Days Alive and Out of Hospital for Children Born with Single Ventricle Heart Disease

Authors

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*Given the large number of patient charts that needed to be reviewed, help was needed from multiple coauthors

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ABSTRACT

Background: Overall illness burden in the first year of life for children born with single ventricle (SV) heart disease remains poorly characterized. This study sought to describe illness burden for SV patients in the first year of life using the metric of days alive and out of hospital (DAOH) as a way to capture both morbidity and mortality in this population.

Methods: This was a retrospective single-center study of SV patients born between 2005-2021 (n=437) who had their initial operation performed at our institution. Patient demographics, anatomical details, and hospitalizations were extracted from our institutional SV database. DAOH was calculated by subtracting number of days hospitalized from number of days alive during the first year of life. A multivariable linear regression with a stepwise variable selection procedure was used to determine risk factors independently associated with DAOH.

Results: Overall median number of DAOH in the first year of life for SV patients was 278 days (IQR 157-319). In a multivariable analysis, low birth weight (<2.5kg) (b=-37.55, p=0.013), presence of a dominant right ventricle (b=-31.05, p=0.014), moderate-severe dominant atrioventricular valve regurgitation at birth (b=-37.65, p=0.05) and undergoing an index hybrid Norwood operation (b=-138.73, p<0.0001) or heart transplant (b=-158.41, p<0.001) were all independently associated with significantly fewer DAOH.

Conclusions: This analysis of DAOH shows that children born with SV heart defects have significant illness burden in the first year of life, demonstrated by lengthy hospitalizations. Identifying risk factors associated with fewer DAOH may aid in family counseling and prognostication of SV patients.