering with parents and families in coproducing change. *An initial and major challenge for NPC-QIC in implementing collaborative improvement was engaging clinicians and individual programs in methods in which they were unaccustomed.*

Design of the Initiative

The NPC-QIC adopted the principles of a learning network—a collaborative clinical learning community. The NPC-QIC was modeled in part on the Institute of Medicine's Learning Healthcare System,[2] a system in which "science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral byproduct of the delivery experience." In a learning network, data are used for clinical care, improvement, and discovery, and evidence informs practice change. The NPC-QIC used the Institute for Healthcare Improvement's Breakthrough Series (BTS) Collaborative Model structure, which involves the development of a key driver diagram: (1) an aim, (2) key drivers or factors hypothesized to produce the desired outcomes, (3) measures that will allow monitoring of progress, and (4) strategies to test that can lead to improvement, as well as regular data feedback and a structure to support teams in testing process changes and learning from one another.[3]

Implementation of the Initiative

Multidisciplinary teams. Each pediatric cardiology center assembled a multidisciplinary team consisting of at minimum a physician champion and including advanced practice nurses, clinic nurses, dieticians, social workers, psychologists, and family representatives. Each center's team was unique, as was the way that the work of registry data entry and executing the work was carried out. Centers incurred the expense of allowing team members to participate in this initiative as well as the yearly cost of participation and cost of travel to face-to-face meetings. Teams were asked to submit monthly data on patient status and care processes, test changes designed to improve their systems, and post reports on their team's progress. Aggregate and summary reports were shared among teams to facilitate learning. Each center submitted a protocol to their local institutional review board (IRB), coordinated by the NPC-QIC project management team in the Anderson Center at Cincinnati Children's Hospital. Although a limited number of local IRB's chose to waive consent for this project, the vast majority of centers consented patients for enrollment.

Coproduction with parents. Because the network focuses on infants, parents and families are essential partners. As the network matured, parents partnered with clinical leaders at every level of NPC-QIC, including the collaborative's executive team, all workgroups and committees, and local site teams. Sisters by Heart, a nationwide support group for parents of children with HLHS, is an integral and formal partner that facilitates parent integration into the work and provides a crucial feedback loop between the collaborative and parents.

Robust data. The NPC-QIC maintains a national registry containing clinical process and outcomes data for infants enrolled which serves dual purposes. First, data from the registry serve as the foundation for improvement, with collaborative-wide

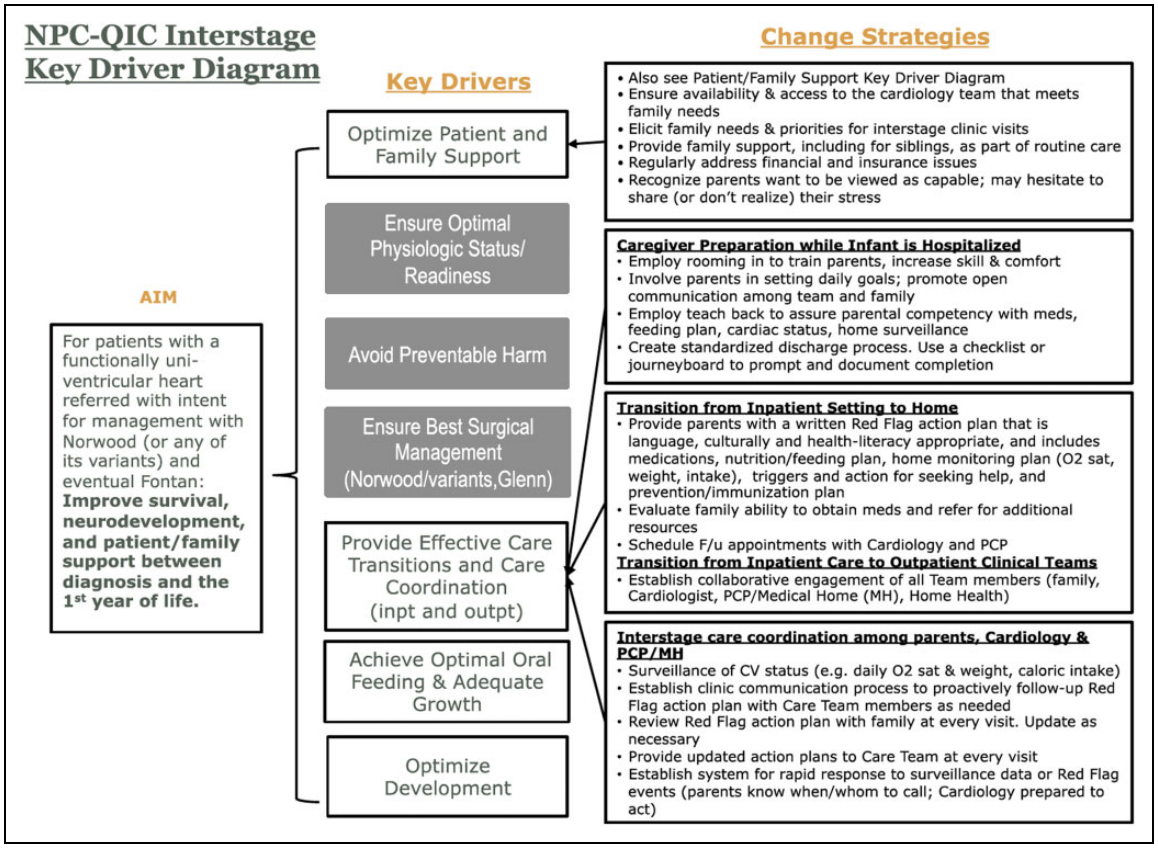

Figure 1. National Pediatric Cardiology Quality Improvement interstage key driver diagram.

data and site-specific data regularly updated using statistical process control charts. Using these charts, sites can compare their adherence to clinical processes and their clinical outcomes with those of the collaborative as a whole. Patient data from individual centers are submitted through a secure portal and stored in a secure Redcap database, housed in the Anderson Center at Cincinnati Children's Hospital. These data are then extracted, analyzed, and returned to centers through an automated reported system. Centers receive real-time statistical process control charts demonstrating their performance on process and outcome measures as well as comparison measures for the collaborative as a whole. These statistical process control charts form the basis of improvement efforts locally as well as nationally. In addition, data in this registry are used for clinical research. Within NPC-QIC, clinical sites that submit data to the registry may propose and execute analytic studies that use these data for discovery. These proposals, and the output of clinical studies using NPC-QIC data, are vetted and shepherded by a robust Research and Publication Committee.

Organized learning. Following the IHI BTS model, semiannual learning sessions bring together clinical teams, parents, and researchers to share lessons about clinical process changes and to plan new strategies. A key driver diagram was created to organize and drive data collection and improvement methods (Figure 1). Workgroups, developed over time, focused on specific issues, including transparency, feeding and growth, mortality, readmission, and neurodevelopmental outcomes. The NPC-QIC's activities facilitate identification of and learning from practice variation, isolation of optimal clinical practices, and rapid dissemination of these practices across centers to improve care and outcomes.

Results

During phase I of NPC-QIC, 2,184 infants were enrolled from 60 surgical centers. Multidisciplinary teams from these centers participated in improvement and research efforts between 2009 and 2016. The NPC-QIC grew from six sites in 2009 with a steady growth of participation in centers through the end of calendar year 2011. Since 2011, the collaborative has had over 50 participating centers and the number of new centers participating has slowed considerably since then. Of participating sites, 80% enroll <10 patients per year, resulting in only a small contribution of any one site to the overall process and outcome measures.

Process Measure Improvement

As with most improvement efforts, there were predetermined clinical practices that were felt to likely be associated with the key clinical outcomes. These process measures focused on four key areas: (1) effective care transitions, (2) appropriate growth monitoring and nutrition intervention, (3) engagement with

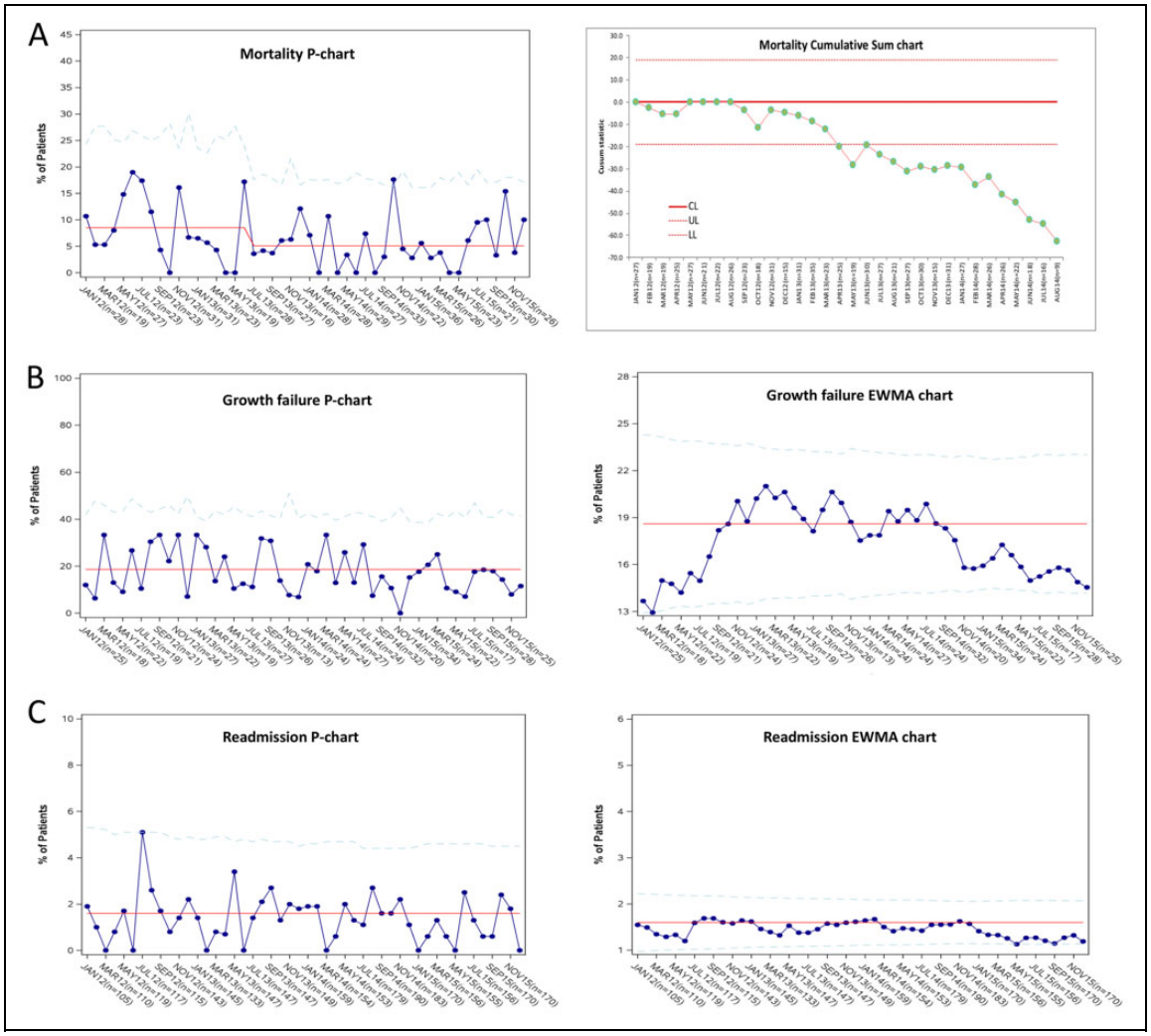

Figure 2. Statistical control charts demonstrating major National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) outcomes.

parents/caregivers, and (4) effective coordination with the infant's medical home. These processes primarily focused on practices at discharge following S1P and during interstage clinic visits. Much of the improvement work of the collaborative was to support clinical teams as they tested changes in their clinical practices to implement these key processes, most of which improved significantly over time.

Outcome Improvement

Interstage mortality. Statistical process control methods demonstrated that interstage mortality decreased from 9.5% to 5.3% during the collaborative.[4] This improvement has been maintained. Although the reduction in interstage mortality was certainly multifactorial, there were no major clinical or interventional innovations in the field to alter interstage mortality during this time period. The NPC-QIC Mortality Reduction Workgroup, comprised of clinicians and parents from multiple institutions, carried out an extensive exploration into clinical and patient risk factors for interstage mortality. One unexpected, novel finding from this exploration of the database was a potential beneficial association with treatment with the medication digoxin and reduced interstage mortality. This finding was then similarly replicated in a second large database. Through the rapid dissemination of these data through the NPC-QIC learning network, the use of digoxin in this patient population has increased two- to three-fold (Figure 1, Figure 2A).

Interstage growth failure. We demonstrated a significant reduction in infants experiencing growth failure from 18% to 10%. The NPC-QIC Nutrition Workgroup developed comprehensive clinical guidelines for nutritional management of this complex population and used a mixed-methods research approach to identify a "nutrition bundle" associated with better interstage growth. The spread of these practices across the collaborative led to the improved growth of patients collaborative wide.[5] As with the reduction in interstage mortality, the improvement in interstage growth is undoubtedly multifactorial, but decreased

variation in nutritional practices likely contributed significantly to the realized improvement (Figure 2B).

Interstage major event readmissions. The NPC-QIC Readmission Workgroup learned a great deal about interstage readmissions. This group demonstrated that readmissions were common during the interstage period and that there was notable variation among clinical centers in the incidence of interstage readmissions.[6] The vast majority of the readmissions were for observational purposes and felt to be preventative for subsequent major clinical events. The NPC-QIC monitored specific readmissions for major clinical events such as cardiac arrest, clotted shunt, arrhythmia, seizures, serious infections, and so on. The rate of these serious readmissions was quite low (median 1.8 readmissions/100 interstage months) and did not change significantly over time (Figure 2C).

Translation to Other Settings

The concept of collaboration over competition will continue to be an exemplar, not only among clinical centers but also among groups that have developed additional registries and clinical networks within our field. Several other groups within pediatric cardiology have since developed systems to work collaboratively to improve outcomes including the Pediatric Critical Care Consortium, Pediatric Acute Care Cardiology Collaborative, and projects within the Pediatric Heart Network. Efforts among leadership of several of these clinical networks within pediatric cardiology have focused on opportunities to collaborate more fully among networks to create efficiencies and further accelerate learning.

Comment

The first phase of the NPC-QIC has had a significant impact on the field of pediatric cardiology. The collaborative accomplished its original clinical goals of improving mortality and growth in patients with HLHS and also solidified collaboration as a critical methodology for learning and improvement in our field. This collaboration extends not only among clinical teams and across clinical sites but also with parents as true partners. The improvements in interstage growth and mortality mean that more infants with a single ventricle are thriving, surviving to their second surgery. Scientific contributions have been robust, identifying specific clinical interventions. Data from the NPC-QIC registry have resulted in nearly 30 publications, covering a wide range of clinical and methodologic topics.[5–25]

The NPC-QIC uses a methodology that has not often been used in pediatric cardiology. Statistical process control analyses and adopting the learning network model were novel to clinical teams. The "all teach, all learn" philosophy has fostered the development of a community of practice involving patients, families, clinicians, and scientists, where sharing what works to improve care and outcomes is done as soon as possible. Partnering with patients and families is now established as part of the routine work of participating cardiology centers. Having patients and families partner with local clinical improvement teams and join collaborate leadership has also been crucial.

Despite this success, there is much work yet to be done. Working together as patients, families, clinicians, and scientists—and using data for improvement and discovery—will allow care and outcomes for children with single ventricle to advance further and faster. The success of NPC-QIC's first phase has enabled the development of its second phase, focused on improving outcomes from diagnosis through the infant's first birthday, expanding the collaborative to include fetal cardiologists, pediatric cardiac surgeons, intensivists, and developmental pediatricians. We have also begun designing the third stage of collaborative work, aimed at improving long-term outcomes in single ventricle survivors with Fontan circulation.

The NPC-QIC can serve as a model for future improvement efforts that will leave a lasting effect on the field of pediataric and congenital heart disease, demonstrating the value of collaboration and use of data for learning.

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Supplemental material

Supplemental material for this article is available online.

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