

Collaboration and Standardized Management Plans to optimize clinical care and research of Posterior Urethral Valves



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Disclosures

- None

Background

- Posterior Urethral Valves (PUV) is a rare, yet devastating disease of the male urinary tract with the potential for kidney injury
- Clinical practice guidelines are lacking
- Standardized Clinical Assessment and Management Plans (SCAMPs) were first described by the cardiovascular department at Boston Children's Hospital in 2010
 - SCAMPs improve on clinical practice guidelines by inviting clinician diversions, data collection and outcome measures

Study Aims

- Through a multispecialty and multi-institutional collaborative we aimed to 1) assess the need for and 2) develop a SCAMP for the management of PUV across five Midwest children's hospitals

Results

- A retrospective analysis identified 274 children born between 1995 and 2005 who were initially cared for at one of the 5 PUMA centers
 - On survival analysis, 30% progressed to End Stage Renal Disease (ESRD) by 15 years of age¹
- Significant practice variability was noted across PUMA centers

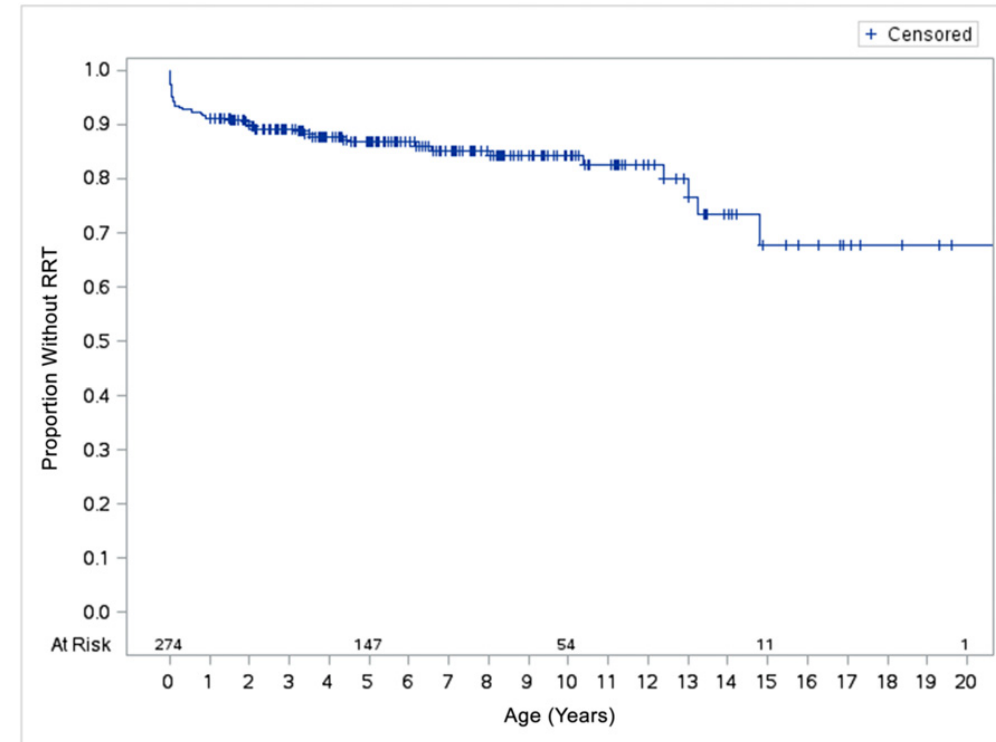


FIGURE 1
Kaplan-Meier estimates of age at RRT (PUV cohort; 1995–2015).

Results

- In areas of disagreement, literature reviews, conference calls and in-person meeting facilitated consensus
- A SCAMP was developed, incorporating expert opinion and contemporary literature for the management of PUV
- Surgeon preference options were added to improve acceptance and variance off pathway will be studied to allow future revisions

Discussion

- To date we have shown the feasibility for multispecialty and multi-institutional collaboration for the management of a rare disease
- This SCAMP represents, to our knowledge, the most comprehensive, evidence based management pathway available for the care of PUV
- Future work will focus on the study of clinical outcomes and SCAMP revisions to optimize PUV management