

# Days Alive and Out of Hospital for Single Ventricle Patients in the First Year of Life

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## Background

- Children born with single-ventricle (SV) heart disease have only one ventricle capable of supporting systemic circulation.
- Data suggest that there are discrepancies between physician and parent expectations and perceptions of prognosis for these children.<sup>1,2</sup>
- Days alive and out of hospital (DAOH) has been demonstrated as an effective way to capture both morbidity and mortality for patient groups, along with being an easily understood outcome measure.<sup>3,4</sup>

## Hypothesis

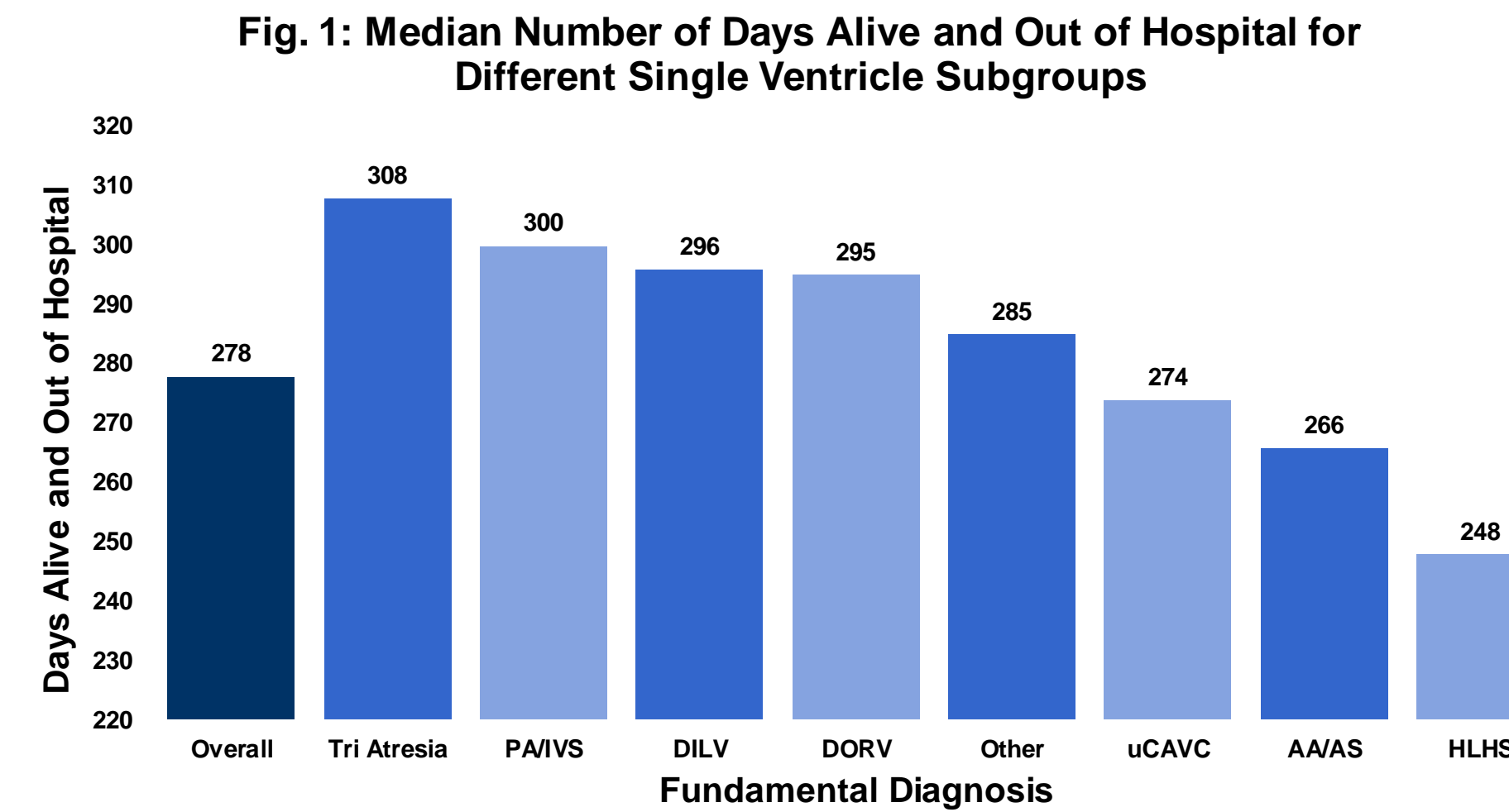
- We hypothesized that different anatomic, demographic, and preoperative risk factors would be predictive of number of DAOH in the first year of life for our SV patients.

## Patients and Methods

- This was a retrospective study of all SV patients born between the years 2005 - 2021 who had their primary operations performed at our institution.
- DAOH in the first year of life was calculated by subtracting the number of days the patient was admitted to the hospital from the number of days the patient was alive during the first year of life.
- Descriptive statistics were used to compare baseline characteristics, number of DAOH and secondary endpoints between different SV subgroups.
- A multivariable linear regression with a stepwise variable selection procedure was used to determine risk factors independently associated with fewer DAOH.

## Results

- N=437 SV patients were included. Overall median number of DAOH in the first year of life was 278 days (IQR 157-319).
- Patients with hypoplastic left heart syndrome (HLHS) had only 248 (65-308) DAOH in the first year of life, while patients with tricuspid atresia (Tri Atresia) had the greatest number of DAOH at 308 (272, 335) (Figure 1).



Tri Atresia = Tricuspid Atresia, PA/VS = Pulmonary Atresia with Intact Ventricular Septum, DILV = Double Inlet Left Ventricle, DORV = Double Outlet Right Ventricle, uCAVC = Unbalanced Complete Atrioventricular Canal, AA/AS = Aortic Atresia/Aortic Stenosis, HLHS = Hypoplastic Left Heart Syndrome

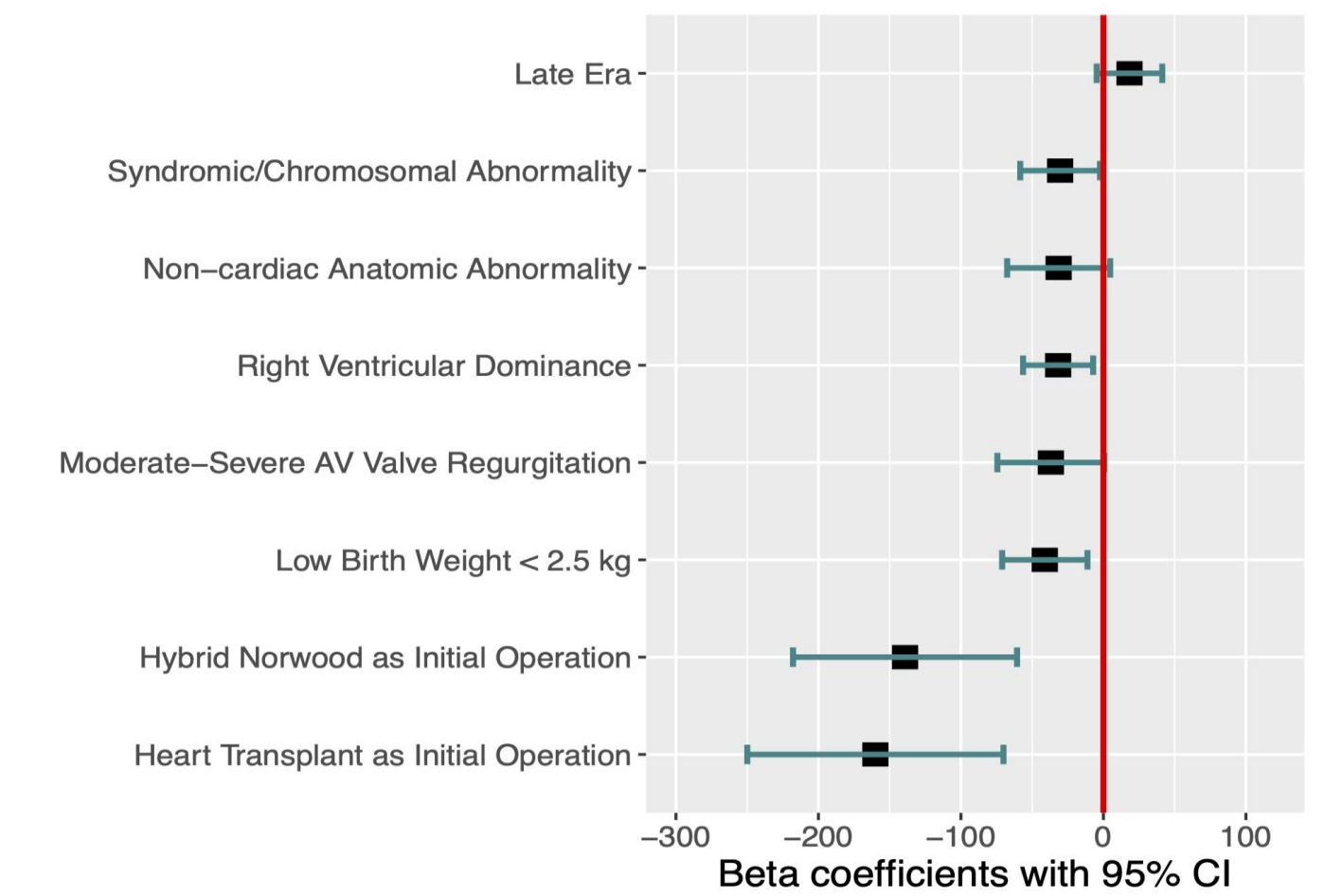
- On average, patients had  $3.0 \pm 1.84$  hospitalizations during their first year of life.
- The need for surgical and interventional procedures in the first year of life was high – the average number of surgical operations and catheterizations per patient was  $1.8 \pm 0.71$  and  $2.2 \pm 1.71$ , respectively.
- Care utilization outside of the hospital in the first year of life was similarly high, with the average number of outpatient clinic visits being  $12.2 \pm 8.93$ .

	Average $\pm$ Standard Deviation
Number of Hospitalizations	$3.0 \pm 1.84$
Number of Surgeries	$1.8 \pm 0.71$
Number of Catheterizations	$2.2 \pm 1.71$
Number of Clinic Visits *	$12.2 \pm 8.93$

\*Only includes patients born after 2012 with a primary Duke cardiologist

## Multivariable Results

- In a multivariable analysis, low birth weight (<2.5kg), presence of a dominant right ventricle, moderate-severe dominant atrioventricular valve regurgitation at birth, and undergoing an initial hybrid Norwood procedure or heart transplant were all independently associated with significantly fewer DAOH.



## Conclusions

- This analysis of DAOH in the first year of life shows that children born with SV heart defects have significant illness burden.
- Identifying risk factors are associated with fewer DAOH may aid in family counseling and prognostication of SV patients.

## References

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