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Commentary: Outcomes of truncus arteriosus repair: Insights from time and numbers

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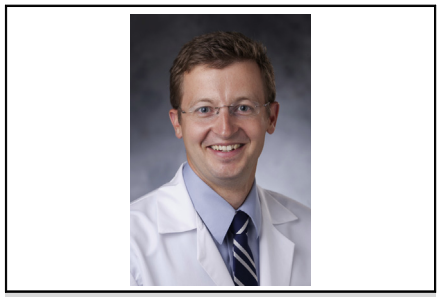

Christoph P. Hornik, MD, PhD, MPH

CENTRAL MESSAGE

Large patient cohorts with complete long-term follow-up provide invaluable information to inform congenital cardiac care. Novel strategies to scale up complete long-term follow-up should be pursued.

In this issue of the *Journal*, Dr Naimo and colleagues[1] share findings from their review of 255 consecutive patients undergoing truncus arteriosus repair at 3 Australian hospitals between 1978 and 2018. The article is remarkable for the size of the patient cohort and the excellent 96% follow-up among survivors to a median of 16.4 years. Leveraging this rich dataset, the authors identified important early and late mortality trends and risk factors, including a 1-year mortality of 13.3%, conditional survival past 1 year of 93.5%, and 20-year survival of 76.8%. Although prior case series, including multicenter reports from the Society of Thoracic Surgeons, have reported outcomes and identified risk factors for patients with truncus arteriosus, cohorts were smaller and duration of follow-up shorter. The value of a larger sample size and longer follow-up may be best illustrated by the reported analysis of neonatal outcomes. Although the proportion of neonatal operations increased over time, mortality remained unchanged and significantly higher than for operations performed outside the neonatal period. Upon closer examination, mortality at 1 and 10 postoperative years was highest among neonates operated on in the first and fourth weeks of life, subgroups that carried the highest prevalence of comorbidities (23/24 neonates operated on in the first week of life) and heart failure symptoms requiring intensive care unit (6/13 neonates operated on in the fourth week of life), respectively. Of note, neither of these were significant risk factors for early and late mortality when analyzed in the entire patient cohort.

The importance of detailed analyses of risk factors for early and late outcomes in age- and disease-specific subgroups is well understood to clinicians and researchers in congenital heart disease. The challenge lies mostly in acquiring data to conduct detailed analyses. Registries, including efforts from the Society of Thoracic Surgeons and the Congenital Heart Surgeons Society, have generated vast amounts of data that identified patient subgroup-specific management strategies for several congenital heart defects, including truncus arteriosus.[2-4] Although registries will undoubtedly remain invaluable to advancing knowledge in our field, alternative data-collection strategies, especially those that permit longitudinal follow-up across institutions, should be pursued. After widespread implementation of the electronic health record (EHR), tools that facilitate access, use, and sharing of EHR data, most notably based on Health Level 7 Fast Healthcare Interoperability Resources standards, are increasingly applied.[5] Although Fast Healthcare Interoperability Resources offers several strategies to unlock to power of EHR data through Application Programming Interfaces, the development of the personal health record, maintained by patients over their life span and across institutions, may be of particular value.[6] Recruiting patients into large-scale efforts to share personal EHR data may transform our ability to directly understand short- and long-term impacts of congenital cardiac care for patients as they transition across healthcare systems over their lifetime. Although complex, personal EHR data-sharing efforts may help make large and long-term studies such as the one by Naimo and colleagues[1] more commonplace in congenital heart care.

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Commentary: Truncus among us

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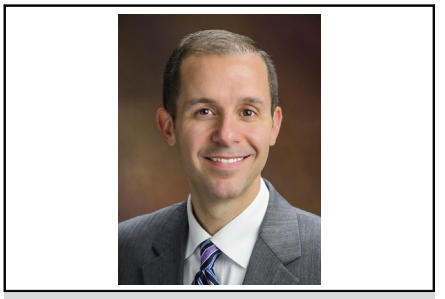

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CENTRAL MESSAGE

TA has been repaired successfully in the neonate for 30 years. Advances in imaging, operative techniques, and perioperative care have contributed to improving morbidity and mortality.

The first complete repair of truncus arteriosus (TA) was performed in 1962 by Sloan, but not published until 1974 by Behrendt and colleagues[1] as part of a larger cohort of patients. Ebert and colleagues[2,3] published a series of complete repair of TA in both 1976 and 1984 on infants aged 6 months or less and reported an operative mortality of 11% to 20%. Because the patients were a few months of age or older, not surprisingly, the most common cause of mortality was pulmonary hypertension. Because of weight loss and congestive heart failure in addition to pulmonary hypertension, Bove and colleagues[4] advocated and reported success repairing TA in the neonate in 1989.

Naimo and colleagues[5] present a 40-year perspective on TA repair in Australia at multiple centers. There are interesting findings that contradict conventional wisdom about preoperative TA physiology and timing of operation among other things. The authors report a neonatal mortality of 23.7% compared with 7.4% in older patients. More specifically, they state that neonates in week 1 of life (because of concomitant anomalies like truncal insufficiency, arch obstruction, and coronary anomalies) and week 4 of life (because of congestive heart failure/pulmonary over circulation) had the worst neonatal outcomes. Only 53% of those undergoing TA repair in the most recent era (1999-2018) had the operation during the neonatal period. Their mortality and timing of operation are contrasted with the North American approach to TA. Today, it is standard of care to repair TA in the first week of life. The Society of Thoracic Surgeons Congenital Heart Surgery Database reports a mortality for TA of 9.5% (interquartile range, 0.0%-15.4%).[6]

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