



National Pediatric Cardiology
Quality Improvement Collaborative

Research Explained

Power of a Learning Network in Congenital Heart Disease

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ABOUT THIS STUDY

This study describes the design and outcomes from Phase I of the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) to improve outcomes in infants with hypoplastic left heart syndrome (HLHS).

Why is this study important?

- The NPC-QIC was the first collaborative improvement project in pediatric cardiology
- Among NPC-QIC participants, 80% enroll fewer than 10 HLHS patients per year. This makes it very difficult for hospitals working alone to try new ways to improve care, or to know if changes in treatment or new approaches are effective.
- The NPC-QIC was set up as a “learning network”, which is a collaborative clinical learning community where clinicians could share data and test new treatments with more patients. This was the first time design had been used in Pediatric cardiology
- The NPC-QIC involved multidisciplinary teams consisting of physicians, advanced practice nurses, clinic nurses, dieticians, social workers, psychologists and family members. Leadership was shared at all levels between clinicians and parents.
- The NPC-QIC’s first goal (Phase I) was to improve the care and outcomes for infants during the Interstage period, i.e. the period between discharge from the Stage 1 surgery (Norwood) and the admission for Stage 2 (Glenn) surgery
- The NPC-QIC proposed 3 specific aims to achieve the Phase I goal
 - (1) decrease the number of babies who died during the Interstage, which was reported at 10-15% at the start of the collaborative
 - (2) improve infant growth during Interstage, since as many as 20% of infants did not meet normal growth goals

- (3) reduce the number of times families had to return to the hospital during the Interstage.
- This article described the results of the collaborative to improve outcomes

How was this study performed?

- The article described the initial formation of the collaborative beginning with 6 sites in 2006
- The NPC-QIC recruited centers to work in a collaborative fashion to improve outcomes
- The first step was to develop a “Key Driver Diagram” with (1) an aim, (2) key drivers i.e. factors that participants thought would produce the desired results, (3) measures that will allow monitoring of progress, and (4) strategies to test that can lead to improvement, as well as feedback and structure to support the teams in testing process changes and learning from each other
- Each hospital center set up a multidisciplinary team that submitted monthly data on patient status and process measures, test changes designed to improve their systems and reports on their team’s progress
- The data was submitted to a central secure portal at the Anderson Center at the Cincinnati Children’s Hospital and analyzed to see best practices and changes in outcomes
- Semiannual learning sessions brought together teams or clinicians and parents from all of the participating centers to discuss results and to plan changes and new strategies

What were the results of the study?

- During Phase 1 (2009-2016) of the NPC-QIC 2184 infants were enrolled from 60 surgical centers
- The process measurements focused on 4 key areas (1) care transitions from hospital to home, (2) growth monitoring and helping with nutrition, (3) working with parents/caregivers, (4) coordination and communication with the infant’s medical home
- During phase I, deaths of infants were reduced by almost 50% within the collaborative without any major clinical or interventional innovations in this time period
- The NPC-QIC Mortality Working Group carried out extensive explorations into clinical and patient risk factors for Interstage mortality and found that taking the common cardiac drug Digoxin was associated with a lower number of deaths
- The Digoxin data was shared within the collaborative and the use of Digoxin increased 2-3 fold within the collaborative
- The NPC-QIC also showed a significant improvement in infants meeting growth and weight goals, with a reduction in infants experiencing growth failure from 18% to 10%
- The NPC-QIC Nutrition Workgroup identified a “nutrition bundle” associated with better Interstage growth that many other hospitals in the collaborative started to use
- The rate of serious re-admissions to hospital was very low at 1.8 admissions/100 Interstage months, and did not change significantly during the Interstage

What it all means?

- Phase I of the NPC-QIC had a significant impact on the field of Pediatric Cardiology both from the impact on outcomes and in the wider field's use of the learning network model
- The improvements in Interstage mortality and growth mean that more infants are thriving and surviving to their second surgery
- Data from the NPC-QIC registry has led to over 30 peer reviewed publications
- The "all teach, all learn" learning network philosophy including a multidisciplinary team with parents has now been adapted to use in other settings including the Pediatric Critical Care Consortium and the Pediatric Acute Care Cardiology Collaborative
- The success of Phase I enabled the development of Phase II which is expanding to improve outcomes from diagnosis to the first birthday, including now Fetal cardiologists, Surgeons, Intensivists, and Developmental Pediatricians
- Phase III is also under development which is aimed at improving long-term outcomes of single ventricles with Fontan circulation