

THE NATIONAL PEDIATRIC CARDIOLOGY QUALITY IMPROVEMENT COLLABORATIVE: A JCCHD Initiative

Improvement Project Charter

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MISSION

The mission of the National Pediatric Cardiology Quality Improvement Collaborative: a JCCHD Initiative is to improve dramatically the outcomes of care for children with congenital heart disease (CHD). There are two initial activities:

1. Plan and implement an improvement project to improve survival and reduce morbidity of infants with hypoplastic left heart syndrome between stage 1 and stage 2.
2. Build a sustainable collaborative network involving all pediatric cardiologists in North America, including a database to inform future improvement projects. This network will provide opportunities for pediatric cardiologists to collaborate on both quality improvement and research projects.

BACKGROUND

Why is JCCHD interested in forming a National Collaborative for Research and Improvement?

A long-term goal of the JCCHD is to involve all pediatric cardiologists in a research and improvement network. Because many of the conditions encountered in pediatric cardiology practice are rare and heterogeneous, there is a critical need for evidence-based approaches to diagnosis and treatment of these disorders. A national repository of patients can facilitate quality improvement and clinical research studies. This would allow the most cost-effective, efficient and safe methods for the diagnosis of diseases can to be more rapidly analyzed. New therapeutic and practice improvement approaches can also be more quickly assessed and results disseminated, providing more timely and optimal patient care. Creation of detailed databases will facilitate power analysis and sample size calculations for future quality improvement projects and clinical research studies. Uniformity in protocols and expertise of centralized personnel will promote quality and decrease the variability of performance. Multi-center studies will more likely attract the favorable attention of study sponsors, foundations and the National Institutes of Health.

Understanding differences in practice that result in differences in outcomes will be critical to transforming pediatric cardiology practice. In the network, quality improvement activities can be more broadly encouraged, standardized and assessed, leading to better patient care and outcomes. In addition, ongoing quality improvement activities will be required by the American Board of Pediatrics for maintenance of certification in pediatric cardiology. It is desirable for JCCHD to be proactive in the design of these activities.

American Board of Pediatrics

The American Board of Pediatrics (ABP) and the Center for Health Care Quality (CHCQ) have developed activities with the aim of *improving the health of all children with serious chronic illness in the United States by improving the quality of pediatric sub-specialty care*. The model for these activities includes 1) national databases/registries of key childhood illnesses (such as congenital heart disease) developed and coordinated with existing databases and 2) subspecialty-wide multi-center collaborative improvement

and research efforts to coordinate improvement activities among pediatric sub-specialists. This NPC-QIC Improvement project will enable pediatricians to fulfill requirements towards Part 4 of the Program of Maintenance of Certification for Subspecialists (PMCP-S), evidence of satisfactory performance in practice.

The remainder of this document will focus on the first activity of the NPC-QIC National Collaborative, improving care for children born with hypoplastic left heart syndrome.

Statement of problem: Congenital heart disease

Approximately 800,000 children in the US have CHD and each year another 40,000 infants are born with CHD. Of the myriad cardiac defects that may be present at birth, univentricular heart (or single ventricle) is the most complex and is associated with the highest rates of morbidity and mortality. Hypoplastic left heart syndrome accounts for approximately 10% of congenital heart defects overall. Therefore, there are approximately 4000 infants born with these defects in the US each year.

The term univentricular heart is applied to children born with hypoplastic left heart syndrome, tricuspid atresia, pulmonary atresia with intact ventricular septum, double inlet left ventricle, and unbalanced atrioventricular canal defects. Virtually all will require surgical palliation in the newborn period (e.g. a Norwood procedure, a shunt or pulmonary artery band) and will proceed along a common univentricular treatment pathway that includes a bidirectional Glenn shunt at 4-6 months, and a Fontan procedure at 2-4 years of age. The ultimate goal of therapy is to provide unobstructed ventricular outflow to the systemic circulation, to protect the pulmonary circulation from elevated pressure and flow, and to eventually establish divided systemic and pulmonary circulations in series.

A substantial risk for morbidity and mortality is encountered by children born with a hypoplastic left heart syndrome. Mortality risk alone in children with hypoplastic left heart syndrome can be 15-20% at the Norwood stage, 10-15% interstage mortality prior to the Glenn procedure, 3-5% at the Glenn and another 3-5% at the Fontan surgery; this amounts to a total 30-45% mortality risk in the first 4 years of life. Children who survive surgical palliation of a hypoplastic left heart syndrome also encounter substantial morbidities that may include vocal cord paralysis, phrenic nerve injury, inability to feed orally, poor growth, gastrointestinal complications, renal dysfunction, seizures, developmental delay, the need for supplemental oxygen and numerous medications, as well as frequent and often prolonged hospitalizations. Thus, infants with hypoplastic left heart syndrome have some of the highest rates of morbidity and mortality encountered in Pediatric Cardiology centers.

Evidence-based guidelines for the inpatient and outpatient care of children with hypoplastic left heart syndrome are lacking, and there is little guidance for pediatric cardiologists about how best to care for these children. In addition, there are too few patients at any one center to accumulate sufficient evidence about optimal care. Dissemination of new information about improving care for these children is slow and inefficient. Outcome measures to determine the effect of therapies are evolving slowly, and there is no standardized clinical record to monitor a patient's course, disease activity or quality of life.

Most pediatric cardiologists provide care for children with a hypoplastic left heart syndrome. In fact, the inpatient and outpatient care of these children requires the input from and expertise of virtually all subspecialties within the field of Pediatric Cardiology. For example and chronologically, fetal cardiologists often make the initial diagnosis, cardiac intensivists provide pre- and post-operative intensive care, echocardiographers are involved in diagnostic studies, cardiac catheterizations specialists perform invasive diagnostic and interventional catheterization procedures, electrophysiologists diagnose and treat early and late post-operative arrhythmias, and outpatient pediatric cardiologists provide long-term management including recommendations concerning chronic medical therapy, exercise participation, birth control and other lifestyle issues. Clearly, quality improvement initiatives for children with a hypoplastic left heart syndrome have the potential to involve the entire Pediatric Cardiology community.

Care transitions

A study about transitions of care for patients suggests that caregivers are often unprepared for their role in the next care setting, don't understand essential steps in care management, and do not have the appropriate contact information for appropriate health care providers.* Of note, there is rarely feedback to discharge planners regarding the execution or outcomes of proposed discharge plans.

An intervention to address these issues in the care of geriatric patients has been developed. The Care Transitions Intervention, developed at the University of Colorado Health Sciences Center, is a patient-centered, interdisciplinary team intervention designed to improve transitions across sites, including home, of geriatric care. The intervention includes providing patients tools to promote cross-site communication, encouragement to communicate assertively with medical personnel, and guidance from a "transition coach."[†] patients who received the intervention reported high levels of confidence in understanding their medication regime and obtaining essential information for managing their condition.[‡] The Care Transitions Intervention is associated with reduced rates of subsequent hospitalization. This work has been adopted by the Center for Health Care Quality for use in the American Board of Medical Specialties Patient Safety Improvement Program.

What parents need

In February and March of 2006, the Washington State Department of Health and Seattle Children's Hospital and Regional Medical Center conducted a web-based survey of parents of children with special health care needs. The survey was publicized through parent organizations, support groups, public health nurses, and selected clinics at Children's Hospital. At the time of the survey *only 31% of parents reported having a written care plan for their child*. However, 86% believed it was important to have such a plan. Parents believed that a written care plan would help with the quality of health care their child receives in different settings, help with transitions between hospital and home, facilitate communications between parents and health care professionals, and summarize health information such as medications, therapies and treatments. Parents suggested that written care plans be simple, brief and flexible.

Efforts to provide increased monitoring of infants

Children's Hospital of Wisconsin developed a home surveillance program for parents of infants with hypoplastic left heart syndrome to detect daily variances in arterial oxygen saturation according to pulse oximetry, weight loss and failure to gain weight. A case series suggested this program was associated with improved interstage survival.[§]

* Parry C, Coleman EA, Smith JD, Frank J, Kramer AM. The Care Transitions Intervention: A Patient-Centered Approach to Ensuring Effective Transfers Between Sites of Geriatric Care. *Home Health Care Services Quarterly*. 2003; 22:1-17.

† Coleman EA, Smith JD, Frank JC, Min SJ, Parry C, Kramer AM. Preparing Patients and Caregivers to Participate in Care Delivered Across Settings: The Care Transitions Intervention. *Journal American Geriatrics Society*. 2004; 52:1817-1825.

‡ Ibid, p1817.

§ Ghanayem NS, Hoffman GM, Mussatto KA, Cava JR, Frommelt PC, Rudd NA, Steltzer MM, Bevandic SM, Frisbee SJ, Jaquiss RDB, Litwin SB, Tweddell JS. Home Surveillance Program Prevents Interstage Mortality after the Norwood Procedure. *Journal Thoracic and Cardiovascular Surgery*. 2003; 126:1367-77.

Improvement Project Aim

The aim of the improvement project is to eliminate mortality, and to improve quality of life and outcomes of infants with hypoplastic left heart syndrome (HLHS) s/p Norwood between discharge from Stages 1 and admission for Stage 2 (i.e. the "interstage period") by July 2010. Our target goals include:

TARGET GOALS

- Eliminate interstage mortality (Initial goal will be to: decrease by 50%).
- Eliminate interstage major events (e.g. cardiovascular and renal compromise, neurologic deficit, etc.) (Initial goal will be to: decrease by 50%)
- Achieve minimum growth goal for 90% all interstage patients
- 100% of patients are discharged with:
 - Written plan for outpatient follow up and care
 - Assessment of need for preventive care
 - Written expectations for care, 'red flag' action plan, nutrition plan and medication list for parents
 - Communication of above to medical home, primary care provider
- Centers utilize standard discharge protocols and ensure there is 'process owner' for patient discharge and home health coordination.
- 100% Clinic visits include
 - Measurement of caloric intake and growth parameters
 - Review and update of nutrition plan
 - Written expectations for care, 'red flag' action plan, nutrition plan and medication list for parents
 - Assessment of need for preventive care

Balancing Measures

Balancing measures assess whether improvements to one part of the system cause unintended consequences. Appropriate measures will be considered and determined during initial data collection.

Key Driver Analysis

The interstage period will be the primary focus of improvement. The key driver diagram below illustrates the areas we will strive to improve to reach our target goals.

Collaborative Expectations

The NPC-QIC Collaborative Leadership Team will:

- Provide evidence-based information on care of patients with hypoplastic left heart syndrome disease
- Offer coaching to improvement teams on applying the Model for Improvement to implement key changes at the learning sessions, on conference calls and through the listserv
- Provide each team **regular (monthly or quarterly, as appropriate)** feedback charts/reports on data collected at each site
- Provide an extranet for posting of individual center performance charts, submitted monthly report and aggregate information, and a library of tools and training materials
- Provide communication methods to keep participants connected to the faculty and to colleagues during the Improvement Collaborative
- Provide tools, forms, and other aids to help with implementation of key areas of care
- Provide data entry support and facilitate utilization of REDCap database

Participating organizations and teams are expected to:

- Secure senior leader support for the improvement team's work in the collaborative
- Organize a team and complete prework activities prior to Learning Session One
- Send a team of at least three, including the physician champion to all Learning Sessions
- Provide resources and support to the improvement team (including support to attend the 3 learning sessions, time to devote to testing and implementing changes at the site, and active senior leadership involvement)
- Perform prework activities to prepare for the Learning Sessions
- Align the goals of the Collaborative work to the work of the organization
- Use the REDCap database to track patients and their care
- Perform tests of change in their setting that lead to improvements towards the desired outcomes
- Participate in Collaborative calls and the listserv to share with and learn from others
- Submit a monthly report in order to share information with Collaborative faculty and other participants. This report includes details of changes made and data to evaluate the impact of these changes.

The National Pediatric Cardiology Quality Improvement Collaborative

KEY DRIVER DIAGRAM

Revised March 24, 2009

Change Strategies

Key Drivers



