



National Pediatric Cardiology
Quality Improvement Collaborative

Research Explained

Development of a validated risk score for interstage death or transplant after stage I palliation for single-ventricle heart disease

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ABOUT THIS STUDY

Why is this study important?

- Some children with single-ventricle heart disease will need to have several surgeries during infancy called staged surgical palliation. The first surgery is called stage 1 or the Norwood procedure and the second is called stage 2 or the Glenn procedure
- The time between these first two surgeries is called the “interstage” period (between stage 1 and stage 2). The interstage period is a high risk time for death for children that require these staged surgeries
- The factors that cause interstage death or need for heart transplantation are not well understood and this study looks at different factors that might predict interstage death

How was this study performed?

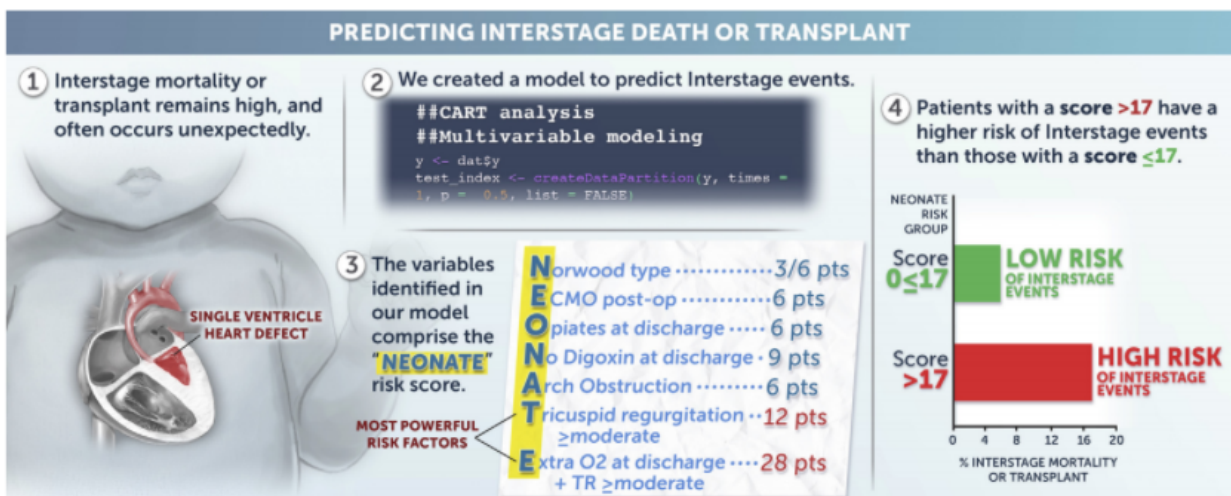
- This study used information from a national database (phase 1 data from National Pediatric Cardiology Quality Improvement Collaborative registry) to develop a scoring system that might predict interstage death or heart transplantation
- After the scoring system was created from part of the registry data, it was then validated with the remaining patients in the database

What was the goal of the study?

- To develop a predictive model (the NEONATE risk scoring system) for patients that are at high risk of interstage death or need for heart transplantation

What were the results of the study?

- Over 2000 patients across the country were analyzed and validated in this study
- There were 7 variables that were found to be most predictive of increased risk for interstage death. These were the following
 1. Type of Norwood procedure (BT shunt, right ventricle to pulmonary artery conduit or Hybrid)
 2. Need for ECMO (heart-lung machine) support following surgery
 3. Discharge home with strong pain medications (opioids such as methadone, oxycodone, etc.)
 4. Discharge home without a medication called Digoxin
 5. Residual aortic arch obstruction
 6. Significant leaky valve (tricuspid valve) without need for extra oxygen support at discharge
 7. Significant leaky valve (tricuspid valve) in combination with need for extra oxygen support at discharge
- Of these seven, the most important variables were numbers 6 and 7 above (significant valve leakage with or without the need for extra oxygen support on discharge home)
- Patients that had a combined score of greater than 17 points were at the greatest risk of death or need for heart transplantation during the interstage period. This was found to be nearly three times the risk of patients with scores ≤ 17 (see image below).



What are the limitations of this study?

- This study only includes patients that were discharged following stage I Norwood surgery and does not include patients that were never discharged from the hospital or died following stage 1 in the hospital
- Different surgical centers have variable surgical techniques and post-operative care that cannot be accounted for in this study

What it all means?

- Predicting what patients are at highest risk of death is challenging and influenced by many factors
- This study provides an objective scoring system to identify patients that were at highest risk of death or need for heart transplantation from a large national database
- The score is meant to be used as an additional tool for the care planning for children in the interstage period
- Children with a high-risk score (defined as greater than 17 points) should discuss the risks and benefits of discharge with close home monitoring against continued inpatient hospitalization until stage 2 procedure with their centers care team