

TITLE: A First Stage Approach to Understanding Value in Hypoplastic Left Heart Syndrome Palliation

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INTRODUCTION: Management of hypoplastic left heart syndrome (HLHS) is complex and resource intensive. Health care systems are under pressure to provide superior value to patients by improving outcomes while decreasing costs.

METHODS: We performed a single center retrospective cohort study of infants with HLHS who underwent Norwood procedure or variant from 2004-2014 and survived to first outpatient follow up. We included patients who exclusively received their inpatient and outpatient care at our institution to isolate patients with complete financial records. Demographic and clinical data were obtained from electronic health records. Costs were calculated using our internal cost accounting system. The primary clinical endpoint was transplant-free survival, deemed the first-order measure of outcome in the value equation. The primary outcome was total institutional cost for survival to initial hospital discharge, to 12 months, and to 60 months of life. Data was analyzed using Wilcoxon rank-sum test, univariate, and multivariate linear regression.

RESULTS: Of 161 HLHS patients identified, 71 met inclusion criteria. Two subjects were excluded due to incomplete financial data leaving 69 patients for analysis (64% male). **Stage I hospitalization (n=69)**, with a median length of stay 34 days (15-435), resulted in a median cost of \$203,817 (\$100,843 – 2,061,650). At **12 months of life (n=55)** the median number of hospitalized days was 76 (24-312) with a median cost of \$369,393 (\$167,242 – 1,921,944). Of those with data available at **60 months of life (n=29)**, the median total cost was \$391,812 (\$243,660 – 1,356,873). Primary overall cost centers included intensive care (31%), operative services (14%), cath lab (8%), and pharmacy (7%). In multivariable analysis, significant drivers of cost early in life included reoperation during stage 1 or stage 2, length of hospitalization, low birthweight, and use of ECMO (all $p < 0.05$).

CONCLUSIONS: Cost related to HLHS management is driven by complications requiring surgical re-intervention and patient factors including low birth weight. While this study provides a basis for understanding the value equation in HLHS care, more work is needed to understand the relationship between clinical outcomes and cost measurement.