



# NATIONAL PEDIATRIC CARDIOLOGY

*Quality Improvement Collaborative*

## *Research Explained*

### **Practice Trends in HLHS**

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#### **Main Findings from this Study**

One of the goals of the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is to reduce practice variation, which then may improve patient outcomes. The NPC-QIC has reported a reduction in interstage mortality between post-Norwood hospital discharge and the Glenn surgery. This important reduction could be due to many different factors such as evolution of surgical practice, improved home monitoring, improved nutrition, and shortened interstage period.

The NPC-QIC published initial studies in 2011 on patient and practice variation examining an initial group of patients. The intent was to reexamine these variations five years later. In the more recent cohort of patients, we found higher rates of prenatal diagnosis and lower rates of preoperative risk factors. Center variation in timing of the Norwood surgery decreased. There were improved discharge communication practices and use of home monitoring programs. Nutritional practices such as route of feeding and calories appeared unchanged.

#### **About this Study**

##### **Why is this study important?**

Though not the intent, the findings in the study can be viewed as most common practices in the field of HLHS palliation. This may help centers that are smaller, new to HLHS surgery, or have suboptimal results. Likewise, this same information can help families compare their own experiences to others and find comfort knowing standards are forming between centers.

##### **How was this study performed?**

This was a retrospective review of patients in the NPC-QIC database. Specifically, it compared 100 patients from an early era (6/2008-1/2010) with 100 patients from a late era (1/2014-11/2014). There are over 50 centers involved in NPC-QIC but data was only collected from the

same 18 care centers for both early and late eras to better evaluate changes in practice variation, surgical variables, and patient characteristics.

### **What were the results of the research?**

We found significant changes in preoperative risk factors, Norwood surgical strategy, discharge communication, and interstage monitoring.-The prenatal diagnosis rate increased from 72 to 82%. Preoperative Norwood risk factors (acidosis, need for ventilator, renal failure, for example) decreased from 58 to 34%. The Norwood surgery was performed on average at 5 days old in both eras, but there were fewer patients receiving the surgery in a delayed fashion in the late era group. The Norwood surgery with an RV-PA conduit (instead of a BT shunt) became more common, increasing from 69 to 84%. Complete discharge communication rates with the primary care provider increased from 27 to 97%. Interstage monitoring of oxygen saturation and weight gain increased from 70 to 99%. In the late era the Glenn surgery on average was performed slightly earlier and the interstage duration was slightly shorter. We found no changes in route of feeding, calorie content of formula, or weight gain. (interstage monitoring and discharge communication

### **What are the limitations of this study?**

The main limitation of this study was the sample sizes examined. We studied 100 patients in each era, similar in size to the initial NPC-QIC practice variation studies. With so few patients, this study was not designed to examine changes in mortality. It was also not designed to answer the question of which changes in practice variation, patient characteristic, or surgical variable may have been responsible for the interstage mortality reduction reported by NPC-QIC.

In addition, this study only evaluated changes in patients enrolled in NPC-QIC phase I (starting at the time of hospital discharge after Norwood surgery). It did not evaluate changes in all patients undergoing Norwood surgery, excluding those that died or were never discharged. NPC-QIC phase II, which began recently, looks at patients starting at birth and will be better set up to study Norwood surgery and early post-operative practice trends.

A final limitation is the inclusion of only 18 centers in this study design. The data presented reflects HLHS care at these centers and may not be representative of care throughout NPC-QIC institutions as well as those not participating in the collaborative. The most common practice trends in this data should not necessarily be taken as “best practice.”

### **What are the takeaway messages considering the results and limitations of this study?**

Even over a small time period of about 5 years, substantial changes occurred in practice variation, patient characteristics like preoperative Norwood risk factor, and surgical variables. We can speculate that better prenatal diagnosis may be allowing for standardization and optimization of the preoperative Norwood condition. These changes suggest that the care of these high risk HLHS patients is constantly evolving, and participation in quality improvement programs like NPC-QIC likely plays an important role in improved patient outcomes. As we enter NPC-QIC phase II, opportunities for improvement remain, especially in nutritional variables.

