Title: Quality Improvement through Collaboration: The NPCQIC initiative

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Abstract

Purpose of review: The National Pediatric Quality Improvement Collaborative (NPCQIC) was established to improve outcomes and quality of life in children with hypoplastic left heart syndrome and other single ventricle lesions requiring a Norwood operation. The NPCQIC consists of a network of providers and families collecting longitudinal data, conducting research, and using quality improvement science to decrease variations in care develop and spread best practices and decrease mortality.

Recent findings: Initial descriptive investigation of the collaborative data found interstage care process variations, different surgical strategies, diverse feeding practices and variable intensive care unit approaches between centers and within sites. Analysis and evaluation of these practice variations have allowed centers to learn from each other and implement change to improve processes. There has been an improvement in performance measures and a 39.7% reduction in mortality.

Summary: The NPCQIC has shown in a rare disease such as hypoplastic left heart syndrome that a network based on multicenter collaboration patient (parent) engagement and quality improvement science can facilitate change in practices and improvement in outcomes.

Key phrases: Congenital heart disease, quality improvement, Hypoplastic left heart syndrome, cardiology outcomes

Introduction

Congenital heart disease (CHD) is the most common birth defect. Despite many advances in health care, children with one of the most serious forms of CHD, hypoplastic left heart syndrome (HLHS), are still a highly vulnerable, medically fragile population. Individual cardiac centers care for small numbers of HLHS children and thus there have been no consensus guidelines for management. Furthermore, for such rare diseases it is difficult for single centers to make significant improvements in the care for these children. Large clinical networks allow centers to use a large group experience to study rare diseases. Quality improvement (QI) science has shown that reducing practice variation leads to better outcomes, safer practice, cost savings and improved operating efficiency. (Anderson et al., 2012; Ghanayem et al., 2003; Jenkins et al., 1995; Johnson et al., 2008; O'Connor et al., 1996; Simone & Lyons, 1998; Srinivasan et al., 2009) Precedent has been set in other groups such as the Northern New England Cardiovascular Disease study group, the Children's Oncology group and Cystic Fibrosis Network demonstrating that multicenter collaboration and QI science improves outcomes.(Birkmeyer et al., 2000; Hewitt M, 2003); O'Connor et al., 1996; Pui & Evans, 1998) These collaborative networks allow teams to learn from each other, test changes to improve quality, use collective experience and data to understand what works and implement changes in practice. (Lannon & Peterson, 2013)

Development of a Collaborative Network

In 2003, the Joint Council on Congenital Heart Disease (JCCHD) was formed as an alliance among pediatric cardiologists, congenital cardiothoracic surgeons and adult congenital heart disease specialists. This group assembled an executive committee of cardiologists (Robert

Beekman, John Kugler, Tom Klitzner, Kathy Jenkins, Gerard Martin, Steve Neish, Geoff Rosenthal and QI lead Carole Lannon) which developed and launched the National Pediatric Cardiology Quality improvement Collaborative (NPCQIC) in 2006. The NPCQIC is a large clinical learning community modeled after the Institute of Medicine Learning Health System framework. (*The Learning Healthcare System: Workshop Summary*, 2007) Within the collaborative, patients, families, clinicians and researchers from multiple centers work together to improve care and outcomes using data for clinical care, improvement and research. The mission statement of the NPCQIC is to "dramatically improve outcomes of care for children with congenital heart disease through a national QI collaborative network of providers working together to collect longitudinal data and conduct QI research intended to accelerate the development and transition of new knowledge into practice" (Table 1).(Kugler et al., 2009)

The initial QI project of the NPCQIC was aimed to reduce mortality and improve quality of life in infants with HLHS and other complex single ventricle lesions during the interstage period (the time between discharge after the Norwood and admission for the bidirectional Glenn procedure). The interstage is a particularly hazardous time for these infants. There is no single corrective procedure for HLHS; instead patients undergo a series of palliative procedures. The first surgery occurs in the newborn period (Norwood operation with a Blalock-Taussing (BT) or Sano shunt or Hybrid procedure). The second stage, a bidirectional Glenn (BDG) procedure is typically performed between 4-6 months and the third stage, a Fontan procedure is performed between 2-4 years of age. Patients with HLHS have shunt dependent pulmonary blood flow during the interstage period between the Norwood and BDG, making this a particularly vulnerable time. Mortality from the Norwood operation has been reported as high as 19 % and then this is compounded by interstage mortality which can be as high as 15%.(Jacobs et al.,

2011; Kugler et al., 2009; Tabbutt et al., 2012; Tweddell et al., 2002) In addition to significant mortality these infants are at risk for poor growth, feeding problems, phrenic nerve injury, renal dysfunction, seizures, developmental delay and prolonged hospital stay. (Dooley & Bishop, 2002) Because of these significant risks the interstage period was chosen for the initial QI effort.

To improve survival and quality of life during the interstage period we chose to focus on appropriate care transitions, optimizing nutrition and improved care coordination as key drivers (Figure 1). The key driver diagram was modified later, with the addition of family engagement as the fourth key driver. Change strategies for each key driver and outcome measure focused on mortality, growth, and care transitions (including discharge communication, follow up care, clinic visit process and care coordination) were identified through literature, expert opinion and family input .(Kugler et al., 2009) Individual centers utilize a web-based database that allows secure data entry from all clinic sites in REDcap (Research Electronic Data capture department of Medical Informatics, Vanderbilt University, TN). Data are entered at specific intervals (enrollment, neonatal surgery, hospital course, and discharge from Norwood surgical admission, interstage clinic visits (scheduled and unscheduled), BDG and death and are then combined from all centers for analysis. To identify small changes with rare events G charts are utilized to calculate days between events. For example, figure 2 demonstrates the number of patients who completed the BDG between each death.

NPCQIC leadership at the collaborative and local level includes parents, clinicians and researchers. Information on the NPCQIC is available on the internet (https://jcchdqi.org/) and available to the public. Participating centers can login for up-to-date center statistics, links to scientific resources, care tools (feeding bundles, emergency room cards, red flag action template) and message boards. Centers receive monthly updated data reports on their outcomes (i.e.

growth, mortality as it compares to the collaborative as whole). The collaborative has grown from 6 original sites to now 57 centers in 33 states. Sites and individual practioners can use their participation to fulfill maintenance of certification (MOC) credits for the American Board of Pediatrics. Workgroups within the collaborative focus on addressing specific issues and problems including transparency, feeding and growth, mortality, readmission, and neurodevelopmental outcomes. There is a Research and Publication Committee that evaluates research requests from participating centers and approves release of de-identified datasets for their analyses. Centers participate in monthly action period calls and semi-annual face-to-face meetings. During action period calls, members call in to learn about research/subgroup updates, new initiatives, share success stories, consider how to address barriers, and open discussion. During the semi-annual meetings, medical teams and parents come together to share information and further develop and spread best clinical practices. Quality improvement measures using "Plan-Do-Study-Act (PDSA)" cycles are utilized to implement test of changes and promote improvement in processes. Sharing of processes between centers is deeply encouraged to identify best practices and improve care.(Langley GL, 2009)

Parents have become key partners in the NPCQIC collaborative. Parents were invited to attend semi-annual meetings and provide their perspective to care from initial diagnosis to admission for the BDG. Because of the valuable insight gained from parents attending the meetings NPCQIC partnered with Sisters by Heart (SBH) to further increase parent involvement. The president of SBH became part of the NPCQIC leadership team in 2013. SBH provides support, hope, and empowerment to families facing, and living with, a diagnosis of HLHS. SBH is working to connect and link HLHS families across the United States, to create a tight-knit national community. SBH has created a patient-powered, national database giving HLHS

families the ability to locate each other. The current SBH database is populated by over 600 families treating at cardiac centers across the nation.

Parents from the HLHS community, along with participating care centers, co-govern NPCQIC. Parents are engaged in all aspects of the collaborative including leadership, research, workgroups, and committees. Notably, NPCQIC's Transparency Workgroup is co-led by a parent and cardiologist and is made up of equal numbers of parents and practitioners (Figure 3). NPCQIC parent and clinician members worked together to identify and develop a resources page on the collaborative website to educate and empower HLHS parents and families and provide resources for clinician teams. The tools and resources include a welcome letter to parents/from parents, a care transitions video, interstage emergency card information, questions to ask when selecting a pediatrician, a hospital packing list, and organizations of interest. Parents also developed a Book of Hope with stories from HLHS families and children and a Single Ventricle Q&A to facilitate conversation and transparency between care providers and parents.

A recent advancement in parent-practitioner partnership began when SBH witnessed parents discussing research articles online, drawing conclusions from abstracts and asking/answering questions about studies related to their HLHS child. SBH approached NPCQIC about their concern of parents drawing inaccurate conclusions and requested NPCQIC provide research write-ups for parents. NPCQIC responded, creating the "Research Explained" series, led by NPCQIC's Research and Publication Committee. "Research Explained" is very popular amongst the HLHS community and provides background of a specific study, results and limitations of the study, and takeaway messages for parents. The Research and Publication Committee includes three parent members who vet studies and assist clinicians in "Research Explained" write-ups.

Over the years, parents have strongly advocated that the QI work extend beyond the interstage. This has led to the development of NPCQIC "Phase 2" which will extend the QI efforts from initial diagnosis through the first year of life, with a keen focus on the need to support parents and families of infants with HLHS. With parent input, NPCQIC widened its scope and now includes the following Phase 2 design teams: 1) prenatal and birth, 2) intensive care, 3) surgical, 4) neurodevelopmental, and 5) family quality of life. Parents and practitioners are working together to identify best practices to improve outcomes and drive the collaborative to share data more transparently in order to "get better faster." Many publications have come from data, best practices and collaborations collected from the NPCQIC. Since its inception the NPCQIC has been able to make important observations on care transitions, feeding and growth, prenatal care, surgical repair, intensive care unit management. The initial observational papers outlined practice variations that allowed centers to learn from each other and implement change to improve outcomes.

Research within the Collaborative Network

Previous studies have reported variable effect of prenatal diagnosis (PND) on outcomes.(Kipps et al., 2011; Tworetzky et al., 2001) Seventy five percent of HLHS infants enrolled in the NPCQIC are prenatally diagnosed. PND was highly variable within the centers, with 100% of infants prenatally diagnosed in some centers and others only 40%. There were significant differences between the infants with PND and those without PND in preoperative ventricular dysfunction, acidosis, preoperative ventilator support, and duration of time of postoperative mechanical ventilation. However, there were no differences between the groups in postoperative complications, interstage death and course at BDG.(Brown et al., 2015)

Surgical data were analyzed from the first 100 patients in the NPCQIC cohort. (Brown et al., 2011) Only centers that entered data for greater than 4 patients over 18 months were included in the analysis. The median age at stage I palliation was 5 days (range 2-78 days), and the most common operation was the Norwood with Sano shunt (55% of the cohort). The mean cardiopulmonary bypass was 137 min (38-403 min) with most sites between 100-200 minutes. The median cross clamp time was 48 minutes (0-148 min). There was significant center specific variation in these two measures. The median circulatory arrest time was 10 min (0-79 minutes) with significant variation between surgical sites. Finally there was variation in the depth of hypothermia with a median temperature of 19◦ (range 14-35.1◦). As the number of centers and infants undergoing the Norwood operation increase it is possible that we will be able to understand the impact of practice variations on outcomes.

Post-operative care was evaluated in this same cohort of patients and again practice variation was seen. The median intensive care unit (ICU duration) was 11 days (3-68 days), with a shorter length of stay among hybrid vs. Sano or BTS (9 days vs. 11 or 18 days). Patients with aortic atresia, who underwent BTS or needed reoperation, remained in ICU longer.(Baker-Smith et al., 2011) Most patients received inotropic support (milrinone>dopamine>epinephrine). The most common complications were neurologic, infection or arrhythmia. Patients who underwent the hybrid procedure had the least number of complications (20%) and the most complications were seen in patients who underwent the Sano shunt (49%). Site volume was not able to be assessed but there was not a higher complication rate in sites that had higher ICU length of stays. This early descriptive study provides thought for further evaluation as the number of patients in the collaborative perhaps now will allow greater comparisons.

Communication between care providers and surveillance strategies varied widely across the collaborative. In the beginning stages of the collaborative there were few centers that met goal of "complete discharge information". Schidlow et al found that only 26% of primary care providers received complete discharge communication including a written medication list, nutrition plan, and red flag list.(Schidlow et al., 2011) In addition, there was a discrepancy between what information was communicated to the primary care provider and the primary cardiologist. There was also large practice variation in interstage surveillance. The majority of infants had pulse oximetry and weight monitoring, however 4 centers utilized pulse oximetry only and 19 had no home surveillance. Other studies have shown improved outcomes when care coordination is improved between subspecialists, primary care providers and families.(Cooley, McAllister, Sherrieb, & Kuhlthau, 2009; Klitzner, Rabbitt, & Chang, 2010) . In a recent evaluation of NPCQIC data we have seen a standardization in processes since 2011 (see figure 4).(Jeffrey B. Anderson MD MBA & Martin MD, 2014) Measures of performance have significantly improved in many aspects of patient care, specifically improved complete care plans, complete communication to the PCP, post-care coordinator identification, updated preventive care plan, updated written medical list and updated written red flag action plan (see figure 5).

Regionalization of care was demonstrated by the observation that the majority of patients received care from a different site then the location of their surgery. There was no significant difference in mortality if patients were cared for at the surgical site or a nonsurgical site. [27]However, there were more emergency room visits and readmissions in the group of patients who were followed at their surgical site. The distance from surgical site did not affect mortality.

Most deaths were at home or in the emergency room. The importance and implication of these differences are unclear.

Poor growth and malnutrition is common in patients with HLHS and can be associated with increased infection risk, increased hospital stay and mortality following surgery.(Cameron, Rosenthal, & Olson, 1995) Previous studies have demonstrated a relationship between poor nutritional status and longer length of stay after the Glenn operation.(Anderson et al., 2009) Despite the high prevalence of growth failure in infants with HLHS there have been no consensus guidelines for feeding and growth. Factors contributing to growth failure include inadequate calorie intake, high metabolic demands, gastrointestinal pathology and genetic and extracardiac anomalies. (Gingell RL, 1989; Srinivasan et al., 2009) Early collaborative data showed significant variation in growth between centers. An early study evaluated 132 infants identified from 16 sites (sites that enrolled >4 pt), and the median time to full enteral feeds was 13 days.(Anderson et al., 2012) Of the patients in this study, eighty three percent had some oral feeds, 46% were supplemented with nasogastric tube (NGT), nasojejuenal (NJT) and 8% with a gastrostomy tube (GT). Measurements evaluated include absolute weight and weight for age (WAZ) at initial admission, at discharge after Norwood and admission for BDG. Zero change in WAZ was scored as >0 = positive growth and <0 negative growth. Sites with positive WAZ used: 1. Standard evaluation of feeding, 2. home scales for interstage weight checks, 3. regular phone contact, 4. specific weight gain /loss red flags. From the identification of the practice variation, a best practices feeding bundle was developed; including: 1. Interstage weight monitoring with home scales, 2. Use of "red flags" for interstage weight monitoring, 3. Regular contact with families at home regarding weight gain and feeding, 4. Availability of a dietician to

manage interstage nutrition questions, and 5. Standardized evaluation of feeding ability post-Norwood prior to discharge to interstage.(Anderson et al., 2012; Slicker et al., 2013)

Anderson et al then evaluated the effect of the nutrition bundle on patients enrolled in the collaborative after the bundle was developed and distributed. (Anderson et al., 2014) These authors evaluated WAZ scores between the time periods before and after the bundle were disseminated. The nutrition bundle eliminated the variation between centers and improved growth in the collaborative. Furthermore the sites with the most improvement were those that had early initial poor outcomes. This article demonstrates that finding and developing best practices results in decreased variation in care and improved outcomes. (Anderson et al., 2014)

Choice of feeding tubes was also analyzed and at discharge from stage 1 palliation 56% of patients required supplementation with a feeding tube.(Hill et al., 2014) Thirty seven percent of these patients did not need supplementation by the end of the interstage period. At the time of stage 2 palliation, 62% were orally fed, 8% NGT, 9% oral and NGT, 14% GT only and 6% oral and GT. The authors found no growth advantage in modality of supplemental feeding tube.

Cross et al evaluated the collaborative wide data to identify risk factors for interstage mortality.(Cross, Harahsheh, McCarter, & Martin, 2014) They found that the diagnosis of HLHS incurred more mortality compared to other single ventricle lesions. The next highest increase in relative risk of mortality was prescription of antiseizure medication at stage 1 hospital discharge. Earlier gestational age had an increased risk of mortality and infants with a gestational age < 34 weeks had nearly 50% mortality. The method of feeding also had increased risk, with those who were NGT and NJT fed having a RR of mortality of 5.5 over oral and GT feedings. Patients with an interstage readmission had an 8% mortality rate vs. 3% without a readmission.

There was a 3.1 relative risk of mortality if no primary cardiologist was identified. There were additional risk factors that were of borderline significance, including; HLHS subgroups of aortic stenosis/mitral stenosis, aortic atresia/mitral atresia, birth weight < 2.5 kg, female gender, and patients with >30% of clinic visits due to red flag events. Some of these risk factors are modifiable and their identification can lead to improved counseling and development of strategies for improved care processes.

The primary outcome measure of the NPCQIC is mortality. To date, 1163 infants have completed the interstage period. Of those, 1050 underwent stage 2 palliation, 18 underwent transplant and there were 96 mortalities. Since January 2013 there has been a significant shift in mortality with a decrease from 10.4% to 5.9% (see figure 5). This improvement in mortality is a relative reduction in interstage mortality of 39.7%. (Anderson JB)There have not been any changes in surgical techniques or medical based therapies to account for this change. This overall reduction in mortality is a significant improvement in outcomes and may be attributed to decreased practice variation and better processes as developed and implemented by the collaborative.(Jeffrey B. Anderson MD MBA & Martin MD, 2014)

Conclusion

The NPCQIC is a unique resource linking many centers caring for children with a relatively rare condition, which has enabled decreased variation in processes, improved interstage growth and a significant decrease in interstage mortality. Databases created by the collaborative allow for creative collaboration and networking for the improvement of science and of patient care. This process can be related to other types of congenital heart disease and be more broadly utilized. Future efforts within the collaborative will include a focus on care and

outcomes from initial (often fetal) diagnosis to one year of age, including collaboration with surgeons and intensivists and an emphasis on developmental screening and family support.

Key Points

Development of collaborations such as the NPCQIC are important in pediatrics as each center may only have a small number of patients and it is difficult to create change and improve outcomes within individual centers.

The NPCQIC provides a collaborative network in which many centers can work together to reduce practice variation and improve patient outcomes.

Utilizing parents as partners in quality improvement, working side-by-side with physicians, nurses, and dieticians is important in the success of the collaborative.

Ref 21 * An important article on the impact of prenatal diagnosis in large number of interstage patients.

Ref 32 **A key article demonstrating decreased practice variation leads to improved outcomes.

Ref 33 * A significant article evaluating growth and feeding modalities.

Ref 34 ** An important article identifying potential risk factors for interstage mortality.

Anderson, J. B., Beekman, R. H., 3rd, Border, W. L., Kalkwarf, H. J., Khoury, P. R., Uzark, K., . . . Marino, B. S. (2009). Lower weight-for-age z score adversely affects hospital length of stay after the bidirectional Glenn procedure in 100 infants with a single ventricle. *J Thorac Cardiovasc Surg, 138*(2), 397-404 e391. doi: 10.1016/j.jtcvs.2009.02.033

Anderson, J. B., Beekman, R. H., 3rd, Kugler, J. D., Rosenthal, G. L., Jenkins, K. J., Klitzner, T. S., . . . Lannon, C. (2014). Use of a learning network to improve variation in interstage weight gain after the Norwood operation. [Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Congenit Heart Dis, 9*(6), 512-520. doi: 10.1111/chd.12232

Anderson JB, B. R., Kugler JD, Rosenthal GL, Jenkins KJ, Klitzner TS, Martin GR, Neish SR, Brown D, Mangeot C, King E, Peterson L, Provost MS, Lannon C. Circulation Quality and Outcomes. in press.

Anderson, J. B., Iyer, S. B., Schidlow, D. N., Williams, R., Varadarajan, K., Horsley, M., . . . Lannon, C. (2012). Variation in growth of infants with a single ventricle. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *J Pediatr, 161*(1), 16-21 e11; quiz 21 e12-13. doi: 10.1016/j.jpeds.2012.01.009

Baker-Smith, C. M., Neish, S. R., Klitzner, T. S., Beekman, R. H., 3rd, Kugler, J. D., Martin, G. R., . . . Rosenthal, G. L. (2011). Variation in postoperative care following stage I palliation for single-ventricle patients: a report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Congenit Heart Dis, 6*(2), 116-127. doi: 10.1111/j.1747-0803.2011.00507.x

Birkmeyer, N. J., Marrin, C. A., Morton, J. R., Leavitt, B. J., Lahey, S. J., Charlesworth, D. C., . . . O'Connor, G. T. (2000). Decreasing mortality for aortic and mitral valve surgery in Northern New England. Northern New England Cardiovascular Disease Study Group. [Multicenter Study

Research Support, Non-U.S. Gov't]. *Ann Thorac Surg, 70*(2), 432-437.

Brown, D. W., Cohen, K. E., O'Brien, P., Gauvreau, K., Klitzner, T. S., Beekman, R. H., 3rd, . . . Jenkins, K. J. (2015). Impact of prenatal diagnosis in survivors of initial palliation of single ventricle heart disease: analysis of the national pediatric cardiology quality improvement collaborative database. [Research Support, Non-U.S. Gov't]. *Pediatr Cardiol, 36*(2), 314-321. doi: 10.1007/s00246-014-1005-4

Brown, D. W., Connor, J. A., Pigula, F. A., Usmani, K., Klitzner, T. S., Beekman, R. H., 3rd, . . . Jenkins, K. J. (2011). Variation in preoperative and intraoperative care for first-stage palliation of single-ventricle heart disease: a report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Congenit Heart Dis, 6*(2), 108-115. doi: 10.1111/j.1747-0803.2011.00508.x

Cameron, J. W., Rosenthal, A., & Olson, A. D. (1995). Malnutrition in hospitalized children with congenital heart disease. *Arch Pediatr Adolesc Med, 149*(10), 1098-1102.

Cooley, W. C., McAllister, J. W., Sherrieb, K., & Kuhlthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. [Research Support, U.S. Gov't, P.H.S.]. *Pediatrics, 124*(1), 358-364. doi: 10.1542/peds.2008-2600

Cross, R. R., Harahsheh, A. S., McCarter, R., & Martin, G. R. (2014). Identified mortality risk factors associated with presentation, initial hospitalisation, and interstage period for the Norwood operation in a multi-centre registry: a report from the national pediatric cardiology-quality improvement collaborative. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Cardiol Young, 24*(2), 253-262. doi: 10.1017/S1047951113000127

Dooley, K. J., & Bishop, L. (2002). Medical management of the cardiac infant and child after surgical discharge. [Review]. *Crit Care Nurs Q, 25*(3), 98-104.

Ghanayem, N. S., Hoffman, G. M., Mussatto, K. A., Cava, J. R., Frommelt, P. C., Rudd, N. A., . . . Tweddell, J. S. (2003). Home surveillance program prevents interstage mortality after the Norwood procedure. *J Thorac Cardiovasc Surg, 126*(5), 1367-1377. doi: 10.1016/S0022

Gingell RL, H., MG. (1989). *Growth problems associated with congenital heart disease in infancy*. New York: Raven Press.

Hewitt M, W. S., Simone JV (eds). . (2003)). Childhood Cancer Survivorship: Improving Care and Quality of Life.External Web Site Icon. *National Academy of Sciences: Washington, DC*.

Hill, G. D., Hehir, D. A., Bartz, P. J., Rudd, N. A., Frommelt, M. A., Slicker, J., . . . Ghanayem, N. S. (2014). Effect of feeding modality on interstage growth after stage I palliation: a report from the National Pediatric Cardiology Quality Improvement Collaborative. [Multicenter Study]. *J Thorac Cardiovasc Surg, 148*(4), 1534-1539. doi: 10.1016/j.jtcvs.2014.02.025

Jacobs, J. P., O'Brien, S. M., Pasquali, S. K., Jacobs, M. L., Lacour-Gayet, F. G., Tchervenkov, C. I., . . . Mavroudis, C. (2011). Variation in outcomes for benchmark operations: an analysis of the Society of Thoracic Surgeons Congenital Heart Surgery Database. *Ann Thorac Surg, 92*(6), 2184-2191; discussion 2191-2182. doi: 10.1016/j.athoracsur.2011.06.008

Jeffrey B. Anderson MD MBA, R. H. B. I. M., John D. Kugler MD, Geoffrey L. Rosenthal MD PhD, Kathy J. Jenkins MD, Thomas S. Klitzner MD PhD, Gerard R. , & Martin MD, S. R. N. M., David Brown MD, Colleen Mangeot MS, Eileen King PhD, Laura E. Peterson BSN SM, Lloyd Provost MS, Carole Lannon MD MPH (2014). *Outcome improvement in a rare disease population through a national pediatric learning network*. Paper presented at the 20th Annual International Scientific Symposium on Improving the Quality and value of Health Care, Orlando, FL.

Jenkins, K. J., Newburger, J. W., Lock, J. E., Davis, R. B., Coffman, G. A., & Iezzoni, L. I. (1995). In-hospital mortality for surgical repair of congenital heart defects: preliminary observations of variation by hospital caseload. [Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Pediatrics, 95*(3), 323-330.
Johnson, B. A., Mussatto, K., Uhing, M. R., Zimmerman, H., Tweddell, J., & Ghanayem, N. (2008). Variability in the preoperative management of infants with hypoplastic left heart syndrome. *Pediatr Cardiol, 29*(3), 515-520. doi: 10.1007/s00246-007-9022-1
Kipps, A. K., Feuille, C., Azakie, A., Hoffman, J. I., Tabbutt, S., Brook, M. M., & Moon-Grady, A. J. (2011). Prenatal diagnosis of hypoplastic left heart syndrome in current era. *Am J Cardiol, 108*(3), 421-427. doi: 10.1016/j.amjcard.2011.03.065
Klitzner, T. S., Rabbitt, L. A., & Chang, R. K. (2010). Benefits of care coordination for children with complex disease: a pilot medical home project in a resident teaching clinic. [Research Support, Non-U.S. Gov't]. *J Pediatr, 156*(6), 1006-1010. doi: 10.1016/j.jpeds.2009.12.012
Kugler, J. D., Beekman Iii, R. H., Rosenthal, G. L., Jenkins, K. J., Klitzner, T. S., Martin, G. R., . . . Lannon, C. (2009). Development of a pediatric cardiology quality improvement collaborative: from inception to implementation. From the Joint Council on Congenital Heart Disease Quality Improvement Task Force. [Research Support, Non-U.S. Gov't]. *Congenit Heart Dis, 4*(5), 318-328. doi: 10.1111/j.1747-0803.2009.00328.x
Langley GL, N. K., Nolan TW, Norman CL, Provost LP. (2009). *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. San Francisco, CA: Jossey-Bass Publishers.
Lannon, C. M., & Peterson, L. E. (2013). Pediatric collaborative networks for quality improvement and research. [Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.

Review]. *Acad Pediatr, 13*(6 Suppl), S69-74. doi: 10.1016/j.acap.2013.07.004
The Learning Healthcare System: Workshop Summary. (2007). Paper presented at the Institute of Medicine Roundtable on Evidence-Based Medicine, Washington DC.
O'Connor, G. T., Plume, S. K., Olmstead, E. M., Morton, J. R., Maloney, C. T., Nugent, W. C., . . . Kasper, J. F. (1996). A regional intervention to improve the hospital mortality associated with coronary artery bypass graft surgery. The Northern New England Cardiovascular Disease Study Group. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *JAMA, 275*(11), 841-846.
Pui, C. H., & Evans, W. E. (1998). Acute lymphoblastic leukemia. [Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.

Review]. *N Engl J Med, 339*(9), 605-615. doi: 10.1056/NEJM199808273390907
Schidlow, D. N., Anderson, J. B., Klitzner, T. S., Beekman, R. H., 3rd, Jenkins, K. J., Kugler, J. D., . . . Lannon, C. (2011). Variation in interstage outpatient care after the Norwood procedure: a report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. [Multicenter Study

Research Support, Non-U.S. Gov't

Research Support, U.S. Gov't, P.H.S.]. *Congenit Heart Dis, 6*(2), 98-107. doi: 10.1111/j.1747-0803.2011.00509.x
Simone, J. V., & Lyons, J. (1998). The evolution of cancer care for children and adults. [Editorial]. *J Clin Oncol, 16*(9), 2904-2905.

Slicker, J., Hehir, D. A., Horsley, M., Monczka, J., Stern, K. W., Roman, B., . . . Anderson, J. B. (2013). Nutrition algorithms for infants with hypoplastic left heart syndrome; birth through the first interstage period. [Practice Guideline

Review]. *Congenit Heart Dis, 8*(2), 89-102. doi: 10.1111/j.1747-0803.2012.00705.x

Srinivasan, C., Sachdeva, R., Morrow, W. R., Gossett, J., Chipman, C. W., Imamura, M., & Jaquiss, R. D. (2009). Standardized management improves outcomes after the Norwood procedure. *Congenit Heart Dis, 4*(5), 329-337. doi: 10.1111/j.1747-0803.2009.00323.x

Tabbutt, S., Ghanayem, N., Ravishankar, C., Sleeper, L. A., Cooper, D. S., Frank, D. U., . . . Laussen, P. (2012). Risk factors for hospital morbidity and mortality after the Norwood procedure: A report from the Pediatric Heart Network Single Ventricle Reconstruction trial. [Comparative Study

Multicenter Study

Randomized Controlled Trial

Research Support, N.I.H., Extramural]. *J Thorac Cardiovasc Surg, 144*(4), 882-895. doi: 10.1016/j.jtcvs.2012.05.019

Tweddell, J. S., Hoffman, G. M., Mussatto, K. A., Fedderly, R. T., Berger, S., Jaquiss, R. D., . . . Litwin, S. B. (2002). Improved survival of patients undergoing palliation of hypoplastic left heart syndrome: lessons learned from 115 consecutive patients. [Research Support, Non-U.S. Gov't]. *Circulation, 106*(12 Suppl 1), I82-89.

Tworetzky, W., McElhinney, D. B., Reddy, V. M., Brook, M. M., Hanley, F. L., & Silverman, N. H. (2001). Improved surgical outcome after fetal diagnosis of hypoplastic left heart syndrome. [Comparative Study]. *Circulation, 103*(9), 1269-1273.

Table 1

1. The goal of the QI initiative is to improve care and outcomes for children with cardiovascular disease

2. The JCCHD will determine major directions in the development of this QI initiative through its delegation to the QI initiative Steering Committee. A strategy will be developed and implemented to facilitate the communication about the initiative with the larger pediatric cardiology community.

3. The QI initiative, through multiple improvement projects, will address the spectrum of pediatric cardiovascular inpatient and outpatient care, including case finding, diagnosis, treatment, recovery, discharge, and follow-up (including hand-offs). The initiative will be a well-focused project.

4. A national, multi-institutional database for the purpose of supporting QI projects will be part of this initiative. Where related databases exist that may be beneficial to the QI initiative, they will be utilized to the extent possible.

5. The QI initiative will seek to involve all pediatric cardiology programs and practices, from small to large. We will make an effort to emphasize inclusion of all programs with pediatric cardiology fellowships because they are our future.

6. Quality improvement science, emphasizing the Model for Improvement, will be the preferred approach taken by these projects.

7. An emphasis will be placed on including patients, parents and families in the design and implementation of projects. We will strive to be inclusive of diverse cultures and values.

8. The QI initiative will take a collegial approach to the involvement of important related specialties, including cardiothoracic surgery, pediatric critical care medicine, anesthesia, nursing, social work and child life.

Figure 1

Figure 2

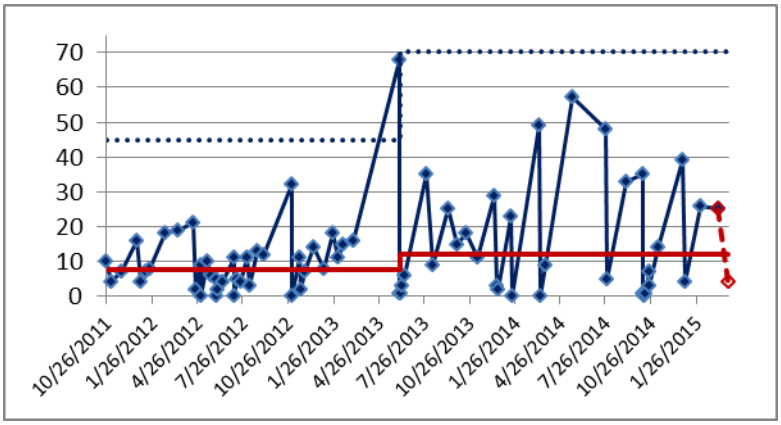
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Figure 3

Co-Governing with parents

- Governance Council
- Steering Committee
- Leadership group
- Business Advisory Committee

Work Groups

- Transparency
- Mortality
- Feeding
- Readmissions
- Research Committee

Figure 4

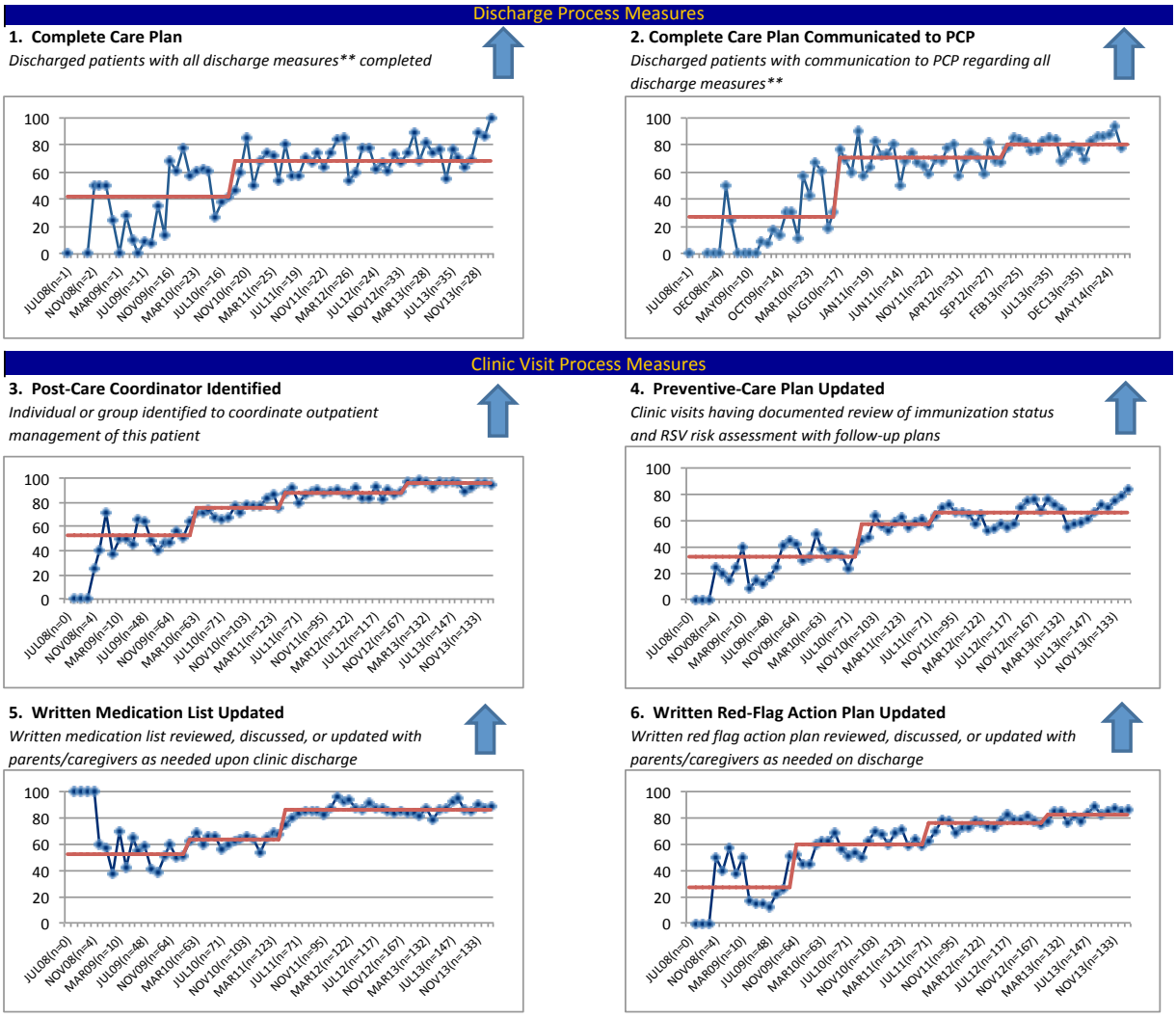
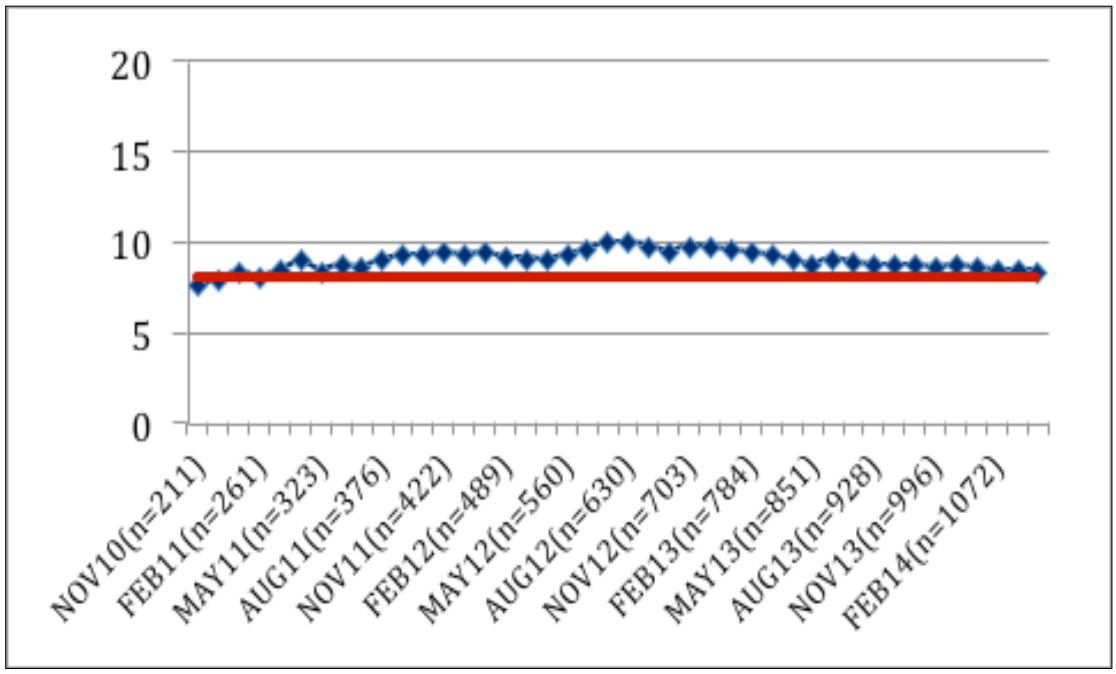

Discharge Process Measures
1. Complete Care Plan
Discharged patients with all discharge measures** completed
2. Complete Care Plan Communicated to PCP
Discharged patients with communication to PCP regarding all discharge measures**
Clinic Visit Process Measures
3. Post-Care Coordinator Identified
Individual or group identified to coordinate outpatient management of this patient
4. Preventive-Care Plan Updated
Clinic visits having documented review of immunization status and RSV risk assessment with follow-up plans
5. Written Medication List Updated
Written medication list reviewed, discussed, or updated with parents/caregivers as needed upon clinic discharge
6. Written Red-Flag Action Plan Updated
Written red flag action plan reviewed, discussed, or updated with parents/caregivers as needed on discharge

Figure 5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NOV12(n=703)
FEB13(n=784)
MAY13(n=851)
AUG13(n=928)
NOV13(n=996)
FEB14(n=1072)

Figure Legend

Table 1. Guiding Principles of NPCQIC (Kugler et al., 2009)

Figure 1. Key Driver Diagram

Figure 2. Mortality G-chart, number of patients who completed Glenn between each death. The last point is the number of patients who completed Glenn since the last death.

Figure 3. NPCQIC Organizational Structure

Figure 4. NPCQIC improved clinical process measures

Figure 5. NPCQIC Cumulative Mortality

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None

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None

Conflicts of Interest:

None